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SEXUALITY WORKPLACE ISSUES AMONG DIRECT SERVICE PERSONNEL WORKING WITH POPULATIONS WHO ARE INTELLECTUALLY DISABLED IN COMMUNITY INTEGRATED LIVING ARRANGEMENTS: A CASE STUDY

By

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B.S., Eastern Illinois University, 1987

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A Prospectus Submitted in Partial Fulfillment of the Requirements for the

Doctor of Philosophy Degree in Education

Department of Health Education and Recreation

in the Graduate School

Southern Illinois University Carbondale

August, 2015

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DISSERTATION APPROVAL

SEXUALITY WORKPLACE ISSUES AMONG DIRECT SERVICE PERSONNEL WORKING WITH POPULATIONS WHO ARE INTELLECTUALLY DISABLED IN COMMUNITY INTEGRATED LIVING ARRANGEMENTS: A CASE STUDY

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A Dissertation Submitted in Partial

Fulfillment of the Requirements

for the Degree of

Doctor of Philosophy

in

Health Education

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June 26, 2015

AN ABSTRACT OF THE DISSERTATION OF

ANITA SEGO, for the Doctor of Philosophy degree in HEALTH EDUCATION, presented on June 26, 2015, Southern Illinois University Carbondale.

TITLE: SEXUALITY WORKPLACE ISSUES AMONG DIRECT SERVICE PERSONNEL WORKING WITH POPULATIONS WHO ARE INTELLECTUALLY DISABLED IN COMMUNITY INTEGRATED LIVING ARRANGEMENTS: A CASE STUDY
MAJOR PROFESSOR: Dr. Roberta Ogletree

Background: The purpose of this study was to explore DSP workplace experiences, preparation, employee training, emotions, and perceptions in regards to types of sexual and affectionate behaviors exhibited by intellectually disabled adults in their care in the CILA setting. The study focused on analyzing these topics in relation to sexuality/affectionate behaviors experienced in the CILA workplace using a qualitative case study method. This analysis provided an understanding of what ideas and values DSPs brought to their roles of guiding the sexuality/affectionate behaviors of residents in their care and identified additional training needs from the DSP perspective to help them better do their jobs.

Methods: Principles found in qualitative evaluation research were used to examine the influence of sexuality and affectionate behaviors and training within its naturally occurring world. The case was comprised of DSPs from the selected organization, located in a rural college town of approximately 25,000 people. Nine DSPs from five different CILA homes participated in the study. Data were generated using semi-structured interviews, observation of behaviors on interview video tapes, observation of emotional verbal cues on interview audio tapes, document analysis, and field notes.

Results: Major themes were identified from data and organized around the research questions. Common categories under affectionate behaviors were dating, flirting, friendship/socialization, holding hands/hugging, media/technology, and problematic behaviors.

Common categories under sexuality behaviors were groping, masturbation/females, masturbation/males, and problematic behaviors. Less common categories were affectionate behaviors-attention seeking/ego, sexuality behaviors – sexual intercourse, and sexuality behaviors – dating and marriage. Once data were categorized, each category's responses were sorted to identify overarching theme areas for recommendations. The themes were Employee Training and Development, Socialization Needs (Affectionate Behaviors, Sexuality, and Relationships), and Language Issues (Positive, Negative, and First Person).

Primary strengths identified included thinking of residents as family, the feeling of strong management support, and lack of significant conflict within the CILA homes. Elements that detracted from the DSP experience included low rate of hourly pay, employee turnover among DSP supervisors, lack of specific sexuality education for both staff and residents, limited retention of mandatory training topics, and lack of communication of sexuality policies and procedures. Conclusions were a need for additional training for DSPs and staff on the topics of human sexuality and affectionate behaviors in CILA homes; examining DSP training to increase knowledge retention in the staff; better communication of policies, procedures, and protocols regarding sexuality and affectionate behaviors that pertain to how situations are handled in CILA homes; and ensuring all training materials use first person language.

Keywords: sexuality, affectionate behaviors, workplace sexuality, direct service personnel, DSP, intellectual disability, ID, mentally retardation, community integrated living arrangements, CILA, group homes, staff attitudes, staff satisfaction, developmental disabilities, disability, sex education, staff training, and workplace issues

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CHAPTER 1

Introduction

WELCOME TO HOLLAND

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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 (Kingsley, 2012). 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). For this study, human sexuality was defined as the constitution of an individual in relation to attitudes or acuity. This was a broad concept that included aspects of the physical, psychosocial, social, emotional, and spiritual makeup of an individual (*Miller-Keane Encyclopedia and Dictionary of Medicine, Nursing, and Allied Health, 2003).* It was not limited to the physical or biological reproductive elements and behavior, but encompassed the manner in which individuals used their own roles, relationships, values, customs, and gender. 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 (2010, p. 124), 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" (2010, 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).

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, 2013). Normal growth during adolescence includes sexual maturation and an increase in body size; these changes are affected

both by heredity and environment (Merck, 2003). During puberty, sexual development usually occurs in a set sequence, resulting in an increased interest in sexual anatomy and behaviors. Masturbation amongst boys is nearly universal, but is somewhat less common among girls. By late adolescence, sexuality has shifted from exploratory to being an expression of intimacy and sharing (Merck, 2003). 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, 2013). 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, 2013).

Love and affection are also regarded as fundamental human needs. For this study affection was defined as a positive feeling or emotional disposition toward another that did not necessarily include the expression of those feelings (Mikkelson & Floyd, 2013). The expression of affection is vital to both the development and maintenance of personal relationships. Affectionate behaviors may include hugging, kissing, saying "I love you" or other similar actions that portray or enact feelings of affection (Mikkelson & Floyd, 2013). Researchers are revealing hidden complexities behind the simple act of kissing, which relays powerful messages to the brain, body, and kissing partner. According to Walters (2008, p. 26), a kiss "triggers a cascade of neural messages and chemicals that transmit tactile sensations, sexual excitement, feelings of closeness, motivation, and even euphoria." Sexuality and the need for closeness with another

person are basic human drives like the needs for food, water, air, or shelter (Mitchell, 1985). The majority of people with ID are in the mild and moderate range, and most of these develop normal reproductive capacities (Craft & Craft, 1983). No one has ever questioned that populations with ID 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).

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, 1985). As a result, many young people with disabilities do not receive sex education, either in school, at home, or in their group home now more commonly referred to as "Community Integrated Living Arrangements", or CILA. While those with developmental disabilities may learn at a slower rate than do their non-disabled peers, 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 Populations with ID 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). Unfortunately, because parents and caretakers have frequently assumed that physical sexual development does not occur, populations with ID have often arbitrarily experienced restricted social-sexual development (Mitchell, 1985). 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). 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). According to Hingsburger (1990, p. 21), "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, "Everyone of use would feel offended if our own personal loving relationships were seen from only a genital perspective" (1990, p. 21).

Allen stated 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" (2003, p. ix). Personal biases of support staff and guardian family members also serve to further restrict individual freedoms. 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). 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 stated, "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 (Munster, 2005). The Populations with ID 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). All people need to feel acknowledged, important, and loved. 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. Anyone living in an institution develops behaviors to cope with the living conditions (Munster, 2005). "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). Munster further stated: "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 (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 in 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 and Settle (2004), society strongly influences the sexual attitudes and behaviors of a population by identifying acceptable sexual activities and placing restrictions on others. 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 indicated institutional staff accepts masturbation as a normal aspect of sexual development and research indicated many staff are in need of sex education (Johnson & Davies, 1989). These studies found parents and staff agreed 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 (Johnson & Davies, 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 Populations with ID (Johnson & Davies, 1989). Subsequently, the topics of abortion and sterilization were the most controversially debated. Staff seemed to have little difficulty imposing their values on handicapped people.

According to Johnson & Davies, (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 (Johnson & Davies, 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 ("s 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).

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). Another factor that may contribute to the lack of sexuality knowledge in this population is that many Individuals with ID 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). This can result in residents with ID behaving inappropriately. Failure to acknowledge sexual attraction may result in tension or social awkwardness (McKinney & Sprecher, 1991). Sexual tension complicates an already difficult type of relationship (McKinney & Sprecher, 1991). According to Gardner and Chapman, the four main reasons for helping residents with ID 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 (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). Residents raised in an environment where persons believe sexuality and/or affectionate behaviors in populations with ID are inappropriate, may be punished or discouraged from expressing those behaviors (Mitchell, 1985). Like any other behavior, sexual responses are learned, shaped, and reinforced by environments (Craft & Craft, 1983). 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).

The degree of discomfort DSP have in discussing human sexuality needed 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). 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). Therefore, sex education for populations with ID tends to be basically biology—sperm, egg, and the virtue of chastity (Hingsburger, 1990). Institutions may not be good at training people as to what constitutes acceptable and unacceptable sexual behaviors (Craft & Craft, 1983). The concept of sex education prompts complex reactions and contradictory attitudes, even when the recipients of the education are of normal ability. Adding the term developmentally disabled to sex education stirs even more conflicting emotions .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 Populations with ID. Sexuality can present management problems is any residential setting (Craft & Craft, 1983; Roach, 2004).

Mitchell (1985) observed in her work as a consultant to residential facilities that problems involving sexual behavior were often ignored or poorly managed. She indicated 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). Sex education should be approached much like other forms of functional education for populations with ID. 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). The

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

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 (Bandura, 2001). 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 was to explore DSPs' workplace experiences, preparation, employee training, emotions, and perceptions concerning types of sexual and affectionate behaviors exhibited by adults who are intellectually disabled in their care in the CILA setting. The study focused on analyzing DSPs thoughts, feelings, and experiences in relation to health and sexuality/affectionate behaviors experienced in the CILA workplace using the qualitative case study method. This analysis provided an understanding of what ideas and values DSPs brought to their roles of guiding the sexuality and affectionate behaviors of those residents in their care and identified additional training needs from their perspective to help them better do their jobs. If the basic level of sexuality experiences for working with populations with ID 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 DSPs and their residents in the future.

A review of the literature indicated that barriers to achieving sexual knowledge and autonomy by current ideologies of care for populations with ID have resulted in the ideological shifts that have outpaced industry practice (Healy, McGuire, Evans & Carley, 2009; Evans,

McGuire, Healy, & Carley, 2009). Further evaluation of the social, cultural, and environmental levels of influence on sexuality was viewed as necessary by results of previous research studies in this field of study (Healy et al., 2009). This study examined the perceived sexuality training needs of DSP and the perceived relevance of such needs as they relate to their professional standards, job responsibilities, compulsory competencies, and mandated training requirements from regulatory agencies.

Need for the Study

Populations with intellectual disabilities are growing within the community setting for several reasons. Students with special needs 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 populations with ID in CILA settings should be conducted to better meet the needs of ID adults and the staff that work with them. Better trained DSPs would 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 have been 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 in 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 was 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 have been 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 (Rohleder & Swartz, 2012). 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 (Kaiser Foundation, 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, et. al, 2000).

It would seem logical that "young" people, either by chronological age, level of functional 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 populations with ID 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 populations with ID 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 was conducted to 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 sexualty training materials to refect more health-centered, holistic approach to sexual health for CILA residents. This study may encourge health educators to critically examine their current beliefs, assumptions, and approaches to human sexuality when working with populations who are special.

Research Questions

The following research questions direct this study:

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

Research Design

An exploratory, descriptive research design employing a case study method was used to generate qualitative data and examine the phenomena of sexuality and affectionate behaviors in the CILA setting. Yin (2003, p. xiii) 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-planning, public administration, public policy, management science, social work, and education." The case study approach allowed for 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 consisted of in-depth interviews of DSP staff, which were 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 were used to explore and gather descriptions about how DSP experienced sexuality workplace issues when working with populations with ID. The way DSP experienced and interpreted the overall occurrence of sexual and affectionate behaviors by populations with ID impacted job stress and employee retention. By using this approach one can better understand the essence of sexuality workplace issues with populations with ID through the social and personal aspects. According to Culatta (2009), 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 community selected for this study was a rural, Midwestern college town of approximately 25,000 people, which had been the location of programs for the ID since 1969. There currently were four different organizations located there providing services such as residential, developmental, vocational, and adult daycare services for clients with ID, as well as supportive services to residents with mild ID who live independently within the community. All of the agencies included a system of housing for their residents known as a CILA. CILA is a residential program for adults with developmental disabilities. Groups of six to eight individuals lived in a structured environment that was supervised 24 hours per day. With the support of trained staff, residents worked on personal goals for independent living and community integration.

CILA homes from one agency which serve low to high functioning residents served as the case under study. The agency chosen was the one from within the target area that the

researcher had the least amount of experience working with in the past. The agency selected has other locations that were included in this study. Agency CILA homes exclusively serving moderate to high functioning residents located within the city limits were solicited first. There were three CILA homes from the chosen organization that met those criteria. All CILA homes were in neighborhood settings and were designed to have a home-like atmosphere instead of an institutional environment (Vernon, 2009).

The agency granted access to potential study participants and use of their facilities for the study. One-on-one interviews of participants were conducted at a location chosen by the participant. Potential sites were 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 were utilized in order to minimize the effects of the study on the residents with ID.

Sampling

Each CILA home had a staff of six to eight employees, and one supervisor, who worked in shifts to cover program services 24 hours per day. The agency had three moderate to high functioning CILA homes, which are staffed with three DSPs who worked the second shift each day. DSPs who worked directly with the residents between the hours of 3 pm and 9 pm, when the residents are actually awake and in the CILA homes, were targeted because those are the hours the residents were in the home and awake. Residents spent the day at therapy or at the adult daycare facility. Residents were typically put to bed in the evening at 9:00 p.m. Staffing was reduced during the evening hours while the residents slept. In-depth semi-structured interviews were conducted with one to three DSPs per home (for a total of no more than eighteen

interviews) as an examination of the experiences and training of DSPs in regards to sexuality and affectionate behaviors in the CILA setting.

Qualitative research typically included a small number of individuals to preserve the individuality of each in the analysis process. This was 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). Potential participants were identified through a staff list provided by the agency. Each participant was asked to participate through an introductory letter, followed by a personal visit with the researcher. A total of 18 DSPs were employed in at these three homes. However, DSPs who worked directly with the residents between the hours of 3 pm and 9 pm, when the residents are actually in the group homes setting were considered a priority for this study. DSPs who worked at least 30 hours per week were recruited for participation first, followed by part-time DSPs or those who only worked on the weekend. Ideally, at least three of the six DSPs per group home would agree to participate in the interview process. Each DSP was given the opportunity to participate in the study and was included in the study if they chose to participate. This study examined the experiences and training of no more than eighteen DSPs with sexuality and affectionate behaviors in the CILA home setting.

If adequate participation could be obtained from the DSPs working in CILA homes serving solely moderate and high functioning residents, participants were solicited from the staff of other CILA homes within the organization that serves a mixture of low and moderate functioning residents. The organization employed a total of 54 DSPs in all locations—six in each of the nine CILA homes serving low, moderate, and high functioning residents within city limits. Participants were recruited until at least two DSPS from at least three different CILA homes are

interviewed and until no more than eighteen 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 also ended.

Data Collection

Upon approval from the Institutional Review Boards of Southern Illinois University-Carbondale and Eastern Illinois University, qualitative data collection began and included six sources of data— semi-structured interviews, observation of behaviors on interview video tapes, observation of emotional verbal cues on interview audio tapes, document analysis, reflective summaries, and field notes. Reviewing documents added important information to the case study. Participants were solicited in person by the researcher, via mail, phone, and by visiting targeted workplaces. Interviews took place in a location most-convenient to the participants. Potential sites included were 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 locations chosen by the participants.

Data Analysis

Because this study employed the case study method, data was 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). A qualitative study seeks to gain an in-depth and thorough understanding of a particular phenomenon or issue. The interviews were audio and video-taped and transcribed by a professional court reporter within four weeks of each interview. Transcripts were reviewed by the interviewee for accuracy (member-checking). Triangulation of data is collecting information using a variety of sources or methods (Maxwell, 2005). This strategy reduced the risk

conclusions would reflect only the systematic biases or limitations of a specific source or method, and allowed for a broader and more secure understanding of the issues under investigation. Triangulation of data occurred through member-checking, documents analysis, field notes by the researcher, reflective summaries by the researcher, and transcribed data. Two raters, working independently, were used to establish inter-rater reliability. The raters were the researcher and one tenured-faculty from a state university. Thematic coding and inductive reasoning were employed in the evaluation of the data to generate themes or categories. Themes allowed 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 were made for this study:

1. DSPs behavior directly influences resident sexuality and affectionate behaviors. Such behaviors directly influence the quality of life for residents with ID.
2. All individuals who participated in the in-depth interviews responded honestly and to the best of their abilities.
3. Access to program staff was granted.
4. Access was granted to program documents.
5. DSPs employed by the agency working in the CILA setting volunteered 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. Some research participants may not interpret an interview question in the way intended by the researcher.
9. Some research participants may not interpret an interview question in the way intended by the researcher.

Delimitations

Restrictions to the study may include the following:

1. This study is limited to direct service personnel who work directly with Residents with ID 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 focused on DSPs of one agency within one city of an agency serving populations with ID in the Midwest.
4. Participants for the interviews were recruited from CILA homes serving high-functioning or moderate-functioning residents.
5. This qualitative study consisted 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 were 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. Participant recruitment may have been more difficult due to embarrassment or hesitation of the participants to discuss the personal issue of sexuality.
3. Those that chose to participate in the interview process may have experienced the program differently than those who chose not to participate.
4. Research participants may have distorted 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 have distorted aspects of their report in order to try to present themselves in a certain light to the investigator.

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 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).

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, 2005, 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).

***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 populations with ID 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 & Abreco, 1989).

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).

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).

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 explored the workplace experiences of DSPs with types of sexual and affectionate behaviors of adults who are intellectually disabled 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 were investigated. The study focused 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 was conducted to determine how their training prepares them to deal with those experiences.

CHAPTER 2

Literature Review

Purpose

The purpose of this study was to explore DSPs' workplace experiences, preparation, employee training, emotions, and perceptions in regards to types of sexual and affectionate behaviors exhibited by adults who are intellectually disabled in their care in the CILA setting. The study focused 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). For this study, human sexuality was defined as the constitution of an individual in relation to attitudes or acuity. This was a broad concept that included aspects of the physical, psychosocial, social, emotional, and spiritual makeup of an individual (*Miller-Keane Encyclopedia and Dictionary of Medicine, Nursing, and Allied Health, 2003).* It was not limited to the physical or biological reproductive elements and behavior, but encompassed the manner in which individuals used their own roles, relationships, values, customs, and gender. For this study affection was defined as a positive feeling or emotional disposition toward another that did not necessarily include the expression of those feelings (Mikkelson & Floyd, 2013).

A major benefit of an interdisciplinary approach to human sexuality and affectionate behaviors 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). Researching the topic of sexuality for populations with ID 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 employee training and training materials help guide staff behavior in regards to sexuality and affectionate behaviors of residents?
2. How do DSPs in CILA settings experience residents' sexuality and affectionate behaviors?
3. How prepared do DSPs feel to deal with workplace issues regarding sexuality and affectionate behaviors?
4. How do DSPs perceive their influence on the sexual expression of residents with ID in the CILA setting?

Historical Review

Sexuality and intelligence level. The purpose of a literature review, according to Yin (2003), 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). 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* (Sgroi, 1989). 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 (Schulz, 2009).

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 (Castles, 2002, p. 3). North Carolina authorized approximately 200 sterilizations per year through the late 1950s (Castles, 2002). 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). The guiding premise of the 1960s and 1970s for populations with ID was their right to live as normal of a life as possible and the reciprocal obligations of being responsible for their own actions (Robmault, 1978). 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 (Karellou, 2003). 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. The application of the principles of normalization to human sexuality requires the acknowledgement of the sexual needs and rights of the ID (Karellou, 2003). 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 (Karrellou, 2003, p. 66; Wilson, et al*.,* 2011, p. 276,). In the United States, the Sexuality Information Education Center of the United States (SIECUS, 2012) 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 (Robmault, 1978). 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 (Robmault, 1978).

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). 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). While most research and

resources were geared towards specific physical disabilities, such as spinal cord injuries, professionals working with populations with ID developed a list of basic rights, sex information, expression, and birth control services for the population they served. According to Robmault (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 (Robmault, 1978). Craft (1985) identified six main rights related to the sexuality of people with ID. They 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" (Craft, 1994, p. 172).

While the field of sexuality education for populations with ID 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 population with ID itself but rather "the competence of their contact care personnel be they parents, teachers, helping professionals, aides, camp counselors, or anyone else" (Robmault, 1978, p. 39). Robmault 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 (Robmault, 1978)?

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). 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). 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 Individuals with ID had less opportunity to acquire a realistic understanding of their sexual selves than did their non-ID peers (Sgroi, 1989).

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). This became the focus of sexuality research and program development by ID professionals during the mid to late 1980s (Sgroi, 1989). 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 populations with ID 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 populations with ID "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 (Brown et al., 1995; McCabe et al., 1994; McCabe & Cummins 1996; McCarthy & Thompson, 1996, 1997; Turk & Brown, 1993). A retrospective study completed in England found physical and psychological abuse was the most prevalent in populations with ID; 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). 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 (2010).

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 (1995). 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 (Mansell, Sobsey & Calder, 1992). 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 populations with ID 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. 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)

stated: “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). 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). 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**.**

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 populations with ID. 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. (See Table 1)

Table 1

Existing Research Summary

Study	Type of Disability	Method	Participants	Instrument	Country	Year
"A Right to Know" – Facilitating a relationship and sexuality program for adults with intellectual disabilities in Donegal	Intellectual Disability	Pilot Study for New Sexuality & Relationship Program	Health Service Executive Centers Staff & Clients with ID		Ireland	2009
Attitudes Towards ID Sexuality	Intellectual Disability	Quantitative	Caregivers & Parents	SAQ-ID	Ireland	2001 2006
Defining "Sexualized Challenging Behavior" in Adults with ID	Intellectual Disability	Qualitative	Staff	Recorded Interviews	Ireland	2009
Effectiveness of a sex education program facilitating social skills for people with intellectual disability in Japan	Intellectual Disability	Quantitative – Controlled Experiment	Clients with ID living in a Welfare Facility	Kikuchi's Scale of Social Skills, 2007 (KiSS-18)	Japan	2011
Interviewing Victims of Sexual Abuse with an Intellectual Disability	Intellectual Disability	Single Case Study - Qualitative	Single health professional working with a single client	Interviews	Netherlands	2010
Judging the Acceptability of Sexual Intercourse Among People with Learning Disabilities	Learning Disability	Mixed Methods	Volunteers	Testing with use of situational vignettes	France	2008
Laypeople's Attitudes Towards the Sexuality of People with Learning Disabilities in Greece	Learning Disability	Quantitative	General Public	GSAQ-LD	Greece	2003
Rights, sexuality and relationships in Ireland: 'It'd be nice to be kind of trusted'	Intellectual Disability	Focus Groups & Interviews - Qualitative	Clients of National Disabilities Services		Ireland	2009

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 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 Tietjen-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 (Tietjen-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 populations with ID. 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, 1996a).

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 (1996b), 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, et al., 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 Taylor, Dear, & Hall (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 (Wolf, et al., 1996).

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; Granello, Pauley & Carmichael, 1999). 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. Wolf, 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 people who are learning disabled (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 Colin (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, (1999), 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 residents with ID. 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 as oppression (Gill, 2010).

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). 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 (Noonan & Gomez, 2011; Shively, 2012). According to

Noonan and Gomez, the delivery of services to people with disability has improved, creating opportunities to broaden their lifestyles (2011). The authors recommend greater opportunities for sex education and relationships for all, including the population s with ID 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).

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 populations with ID used participants who had little or no experience with populations with ID
- 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, et al., 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). 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).

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 comes 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). 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).

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). 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). 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; Johnson, Knight, & Alderman, 2006). The expression of sexuality on the part of populations with ID is not a special privilege to be granted only to a select few, but a basic human need and a right (Mitchell, 1985).

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).

Defining DSP Sexual Attitudes

What is an attitude? Allpot (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). 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). One's perceptions of others influence one's behavior toward them and members of their group (McKinney & Sprecher, 1991). Most sexual activity occurs in interaction with others, whether that is real, imagined, or implied (McKinney & Sprecher, 1991). A key component of sexuality is relating to another human being (McKinney & Sprecher, 1991).

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 (Johnson & Davies, 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 (Johnson & Davies, 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 population with ID 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 (Johnson & Davies, 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 people with ID 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). 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 (Bonner & Gendel, 1989; Driscoll, Coble, & Caplan, 1992; Walker & Harrington, 2002; Yallop & Fitzgerald, 2010). 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 & Bryde, 2004). 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 (1996a) 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, 1999; 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 population with ID 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, populations with ID 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 (Christian, Stinson, & Dotson, 2001; Yool, Landgon & Garner, 2003). 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 (Cuskelly & 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). 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). 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).

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). Bandura contends that a person's behavior both influences and is influenced by personal factors and the social environment. In his Social Cognitive Theory (SCT), 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, 1991). 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. Reinforcement is integral to learning in SCT (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, et. al, 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 to 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 populations with ID 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 (Pajares & Miller, 1994; O'Leary, et. al., 1992). 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

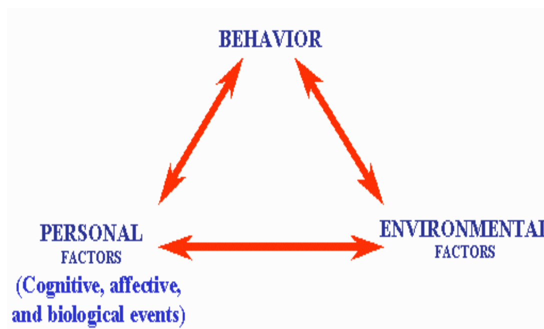

Figure 1 Social Cognitive Theory (Pajares, 2002)

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

residents with ID. 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 residents with ID.

Table 2

Implications for Intervention - (Glanz, Rimer, & Lewis, 2002, p. 169)

Concept	**Definition**	**Implications**
Environment	Factors physically external to the person	Provide opportunities and social support
Situation	Person's perception of the environment	Correct misperceptions and promote healthful norms
Behavioral Capability	Knowledge and skill to perform a given behavior	Promote mastery learning through skills training
Expectations	Anticipatory outcomes of a behavior	Model positive outcomes of healthful behavior
Expectancies	The values that the person places on a given outcome; incentives	Present outcomes of change that have functional meaning
Self-Control	Personal regulation of goal-directed behavior or performance	Provide opportunities for decision making, self-monitoring, goal setting, problem solving, and self-reward
Reinforcements	Response's to a person's behavior that increase or decrease the likelihood of reoccurrence	Promote self-initiated rewards and incentives
Self-efficacy	Confidence in performing a behavior & overcoming barriers in the way	Approach behavior change in small steps to ensure success

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. 25).

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 ***r***epresents 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 (Juergens, Smedema, & Berven, 2009). 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 residents with ID.

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). Greenspan and Wieder (1998) acknowledged 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” (Greenspan and Wieder, 1978, pp. 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).

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 synergic enterprise of body and experience; the relationship between the two is the real determinant of human behavior (Shontz, 1974).

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; Lunsky, et. al., 2007).

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 populations with ID such as group/CILA homes and state institutions**.** Because of the complexity of the regulation of state institutions and organizations for housing residents with ID, an expert from a state institution will be used in this study to provide consultation for the proposed project. This professional has the training, research, regulatory, and clinical expertise required to work with this project.

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 Methods

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). 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 & Plano Clark, 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 (Plano Clark, et. al., 2008). 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, 1991).

Krefting 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 (Best & Kahn, 2010; Creswell, 2007; Creswell, 2008). 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 (Best & Kahn, 2010; Creswell, 2007; Creswell, 2008).

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).

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). 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). 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. According to Yin, the case study allows investigators to "retain the holistic and meaningful characteristics of real-life events" (2003, p. 7). This strategy includes direct observation of the events being studied and interviews of the persons involved in the events. A strength of the case study is its ability to deal with a variety of evidence—documents, artifacts, interviews, and observations. 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).

Sampling and instrumentation decisions actually delimit the settings, actors, processes, and events to be studied (Miles & Huberman, 1994). 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, 2012). 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). Sampling involves decisions not only about which people to observe or interview, but also about settings, events, and social processes (Miles & Huberman, 1994). Qualitative researchers usually work with small samples of people, nested in their context and studies in depth (Miles & Huberman, 1994). Qualitative samples tend to be purposive, rather than random (Kuzel, 1992; Morse, 1994) 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).

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). Further, with small numbers of cases, random sampling can increase bias (Miles & Huberman, 1994). 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). 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).

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). Most research questions do not come out right on the first cut, no matter how experienced the researcher or how clear the domain of the study (Miles & Huberman, 1994). The task is to determine what the researcher wants to find out about these topics. Formulating too many general research questions can

fragment the collection of data. Having a large number of research questions makes it harder to see emergent links across different parts of the database and to integrate findings (Miles & Huberman, 1994). A solution to research question proliferation is the use of major questions, each with sub-questions, for clarity and specificity (Miles & Huberman, 1994). Formulating the questions is an iterative process, with each version becoming sharper and leaner.

Research questions for qualitative studies depend on the method being used to gather the information. Creswell (2007) advocates four types of research questions for qualitative studies. They are exploratory, explanatory, descriptive, and emancipator (engage in social action). Qualitative research questions are open-ended, evolving and non-directional, and are generally kept to five to seven questions. They generally ask "what" or "how" instead of "why." Research questions for quantitative studies typically ask "what," "who," "where," and "when" (Best & Kahn, 2010; Creswell, 2007; Creswell, 2008). Research questions should be kept in hand and reviewed during fieldwork. This closeness focuses data collection. Unless something has obvious, direct, or potentially important link to a research question, it should not appear in field notes.

Defining Case

Case studies are intensive analyses and descriptions of a single unit or system bounded by space and time. Through case studies, researchers hope to gain in-depth understanding of situations and meaning for those involved (Hancock & Algozzine, 2006). 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). 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). 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 (Hancock & Algozzine, 2006; Miles & Huberman, 1994). 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). 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). 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).

This case study used an exploratory, descriptive research design to generate qualitative research and examine the phenomena of sexuality and affectionate behaviors in the group home setting. Yin (2003, p. xiii) 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). The case study’s strength is its ability to deal with a full variety of evidence—documents, artifacts, interviews, and observations (Yin, 2003). 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). 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).

Research design is the logic that links the data to be collected to the initial questions of the study (Yin, 2003). 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). 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).

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). 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). 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). 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).

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). 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). 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). 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). Finally, specific time boundaries are needed to define the beginning and the end of the case (Yin, 2003). 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. Previous literature can become a guide for defining the case and unit of analysis (Yin, 2003).

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 (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). 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 (Best & Kahn, 2010; Creswell, 2007; Creswell, 2008). 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 (Best & Kahn, 2010; Creswell, 2007; Creswell, 2008).

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, 2008a). 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). 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, 2008a). 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 in to themes; and representing the data through the use of tables, figures and discussion. Neutens and Rubinson, (2014), 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, 2008b). 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 generate 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 practiioners 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 , 2015; Institutional Clinical Psychiatrist, 2015; CILA Manager, 2015; & CILA Human Resource Director, 2015). Second, most of the studies dealing with staff working with mentally ill or populations with ID looked at staff attitudes towards their own sexuality and personal behaviors in comparison with how they felt towards the sexuality of Individuals with ID 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 population with ID, 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 people with ID 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 (Johnson & Davies, 1989).

CHAPTER 3

Methods

The purpose of this chapter is to describe the research design of the study, the sampling process, and the study setting. Data collection and analysis procedures are explained as well as the importance of establishing trustworthiness when using 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 were the primary sources of data collection. In addition, job applications, job descriptions, agency webpages, employee handbooks, DHS mandated training manuals, other employee training materials, and other DSP related handouts were collected as data. Interviews were audio and videotaped and field notes were taken during the interviews as well. The researcher wrote analytic memos and contact summaries following each interview.

The purpose of this study was to explore DSP workplace experiences, preparation, employee training, emotions, and perceptions in regards to types of sexual and affectionate behaviors exhibited by adults who are intellectually disabled in their care in the CILA setting. The study focused on analyzing DSPs thoughts, feelings, and experiences in relation to health and sexuality/affectionate behaviors experienced in the CILA workplace through interviews. This analysis provided an understanding of what ideas and values DSPs brought to their roles of guiding the sexuality and affectionate behaviors of those residents in their care and identified additional training needs from their perspective to help them better do their jobs. If the basic level of sexuality experiences for working with populations with ID 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 in the future.

Research Questions

The following research questions direct this study:

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

Research Design

Qualitative research methods are the best strategy for discovery and exploring a new area (Miles & Huberman, 1994). 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). A qualitative approach based on interviews, observations, field notes, and document analysis was used to provide a context for data collection that challenged participants to discuss topics that may have been uncomfortable for them. An exploratory, descriptive research design employing a case study method was used to generate qualitative data and examine the phenomena of sexuality and affectionate behaviors in the CILA setting. This approach focused on the expression of the caregiver's underlying experiences and shared a respect for those subjective experiences (Brammer, Shostrom &

Abrego, 1989). Further, this approach placed an emphasis on concepts such as self-actualization, choice, personal responsibility, values, and meaning (Brammer, Shostrom & Abrego, 1989).

In-depth interviews were 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 was used to provide a context for data collection that challenges participants to discuss topics that may be uncomfortable for them. DSPs were interviewed to determine their perceptions of common sexuality workplace issues working with populations with ID 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.

Using this approach helped me understand the essence of sexuality and affectionate behaviors experienced in the workplace in CILA homes through the social and personal aspects reported by the DSPs during their interviews. A qualitative research design based on a case study approach and utilizing the Social Learning Theory (Bandura, 1986) was used to build an interwoven framework to aid in the understanding of how sexuality was experienced in the group home setting by the DSPs. For this study, I was the only person collecting the data. This allowed me to be both adaptive and responsive to situations as they came up within my study. I was 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 was able to expand my understanding of the research topic from both verbal and non-verbal communication sources (Merriam, 2009). 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.

Study Setting

For qualitative research the natural setting is generally the direct source of data, however multiple sources of data are generally collected (Best & Kahn, 2010; Creswell, 2007; Creswell, 2008). This particular case study was bound by time and place. The duration of this study was four months during the Spring Term of 2015. The study took place in a community in a rural Midwest City that had 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 became a national hub for services and organizations for populations with ID. There were four different organizations providing services such as residential, developmental, vocational, and adult daycare services for clients with ID, as well as supportive services to residents who had mild ID who lived independently within the community. All of the agencies included group homes called "Community Integrated Living Arrangements", or CILA. CILA is a residential program for adults with developmental disabilities. Groups of six to eight 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 community selected for this study was a rural college town of approximately 25,000 people. The agency chosen for this study was the one agency within the community that the researcher had the least amount of previous interaction. The agency selected has other Midwest locations that were not included in this study. Only agency CILA homes exclusively serving moderate to high functioning residents located within the city limits were included. There were

three CILA homes from the chosen organization that met those criteria. Each home had a staff of six to eight employees, and one supervisor, who worked in shifts to cover program services 24 hours per day. Six of the employees at each home were DSPs. Residents spent the day at therapy or at the adult daycare facility. All residents were typically required to go to bed at 9:00 p.m. Three DSP were 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 were in neighborhood settings and were designed to have a home-like atmosphere instead of an institutional environment. Strong family relationships were encouraged in the CILA process. The corporate office was located within an adult-daycare facility located on the local town square. The corporate office included a large training room used for agency meetings and training sessions. Permission was granted by the agency to use any necessary facilities to complete the study.

Selection decisions took 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 have also been influenced by the study setting. The agency granted access to potential study participants and use of their facilities for the study. The manager of the CILA Home Program and the Human Resource Director were directly involved in the planning process for this research project. One-on-one interviews of participants were conducted at a location chosen by the participant. Potential sites were 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 was 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. Participants were

actively solicited from the agency for a four month period of time to ensure all DSPs who wanted to participate in the study were able to do so.

Sampling

Potential participants were identified through a staff list provided by the agency. Each participant was asked to participate through an introductory letter, followed by a personal visit with the researcher. A total of 18 DSPs were employed in at the three targeted homes. However, DSPs who worked directly with the residents between the hours of 3 pm and 9 pm, when the residents were actually in the group homes setting were considered a priority for this study. DSPs who worked at least 30 hours per week were recruited for participation first, followed by part-time DSPs or those who only worked on the weekend. Ideally, at least three of the six DSPs per group home would agree to participate in the interview process. Each DSP was given the opportunity to participate in the study and were included in the study if they chose to participate. This study examined the experiences and training of no more than 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). 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 allowed for more depth into the research topic, aided in the discovery of contrasting and comparative information that may have helped in the understanding of the phenomenon at hand, and helped identify the overall culture of the organization being studied (Miles & Huberman, 1994).

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, 2012, 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). Participants were recruited until a saturation of data was accomplished. This was indicated by the point when interview data starts became repetitive and failed to identify any new experiences or concepts. If adequate participation could not be obtained from the DSPs working in CILA homes serving solely moderate and high functioning residents, participants were solicited from the staff of other CILA homes within the organization that served a mixture of low and moderate functioning residents. The organization currently employed a total of 54 DSPs throughout the organization—six in each of the nine CILA homes serving low, moderate, and high functioning residents within city limits. Participants were recruited until at least two DSPS from at least three different CILA homes were interviewed and until no more than eighteen different DSPs had participated in the study overall. If all eighteen DSPs working in the three CILA homes serving moderate to high functioning residents had agreed to participate, the recruitment process would also have ended.

Data Collection

Upon approval from the Institutional Review Boards of Southern Illinois University-Carbondale and Eastern Illinois University, qualitative data collection began and included eight

sources of data—participant demographic information questionnaire, semi-structured interviews, observation of behaviors on interview video tapes, observation of emotional verbal cues on interview audio tapes, document analysis, language usage analysis, reflective summaries, and field notes. Varying the types of data collection in the research contributed to confident analysis, or trustworthy results (Best & Kahn, 2010; Creswell, 2007; Creswell, 2008). 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 provided "thick descriptions" that are vivid, nested in a real context, and had a ring of truth that has the potential for strong impact on the reader. The qualitative data collection process allowed the researcher to go beyond "snapshots" of "what" and "how many?" to identify just how and why things happened as they did in an actual setting (Miles & Huberman, 1994, p. 10).

The inherent flexibility of qualitative methods, which allowed the data collection times and methods to be varied as a study proceeds, gave further confidence that the researcher had really understood what had been going on in case setting (Miles & Huberman, 1994). Qualitative data, with 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, prejudgments, or presuppositions and for connecting those meanings to the social world around them (Miles & Huberman, 1994). Because the researcher was the primary instrument for data collection and analysis in qualitative research, she spent significant amounts of time with the DSPs being studied (Best & Kahn, 2010; Creswell, 2007; Creswell, 2008; 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). Researchers with good communication skills will be able to easily establish rapport with participants (Best & Kahn, 2010; Creswell, 2007; Creswell, 2008; 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 (2005).

The purpose of the interviews was to explore and gather descriptions about how the sexuality and affectionate behaviors of residents with ID experienced by DSPs in the workplace impacted the DSP, and how well the required training prepared the DSPs to deal with those experiences. The aim was to involve a range of DSP who had 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 allowed participants an opportunity to share and express their opinions of what they had experienced, how they dealt with the situation(s), and how well prepared they felt to deal with those situation(s). The exploration that took place in this study was 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 observed sexual and affectionate behaviors and who had to deal with the subsequent issues within their work environment. The way a DSP experienced and interpreted the phenomena of sexuality and affectionate behaviors in the workplace setting may have affected how he/she influenced resident

behavior. The findings and recommendations of this study will be shared with the agency at the conclusion of the project.

Upon approval from Southern Illinois University's Human Subjects Committee, potential participants were contacted at their workplace through the use of signs, flyers, phone calls, and individual letters requesting their participation. Each participant was visited by the researcher in person before the actual interview to help them feel more comfortable with the researcher. Additional DSPs were identified through the staff list of the participating organization, through the staff listing on the organization’s website, by referral by agency staff, and by recommendations of other participating DSPs. Personal interviews were conducted at a time and location of convenience to the interviewees. Locations were reserved in advance of the interview. On the evening prior to the interview appointment, selected participants received 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 participated in an audio/videotaped semi-structured interview lasting 45-60 minutes with an agreement that follow up interviews, as needed, would 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 included a mixture of both structured and less structured interview questions (Merriam, 2009). Questions were used to get participants involved and were sequenced from general to specific. The interviews were guided by using a list of questions and prompts. Interview questions were 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 Appendix E).

Member checking was 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 experienced and interpreted the overall occurrence of sexuality workplace issues working with populations with ID in the workplace impacted how they made 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.

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 was maintained. In addition, a reflexivity journal to document the researcher's thoughts and feelings throughout the investigative process was also maintained (Best & Kahn, 2010; Creswell, 2007; Creswell, 2008). This allowed for increased depth and rich detail that is part of the qualitative research process. In addition, since the researcher is the parent of an adult with disabilities, the reflexivity journal was be used as a tool to track any potential bias on the part of the researcher. It was also used to track unexpected findings or trends in shared experiences that might have needed further exploration during the research process. It was essential that information was "easily identified, well organized, consistent, and maintain clarity" (Krueger & Casey, 2009, p. 9). Field notes contained "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 & Casey, 2009, p. 9).

Audio/videotape behavior observations. Observations of non-verbal behaviors, facial expressions, and comfort levels with discussions topics were conducted from the video tapes of each interview session. Interview participants sometimes reversed their positions during the timeframe of the interview or follow-up process. When there is a shift in opinion, the researcher typically traced the flow of the conversation to determine clues that may explain the change (Krueger & Casey, 2009). The interview data were examined for frequency or extensiveness, meaning some topics or issues were brought up more frequently than others. These topics could be considered more important or of special interest to participants. Also to be considered were comments that were not said or only received limited attention. Occasionally, participants talked about a topic with special intensity or depth of feeling. Interview sessions were video-taped to aid in the analysis of intensity that were communicated by the voice tone, speed, emphasis on certain words, and through the body with non-verbal communication cues (Krueger & Casey, 2009). Intensity may be difficult to spot with transcripts alone; this was the reason for the video-taping. Specificity was a vital component of data analysis. When interviews had been videotaped, they provided a permanent record that was coded again and again by investigators with different perspectives (Copland & White, 1991).

For this study, observations in the group home setting were not included because the focus of the study was the DSPs, not the residents with ID they serve. Observing the DSPs in the workplace would have entailed observing the residents with ID. 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 have remained.

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 analyzed were 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 was to explore what types of training DSPs received on the topics of human sexuality and development, how those materials approached the topic of sex education, and how those materials prepared the DSPs for the sexuality issues that occur in the CILA setting.

Once documents had been found, authenticity was established by the researcher. Authenticity was determined by establishing information such as: (a) where documents came from, (b) if they had been edited, and (c) the authors' sources of information. After authenticity has been established, the researcher conducted content analysis on the documents and created a coding form that helped the researcher describe the substance of the documents (Best & Kahn, 2010; Creswell, 2007; Creswell, 2008; Bogdan & Biklen, 2012).

Data Analysis

Because this study employs the case study method, data analysis was completed through content analysis. The content analysis method is a process that allowed 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 were audio/video-taped and transcribed by a professional court reporter within four weeks of each meeting. Transcripts were completed for all interviews in a consistent style. The transcripts were double-spaced, with the comments of the moderator made easily identifiable by bold print. Transcripts were prepared by a court reporter. The interviews were transcribed word for word, without correction for grammar. If some words were unintelligible, three periods "…" were used to indicate that words were missing from the transcript. Special or unusual sounds that could help analysis were noted in the transcript. If there was laughter, loud voices, shouting, or if someone is interrupted, it will was noted in the interview transcript. Transcripts were delivered to the court reporter within one week of the finished interview. Completed transcripts were returned to the researcher within two weeks to four weeks. A back-up copy of the transcript was created as a Microsoft Word file and stored on a secure computer. Once the completed transcript had been returned to the researcher, it was sent to the interviewee for review and confirmation (member-checking). Thematic coding and inductive analysis was employed in the data analysis to generate themes or categories based on the transcribed data. The themes allowed the researcher to gain an overall perspective about the phenomena of how DSPs experience sexuality and affectionate behaviors in the workplace and related employee training.

Data analysis began with activities in pre-coding and descriptive coding. Data analysis for this study began with writing notes and memos during the interview process, which allowed not only the capture of analytical thinking of the data but also facilitated thinking and the stimulation of analytical insights (Maxwell, 2005). Coding began as data was collected by jotting down key words or phrases for future references during the interviews (Saldana, 2013). The next step was listening to the interview tapes and reading the interview transcripts. All transcripts

were read in one setting. This quick read allowed the researcher to view the whole scope and to refresh his or her memory of where information was located, what information was missing, and what information occurs in abundance.

Transcripts from the interviews were reviewed and “significant statements” were highlighted as well as sentences or quotes that provide an understanding of how DSPs experienced sexuality and affectionate behaviors within the workplace. Descriptive coding was 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 broke down the data into discrete parts for later comparison. Descriptive coding led to the creation of an index of the data’s contents. It was the essential groundwork for secondary coding and further analysis and interpretation (Wolcott, 1994).

Emotion and value coding methods were used to analyze the transcripts in the development of “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 labeled the emotions recalled and/or experienced by the participant, or inferred by the researcher about the participant and were “especially appropriate for studies that explore intrapersonal and interpersonal participant experiences and actions” (Saldana, 2013, p. 105). The transcripts, audio and videotapes were coded for emotional responses. A textual description was 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. The value coding was particularly suited for case studies such as this one to identify intrapersonal and interpersonal participant experiences, and explore cultural values and identity (Saldana, 2013). Using multiple sources for value coding (field notes, interview transcripts, and documents) "corroborates the coding and enhances trustworthiness of the findings because what a participant stated are his or her values, attitudes, or beliefs may not always be truthful or supported by his or her actions" (LeCompte , Preissle, & Tesch, 1993, pp. 264-265).

A review of processes in the workplace and process (or action) coding methods were used to analyze how the workplace policies, procedures, mandates, and management staff influenced DSPs and what they experienced in the workplace. Process coding is appropriate for studies that searched 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 247). Data were analyzed specifically for how DSPs respond to the situations they experience in the CILA work environment.

Information about the context of the stories was gathered to help classify the stories in the contextual areas of workplace, personal, time and place. The process of restorying was used to organize the stories into a framework that makes sense. The qualitative data analysis was a description of the story and the themes that emerged from it. The study was a collaborative process, which actively involved participants in the research. This process involved the negotiation as to the meaning of the stories and how DSPs feel sexuality and affectionate

behaviors impact their workplace today. The collaboration process resulted in a validation check to the analysis.

After all interviews are completed, coded, and major themes had been generated, a summary report was given to a trained qualitative researcher. Each participant's name and personal identifiers were removed to maintain confidentiality in the summary report. Each participant's name was converted to pseudonym using a random name generator for all reporting purposes. Each participant was asked to prepare a written reaction to the summary report, indicating their analysis, feedback, and experiences with the issues raised from the interview process. The written analysis provided the richest information and aided in the depth of detail required for good qualitative studies (Seskin, Still, & Boroski, 2002). Each written reaction report was read and analyzed to determine if any additional follow-up questions or clarification was required from the participants or if any additional documents need to be obtained for analysis. Data analysis in this stage included 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.

Finally, any additional data needed that was identified through earlier data analysis processes was gathered. Adaptation of the coding process was completed as necessary, and any new themes or categories were adapted or generated. A final summary report merging the data from the interviews, the field notes, document analysis, the audio/videotape observations, and the member-checking was created (See Appendix I).

Ethical Considerations

Risks associated with participation in this study were very low. Participation was voluntary and participants could discontinue the survey at any time without penalty. Every effort

was made to assure participants of their confidentiality. SIUC and EIU Human Subjects Committee approval was obtained before any participant involvement.

A purposeful sample of DSPs employed by a group home in a rural Midwest community was utilized for this study. DSPs who were employed as a caregiver of residents with ID in the CILA home setting were interviewed. The DSPs participated in a semi-structured, audio/videotaped interview lasting 60-90 minutes with an agreement that follow up interviews, as needed, would be conducted. Participants who completed the interview process received a coupon for a large pizza as incentive for their participation in the study.

Validity/Trustworthiness

Validity was 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). 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). To deal with "reactivity" I emphasized to participants that I had no stake in how they experienced sexuality and affectionate behaviors in the workplace. To deal with bias, I brought to my awareness my personal perception about sexuality and affectionate behaviors in group home settings and constantly monitored how this may have influenced how I analyzed 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 was reduced through the use of two raters. Two raters, working independently, were used establish inter-rater reliability. The raters were the researcher and one

tenured-faculty from a state university. This protocol did not require multiple people to be present during the interviews or observation process, but rather allowed 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).

Training was provided to the tenured faculty member at two stages of the study. First, training was provided to complete the video observation forms. A video observation form was created by the primary researcher after analysis of required training materials, employee recruitment and management materials, and professional materials used by DSPs. The training consisted of the two researchers (primary and tenured faculty member) reviewing and adapting the video observation form based on the researchers' experiences with qualitative studies and the use of videotapes as a data source. The tenured faculty member was given a summary of the research project's purpose, problem statement, research questions, study setting, research design, sampling methods, and data collection methods. Both researchers practiced completing the form by reviewing a simulated interview audio/videotape and then compared their completed form and results with each other.

Later in the project, the tenured faculty member was reminded of the project basics, including research questions, and provided copies of the interview transcripts. To address validity, the data was checked by two researchers independently. Thematic coding and inductive analysis were employed by the data analysts to generate themes or categories based on the transcribed data by both researchers. A discussion to compare results and identify possible alternative explanations and suggestions for data collection was held to identify any potential contrary findings to reduce bias (Yin, 2003). Discussion was held about exploring the topics of

gender and Lesbian/Gay/Bisexual/Transgender/Queer/Intersex/Asexual/Ally (LGBTQIA) influences and impact on populations in CILA homes but both researchers were in agreement that the transcripts and research questions had not generated enough data to include these topics in this study. A comparison of the project categories and themes results from the independently conducted data analysis conformed for both categories and overall themes.

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 and was used in this study as well. This protocol used 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 was obtained through audio/videotape observations and analysis; memos and field notes, transcribed interview data, and member-checking. According to Bloomberg and Volpe (2008, p. 64): "triangulation design is a process where a researcher uses multiple perceptions to clarify meaning". Analysis was 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

was maintained through the use of triangulation, peer review, member checking, and clarifying biases.

Verification Techniques

The following verification techniques were used for the qualitative components and that data analysis of this study:

- The interviews were audio/video-taped and transcribed by a professional court reporter within two weeks to four weeks of each meeting. In addition, the researcher chose two interviews at random to transcribe as well. The two versions of the transcripts of the same interview were cross-checked for accuracy. The results of the check for transcript accuracy were no problems were identified in the quality of the transcription reports in regards to the participant responses in the transcripts matching the participant responses on the audio/videotapes.
- Qualitative content analysis was used to develop a series of codes for the interview transcription and the observation notes from the interviews. The content analysis method process allowed 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 were 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 Check (or Respondent Validation) included the paraphrasing of my understanding of something they said and ask them to react to it during the interview, as well as participants reviewing their transcripts, meeting with researcher to go over their transcripts, follow-up emails and texts with questions from the researcher, follow-up

emails and texts from the participants with new ideas or clarifications of previous statements, and participants reviewing a report of the final codes and final summary concepts from all the interviews.

- Transcript were read and re-read throughout the coding process to see where the data supported or conflicted with my findings. The coding process continued until no new information or issues were found.
- Triangulation of data was completed through the use of interviews, field notes, transcripts, and document analysis.

Demographic data included sex, level in school, race/ethnicity, age, job title, and length of employment with agency. Data for the qualitative components was analyzed in the following manner--interviews were audio/videotaped and transcribed by a professional court reporter within two weeks to four weeks of each meeting; Qualitative content analysis was used to develop a series of codes for the interview transcription. The content analysis method process allowed 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 were used to identify key descriptive themes within the qualitative data.

Summary

The purpose of this study was to explore the experiences of DSPs with sexuality and affectionate behaviors of intellectually disabled individuals at a mid-size agency providing services for residents with ID in a small, rural, mid-western town. The relationship between factors associated with the sexuality behaviors of residents with ID in traditional group home settings and the perceptions of DSPs to deal with those behaviors was analyzed in this qualitative study. This study examined the perceived sexuality training needs of DSP and the perceived

relevance of such needs as they relate to their professional standards, job responsibilities, compulsory competencies, and mandated training requirements from regulatory agencies. Furthermore the knowledge, attitudes, and behaviors of DSPs and DSPs on the topic of sexuality needs in ID populations was analyzed. If the basic level of sexuality experiences for working with populations with ID by DSPs could be identified, training programs could be developed to build skills in regards to sexuality workplace issues to enhance the group home experience for DSPs and residents in the future. Chapters four and five will give a detailed account of the findings of the study and appropriate conclusions and recommendations.

CHAPTER 4

Results

Purpose of the Study

The purpose of this chapter is to present the results of the data collection and data analysis that took place in this study. It provides the analysis of data with a summary of the findings and detailed descriptions of the DSP experience through the perspectives of the participants. The purpose of this study was to explore DSPs' workplace experiences, preparation, employee training, emotions, and perceptions in regards to types of sexual and affectionate behaviors exhibited by adults who are intellectually disabled in their care in the CILA setting. For this study, human sexuality was defined as the constitution of an individual in relation to attitudes or acuity. This was a broad concept that included aspects of the physical, psychosocial, social, emotional, and spiritual makeup of an individual (*Miller-Keane Encyclopedia and Dictionary of Medicine, Nursing, and Allied Health, 2003).* It was not limited to the physical or biological reproductive elements and behavior, but encompassed the manner in which individuals used their own roles, relationships, values, customs, and gender. For this study affection was defined as a positive feeling or emotional disposition toward another that did not necessarily include the expression of those feelings (Mikkelson & Floyd, 2013).

The study focused on analyzing DSPs thoughts, feelings, and experiences in relation to health and sexuality/affectionate behaviors experienced in the CILA workplace using the qualitative case study method. This analysis provided an understanding of what ideas and values DSPs brought to their roles of guiding the sexuality and affectionate behaviors of those residents in their care and identified additional training needs from their perspective to help them better do their jobs. If the basic level of sexuality experiences for working with populations with ID by

DSP can be identified, training programs can be developed from the data to build skills in regards to sexuality workplace issues to enhance the CILA experience for both DSP and their residents in the future.

Research Questions

The following research questions direct this study:

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

Study Setting - CILA Homes

CILA is defined as a residential program for adults with developmental disabilities. Groups of six to eight individuals lived in a structured environment that is supervised 24 hours per day. With the support of trained staff, residents worked on personal goals for independent living and community integration. The agency chosen for this study was one of four CILA agencies within the community. The community selected for this study was a rural college town of approximately 25,000 people. The agency selected had other locations that were not included in this study. The plan was to only include CILA homes within the agency that exclusively served moderate to high functioning residents. However, the agency changed their housing allocations so that each CILA home contained a variety of functioning levels.

The participant recruitment plan for this study was adapted to allow recruitment from all eligible CILA homes within the agency with the city limits. Each home had a staff of six to eight employees, and one supervisor, who worked in shifts to cover program services 24 hours per day. Six of the employees at each home are DSPs. All group homes were in neighborhood settings and are designed to have a home-like atmosphere instead of an institutional environment. Strong family relationships were encouraged in the CILA process. Most of the CILA homes in this agency were four bedroom homes, with two bathrooms, a kitchen, a living room, and a laundry room. Most of these houses had eight clients living there on a full-time basis, with two clients sharing each bedroom. Participants were recruited from five different CILA homes. A total of nine DSPs were interviewed; four worked in homes that served only female clients; four worked in homes that served only male clients, and one worked in a coed home.

Data Collection

Approval from the Institutional Review Boards of Southern Illinois University-Carbondale and Eastern Illinois University was received. Qualitative data collection began and included eight sources of data—participant demographic information questionnaire, semi-structured interviews, observation of behaviors on interview video tapes, observation of emotional verbal cues on interview audio tapes, document analysis, language usage analysis, reflective summaries, and field notes.

Interview process. Participants took part in the study by completing the participant demographic information questionnaire. They also participated in an initial meeting, an in-person interview, follow-up emails, phone calls, texts, instant messaging, a member-checking meeting to review their interview transcript, and a final review of a summary report including all data categories, themes, important issues, and potential DSP needs identified throughout the

research process. A total of nine participants completed the interview process. Participants' identities were kept confidential and participation was voluntary.

Every DSP that wanted to participate in the study was allowed to be a part of the study. Additional volunteers were solicited by existing participants through the use of flyers, at the request of CILA home supervisors, through announcements at team meetings, and recruitment announcements through the use of social media. After solicitation, no additional volunteers could be found to be included in the study. Each participant completed a demographic information sheet, a consent form to participate in the study, and a consent form to be audio/video-taped. Participants were informed that the audio/videotapes would be reviewed by the transcriber (court reporter, as well as two independent researchers during the data analysis and coding process.

The study was an attempt to understand the perspectives of DSPs through face-to-face interviews. The interviews were in a semi-structured format and participants who were interviewed were not identified in any manner that would compromise their confidentiality. Participants understood they could withdraw from answering any of the questions at any time during the process. They discussed the topics of sexuality and affectionate behaviors/experiences in their workplace, as well as the training they had to prepare them for those experiences. Participants were allowed to pick the site of their taped interview. Two participants chose to be interviewed in the home of the researcher and the other seven chose to be interviewed in the office of the researcher, which is located away from all of the CILA homes. Every effort was made to give the participants privacy during the interview process—a do not disturb sign was posted on the office door and the door was kept closed during the interview process. For those participants who chose to be interviewed at the researcher's home, no one else was in the home during the time of the interview except the participant and the researcher.

The inquiry began with broad and general questions about their workplace and moved towards more specific questions about their experiences with sexuality and affectionate behaviors. The narrative approach was used so that the DSPs were telling their stories and their own personal experiences, giving the researcher the opportunity to chronicle their perceptions of their professional responsibilities and activities in their own words (Best & Kahn, 2010; Creswell, 2007; Creswell, 2008). The experiences of the DSPS were unique, allowing them to share experiences pertaining to the research topics that they felt were most relevant. Following the interviews, all stories were coded by this researcher to formulate themes and categories, ensuring that elements of participants' stories would be presented within this study (Best & Kahn, 2010; Creswell, 2007; Creswell, 2008).

Audio/videotapes. Participants completed a release form to participate in the study and a separate release form which gave permission for their interview to be audio/videotaped. Participants were informed the audio/videotapes would be transcribed by a professional court reporter and reviewed by another trained researcher. All participant interviews were recorded using two different recording devices—a primary recorder and a backup recorder. Tapes were not reviewed until all transcripts were transcribed and returned from the court reporter. Key words, concepts, and stories were used to create preliminary codes for the creation of a video observation form. Training and practice was conducted with the second researcher. All video tapes were evaluated using the video observation form by two researchers working independently. The researchers met to compare and contrast the results and a summary report of preliminary findings was prepared. Information included in the final summary report was used to go back and re-evaluate the interview transcripts for additional ideas, concepts, and details.

Document analysis. Documents are social products that must be examined critically because they reflect the interests and perspectives of their authors and carry values and ideologies, either intended or not (Saldana, 2013). Agency documents used for document analysis were the Agency Employee Handbook, the Agency DSP Training Notification/Registration Form, the agency website, DHS Mandatory Training Modules, SACIS Employee Training Session Handouts, the Agency Volunteer Information Packet and Application, Agency DSP CILA DSP Job Description, DSP Code of Ethics, and Agency on the Job Training Materials. The document analysis protocol form was completed for each type of document. The form included the document title, document date, type of document, author(s), intended audience, intended purpose, and types of language used within the document—positive or negative. A language use analysis form was created and each document was analyzed for specific language used. Specific words analyzed were abuse, assault/sexual assault, crisis, harassment, inappropriate, perpetrator, rape, sexual exploitation, sexual violence, stigma, trauma, victim, victimization, advocate, advocacy, confidential, health relationships, help/helping, reclaim, recovery, prevention, respect/sensitivity, and survivor(s).

Data Analysis

Once transcripts were returned from the court reporter and verified by the participant, transcripts were cut and pasted and maintained in an Excel spread sheet for qualitative coding purposes. Descriptive information (e.g. date received, e-mail address of respondent, phone number of respondent), and open-ended comments each received their own cells in a matrix, enabling comparison and development of categories. Categories were also generated by physically cutting up a copy of the transcripts and arranging the different stories, quotes, and incidents on large pieces of paper until similarities and possible code categories were identified.

The coding cycles used in this project were divided into three main sections: initial steps of data analysis, secondary steps of data analysis, and final steps of data analysis. The initial steps happened during the initial coding of the data and were considered to be more exploratory in nature. The secondary steps were more challenging because they required more analytical skills such as classifying, prioritizing, integrating, synthesizing, and conceptualizing (Saldana, 2013). The list of codes and categories kept evolving throughout the study as new information came in or participants provided clarification of earlier statements. The final steps were to organize the different categories into themes.

Participant demographic information questionnaires were delivered to the participants in the introductory visit and collected from each participant at the beginning of their interview. In the initial steps of data analysis, descriptive statistics were tabulated to create a summary of the participant demographics. Information collected and summarized were age, sex, race, educational level, major, degrees held, status of employment (full- or part-time), length of employment with the agency, and previous training on human sexuality topics. Field notes and reflective summaries were used throughout the data collection process and were included in the data analysis process to identify key stories and concepts.

Precoding and initial coding were used to begin creating a code list and to create the video observation form, the language usage analysis forms. Precoding and initial coding are considered to be exploratory methods that use exploratory and preliminary assignment of codes to the data before more refined coding systems are developed and applied (Saldana, 2013). These provisional types of coding typically begin with a “start list” of researcher-generated codes based on what preparatory investigation suggest might appear in the data before they are analyzed.

This type of precoding was used to create the language usage form for document analysis and the video observation form used to analyze the audio-videotapes of the interviews.

Descriptive coding summarizes in a word or short phrase (most often a noun) the basic topic of a passage of qualitative data (Saldana, 2013). Descriptive coding was used to develop a basic vocabulary of data to form categories for further analysis. Descriptive codes were gathered from data collected across various time periods and charted into categorized summaries or indexes of the data content. It set the essential groundwork for the secondary steps of data analysis as well as further analysis and interpretation (Wolcott, 1994). Field notes and narrative summaries were considered to be of particular importance during the initial steps of data analysis because they assisted in interpreting the meanings of the physical environments of our social world. Descriptive coding was one approach to document the rich description of field notes that were the used to describe the work environment that participants create, handle, work within, and experience on a daily basis. It was chosen for use in this study for those reasons.

Emotion codes label the emotions recalled or experienced by the participant, or inferred by the researcher about the participant. According to Saldana (2013), emotion coding was most the most appropriate choice for qualitative studies that explored intrapersonal and interpersonal participant experiences and actions. The study and analysis of emotions provided a deeper insight into the participants' perspectives, viewpoints, and interpretation of life situations. Virtually everything one does has an accompanying emotion: "One can't separate emotion from action; they are part of the same flow of events, one leading into the other" (Corbin & Strauss, 2008, p. 7).

The primary tools used for emotion coding were field notes and the audio/videotapes of the participant interviews. Emotion coding included the ability to read non-verbal cues, to infer

underlying affects, and to sympathize and empathize with the participants in order to allow for richer descriptions of the participant experiences (Saldana, 2013). The emotion coding process also included analyzing the audio portions of the videotapes for voice inflections and vocal nuances to help track the emotional journey or storyline through the use of the emotional codes generated. Since the topic of sexuality has been viewed as controversial, especially in regards to populations with ID, it was important that participant emotions were evaluated as part of this study.

Value coding is the application of codes to qualitative data that reflect participants' values, attitudes, and beliefs in regards to their perspectives of their worldview. Saldana (2013) defined a value as the importance we attribute to oneself, another person, thing, or idea. Value coding was particularly valuable to this study that explored cultural values, identity, intrapersonal and interpersonal experiences and actions in a case study format. Values coding was appropriate method of coding for interview transcripts, field notes, observations of human behavior such as when reviewing videotaped interviews. Values within an individual are influenced and affected by the social and cultural networks to which he or she belongs. Since CILA homes are both a social and cultural network for both the staff and the clients, values in regards to sexuality, affectionate behaviors, and training were evaluated in this study through the use of interview transcripts, interview audio/videotapes, reflective summaries, and field notes.

Focused coding followed initial coding. It included completing a search for the most frequent or significant codes to develop the most relevant categories and required decisions about which initial codes made the most analytic sense. Focused coding is considered to be a second cycle coding method that categorizes coded data based on thematic or conceptual similarity (Saldana, 2013). Second cycle coding methods are advanced ways of reorganizing and

reanalyzing data coded in earlier coding stages. Focused coding was used to incorporate reflective analytic memo writing, both as a code- and category-generating tool. This method used additional qualitative data to support or modify the researcher's observations developed in earlier stages of the study (Saldana, 2013). For this study additional qualitative data were generated through continued contact with DSP participants through phone calls, emails, and texts, as well a meeting for each participant to review their interview transcripts and a final meeting for each participant to review a summary report of preliminary findings. Focused coding enabled the researcher to compare newly constructed codes during this cycle across other participants' data to assess comparability and transferability (Saldana, 2013).

The final steps of analysis were to identifying the overlying themes that resulted from the initial coding, descriptive coding, emotion coding, value coding, and the focused coding. According to Saldana (2013, p. 175), a theme is an extended phrase or sentence that intensifies what a unit of data is about and/or what it means." The final themes identified through the coding process were Employee Training and Development, Socialization Needs (Affectionate Behaviors, Sexuality, and Relationships), and Language Issues (Positive, Negative, and First Person). A summary of the data analysis process is provided in Table 3.

Table 3

Data Analysis Summary

Process	Form or Data Generated	Type of Analysis or Concurrent Coding Methods
Initial Steps of Data Analysis		
Interview	Participant Demographic Information Questionnaire	Descriptive Statistics
	Field Notes	Precoding, Initial Coding, Descriptive Coding
	DSP Interview Transcripts	Precoding, Initial Coding, Descriptive Coding, Emotion Coding, Value Coding
	Reflective Summaries	Emotion Coding, Value Coding
	Interview Videotapes	Precoding, Descriptive Coding, Emotion Coding, Value Coding
	Summary Report of Preliminary Findings	Descriptive Coding, Emotion Coding, Value Coding
Document Analysis	Document Analysis Protocol	Precoding, Descriptive Coding
	Language Usage Analysis	Precoding, Descriptive Coding, Emotion Coding, Value Coding
Secondary Steps of Data Analysis		
Interview	Interview Transcripts	Focused Coding, Reflection & Adaptation of Previous Codes As Necessary
Document Analysis	Document Analysis Protocol	Focused Coding, Reflection & Adaptation of Previous Codes As Necessary
	Language Usage Analysis	Focused Coding, Reflection & Adaptation of Previous Codes As Necessary
Final Steps of Data Analysis		Development & Organization of Themes

Participant Demographics

The participants ranged in age from 22 years old to 30 years old. The average age of all participants was 26 years old. Five participants were female and four participants were male. Five participants identified themselves as Caucasian and four participants identified themselves as Black/African American. Participants had educational backgrounds ranging from high school through graduate school. One participant had a high school education. Four participants had recently completed their Bachelor's Degree, while one participant was working on completing their Bachelor's Degree. Two participants had recently completed their Master's Degrees and one participant had just starting working on obtaining their Master's Degree. Participants majored in different fields of study including Sports Studies, Family Services, Psychology, Business Administration, Health Administration, Community Health, Health First Responder, and Kinesiology (See Table 4).

Table 4:

Demographic Characteristics of Participants

Name	Age	Sex	Race	Education	Major	Degree
ANA	24	F*	Black/African American	Working on Graduate Degree	Sports Studies Community Health Minor	BS - Kinesiology
BEN	24	M	Caucasian	Bachelor's Degree	Health First Responder	BS – Health Studies
CLAIRE	28	F	Caucasian	Bachelor's Degree	Health Administration	BS – Health Studies
DARIUS	22	M	Black/African American	High School	None	High School
EVA	23	F	Black/African American	Senior - University	Community Health	Pending
FINN	27	M	Caucasian	Bachelor's Degree	KSS (Teacher Certification Major), Health/Driver Ed Minor	BS – KSS/HST
GIA	30	F	Caucasian	Master of Science	Business Administration (BS) Family Services (MS)	MS – Family & Consumer Science BS – Business Administration
HENRY	30	M	Black/African American	Master of Science	Psychology	MS – Psychology BS - Psychology
IVY	23	F	Caucasian	Bachelor's Degree	Health Administration Minor – Business Administration	BS - HST

M=Male, F=Female, BS=Bachelor of Science, MS=Master of Science, KSS – Kinesiology, HST=Health Studies

Eight participants typically worked the second shift, while one participant typically worked the first shift. Four participants worked in homes that served exclusively men; four worked in homes that served exclusively women; and one participant worked in a home that was coed. Seven participants worked full-time and two participants worked part-time. One participant worked 20-24 hours a week; one participant worked 25-29 hours a week; six participants worked 35-40 hours a week; and one participant worked over 40 hours a week. Every employee had been with the agency for over one year. The oldest employee had worked for the agency for five years (See Table 5).

Table 5

Employment Status of DSPs

Characteristic	Number	Percent
Job Appointment Level		
Full Time	7	.78
Full Time < 9 months	0	0
Part Time	2	.22
Prefer Not To Answer	0	0
Missing	0	0
Total	9	100.0
Average Hours Worked Per Week		
Over 40	1	.11
35-40	6	.67
30-34	0	0
25-29	1	.11
20-24	1	.11
15-19	0	0
10-14	0	0
Less than 10	0	0
Prefer Not to Answer	0	0
Total	9	100.0
Length of Employment at the Agency		
5 years	1	.11
4 years	2	.22
3 years	2	.22
2 years	2	.22
1 year	2	.22
6-11 months	0	0
Less than 6 months	0	0
Prefer Not to Answers	0	0
Total	9	100.0

A random name generator was used to develop the list of pseudonyms for the participants. The participants appear in no particular order and they were interviewed in no particular order. Each participant had different levels of previous training or coursework in the areas of sexuality and affectionate behaviors (See Table 6).

Table 6

Sexuality & Human Development Training History of Participants

Participant Name	Middle School Health	High School Health	Child Development Class	Human Growth & Development	Human Sexuality	Completed DHS Sexual Abuse Module	Other Related Training
ANA	No	Yes	Yes	Yes	Yes	No	None
BEN	Yes	Yes	Yes	Yes	Yes	Yes	Self Defense
CLAIRE	Yes	Yes	Yes	Yes	No	Yes	None
DARIUS	No	No	No	No	No	No	None
EVA	No	No	Yes	Yes	Yes	Does Not Remember	Sexual Assault Counseling & Information Service (SACIS)
FINN	Yes	Yes	Yes	Yes	Yes	Yes	None
GIA	Yes	Yes	Yes	Yes	Yes	Yes	Appropriate Relations Training
HENRY	No	Yes	Yes	Yes	Yes	Yes	None
IVY	Yes	Yes	Yes	Yes	No	Yes	OIG/DHS
Column Totals:	Yes = 5 No -= 4	Yes = 7 No -= 2	Yes = 8 No -= 1	Yes = 8 No -= 1	Yes = 6 No -= 3	Yes = 6 No -= 2 Unknown = 1	

Personal Participant Descriptions

Personal participant descriptions were created for each participant using several different tools to provide a more comprehensive description of their personalities and overall demeanor. Participants were asked to describe themselves and their working style in their interview. Next, a

video observation form was created after analysis of required training materials, employee recruitment and management materials, and professional materials used by DSPs. Descriptive words typically used to describe both successful and unsuccessful employee traits were summarized into a checklist. These successful and unsuccessful employee traits were taken from the mandatory training materials created by the different regulatory agencies for CILA homes. Finally, the audio/videotapes were reviewed by two researchers trained in qualitative research methods. One of the researchers was the author of this study and the other was a tenured faculty member from a local university. Participants were informed in advance that their audio/videotape would be viewed by both researchers.

Behaviors and non-verbal communication categories included in the observation form for analyzing overall behaviors exhibited by participants during the interview process were accepting, animated, attentive, blushes, bubbly, comfortable, confident, cooperating, crosses arms, defensive, direct and/or forceful, direct eye contact, increased eye movement, fidgets and/or head bobs, forthright, friendly, frustrated, helping others, independent, open, outgoing and/or passionate, parental, quiet and/or private, trustable, uncomfortable, uncooperative, voice change in tone and/or inflection, walled off, and warm. Categories analyzed using the observation form for when DSPs were talking about resident sexuality behaviors, resident affectionate behaviors, perceived support by co-workers, perceived support by supervisors and management, and attitudes about training were accepting, appropriate, attentive, competing, comfortable, cooperating, demanding, dependent, disruptive, exploring, frustrated, helping others, imitating, inappropriate, independent, initiates activity, intent, knowledgeable, making choices, requesting help, shocked, uncomfortable, uncooperative, unsafe activity, and using appropriate manners. Categories analyzed using the observation form for when DSPs were

talking about resident and staff behaviors within the home on the audio/videotapes were also used to identify the DSPs perceptions of what happened in the workplace as well as specific examples and impactful stories for further analysis.

The checklist that used a five-point scale, with one being the lowest level of observation of the attribute, and five being the highest level of the attribute being observed (See Appendix G). First, the author of this study created the video observation form. The purpose of the video observation form was to provide a more accurate and in-depth picture of the participant's comfort level with the research topics as well as to improve the researcher's description of the participant's personalities and non-verbal communication and behaviors. Second, training was provided to the tenured faculty member in advance of the review process. The training consisted of the two researchers reviewing and adapting the video observation form based on the researchers' experiences with qualitative studies and the use of videotapes as a data source.

The tenured faculty member was given a summary of the research project's purpose, problem statement, research questions, study setting, research design, sampling methods, and data collection methods. A discussion took place that explained the terms used in the form and what kinds of behaviors or examples would be included in each term category. For example, initiates activity was exemplified by an employee noticing that a resident used a particular hand motion whenever they wanted a snack and the DSP then shared that knowledge with the rest of the staff to better serve the resident in the future and help the staff better work together. Both researchers practiced completing the form by reviewing a simulated interview audio/videotape and then compared their completed form and results with each other.

After a final question and answer session to ensure the tenured faculty member understood the basics of this project and how to use the video observation form, the form was

completed by the two independent observers while watching the interview videotapes in separate sessions. The two researchers reviewed all of the responses given by the participants to the different interview questions to look for emotions, reactions, and passionate responses to the different research topics. Third, the two researchers met to compare notes, perceptions (including impactful stories), and results of their completion of the video observation form for each participant. Fourth, a personal participant description narrative was developed and shared with the participants for their review, input, and response. In some cases, the participants even solicited the input from their friends and family to help give a more complete picture of their personality and communication styles.

Personal Participant Descriptions

The personal participant description narratives appear below.

Ben. Ben was a Caucasian male who has dark brown hair, brown eyes, and was of median height. He was very athletic and outgoing. He was muscular and had the typical build of a football player. He could be physically intimidating except for the way he carried his body and the way he maintained his stance. He was very calming to be around. He was a “teddy bear” type of personality who was very kind to all those around him. He described himself as patient and did not let much get to him. He stated he could talk to anyone without hesitation and he was very good at allowing people to open up around him and share their emotions. Ben worked in a house with all men, which had some of the oldest residents in of all the CILA homes.

Darius. Working with Darius was like being in the room with quiet power. He was very large, very strong, and very, very quiet. He was a tall African American male who was very athletic. He was soft-spoken but passionate about helping others. Darius was not currently in school but moved down to the area to be with his girlfriend Eva, who was also employed by the

agency and who also volunteered to be in the study. Eva described him as easy to get along with, someone you would love to hang out with, and as someone who was very funny. She said he loved hanging out with his friends and had a real passion for football. She mentioned that he had a serious side as well and planned on being very successful in life. Darius was typically a very calm personality who described himself as mellow. He was thoughtful, careful, and measured in both his speech and his actions. He did not consider himself to be parental but described himself as a big brother or mentor to those he helped. He had a very strong moral compass and was very serious about what he considered to be either right or wrong. Darius worked in a house with all men, which was described as the most sexually active of all the CILA homes by the DSPs interviewed during this project.

Ana. Ana was a vivacious, bubbly personality who was active in social organizations. She was a student leader, who actively solicited interactions within the community. She was well liked by both her fellow students and her fellow employees, per their reports. She considered herself to be a staff leader in her group home. She was a tall, slender, African-American woman who was 23 years old. She had shoulder-length dark hair and attractive features. She actively participated in her sorority as an officer. She had an easy-going personality and frequently smiled. She laughed easily and her eyes tended to sparkle and become animated when she talked. She talked with her hands a lot to emphasize words that she felt were important. She sat back farther in the chair when she was thinking about the words she was choosing to make her point. When she was reflecting on questions, she had a tendency to look towards the right or towards the floor. Ana worked in a house with all men, which had some of the oldest residents in of all the CILA homes.

Ivy. Ivy was a demure, quiet, peaceful personality. She was very pragmatic but charming and polite. She was small in stature but had a commanding presence. She was very observant and watched very closely what went on around her. She was Caucasian, about 5 foot 2 inches in height and had a slender frame. Ivy had curly, light brown hair, glasses and a friendly smile. She described herself as silly and "a-dork-able." She was very kind, inquisitive, and patient with those around her. She had a job the entire time she was working on her undergraduate degree and was very goal-oriented. She planned on making a career of working in agencies that have CILA homes and hoped to move up to management in the very near future. Ivy worked the day shift in a house of all women.

Claire. Claire was an intense, single parent who took her role at work seriously. Her son was autistic and extremely high-energy (ADHD); this caused Claire a lot of stress both as a mother and as an employee. She worked two part-time jobs to support her family but she had to let one of them go because of the needs of her son. She described herself as a plump individual who had blue eyes and short dark hair. She had a few freckles that made her self-conscious. Claire felt like she was different than a lot of the students that attended the same university she does. She felt like she took life much more seriously than her fellow students and their behaviors frustrated her at times because she felt they behaved irresponsibly. She had similar feelings about some of her fellow employees.

Claire had a very social personality and was witty and occasionally sarcastic. She was highly intelligent, analytical, and had excellent planning skills. She cared deeply about those who were in her care and was very nurturing. She was very confident and was very good at taking charge of situations. She was firm, forceful, and forthright in an open, caring manner. She

worked very well independently. She was very comfortable taking a parental role with the clients she served. Claire worked in a house with all women clients.

Henry. Henry was an older African American male who chose to make working with populations with ID his career. He had both a Bachelor's Degree and a Master's Degree in Psychology. He had worked in the agency for an extended period of time and accepted a position with another agency during the course of the study, which was a promotion. He was a serious personality that was very comfortable with the sexuality and affectionate behaviors of the clients he served. He was very competent in the role of DSP and was very trustworthy. He had a strong relationship with upper management and served as a house leader for the other staff. Henry had an easy laugh and the ability to make anyone smile, according to the other DSPs. He was very popular among the staff and the clients. Henry worked in a coed home.

Gia. Gia had a very direct personality and was very open when talking about topics that might make some people uncomfortable. She was focused, goal-oriented, and a natural leader. She was empathetic, kind, and a passionate advocate for people with ID. Gia was married and just had her first child. Gia was one of the most serious and active participants throughout the course of the study. She solicited contact with the researcher to provide additional information or examples of related events that occurred at the workplace during the study.

She planned on making a career of working with populations with ID and was completing a Master's Degree in Family and Consumer Science with a concentration in Family Services. She attended as many training and workshops as she could to help prepare her professionally for her chosen career and in order to better help the clients. Words used to describe Gia by the other staff were accepting, focused, confident, comfortable, open, helpful, responsible, trustable, progressive, direct, forthright, friendly, independent, outgoing, passionate, and respectful of

others. Many of the participants mentioned that Gia suggested they participate in the study. Gia was promoted to management during the course of the research project. Before her promotion, Gia worked in a house with all women clients.

Finn. Finn was a Caucasian, athletic male with an easy-going personality. He was tall, broad, and looked like a stereotypical football coach. He sat in a relaxed manner—sort of blending into the chair. He was a natural leader and well-liked by the other staff members, according to their reports. His girlfriend was also employed by the agency and worked in another CILA home. (Side note: she was asked to participate in the study and refused. In addition, she broke up with Finn during the study—a situation that left him visibly sad.) Finn had an uncle who had special needs who served as his inspiration to go to work in a helping profession. Finn reported that he had always helped out at Special Olympics, ever since he was a kid. His mom also stressed how important it is to help others. His entire family had always been active in working with populations who are ID because of his uncle.

He was considered to be very compassionate by the other staff members, who mentioned they had frequently looked up to him for guidance. However, he considered himself to be a little shy. He had a quick sense of humor and quickly gravitated to anyone who needed cheering up or who appeared to be having a bad day, according to other staff. He exhibited a lot of patience and had a very calming personality. Finn worked in a house with all men, which was described as the most sexually active of all the CILA homes by the DSPs interviewed during this project.

Eva. Eva was a female small in stature but with a huge, bubbly personality. She had a vibrant smile that was the type that really does "light up a room." She was compact but wiry and strong. Eva described herself an easy-going person who loved to laugh and be around positive people. She felt she could be very secretive when necessary but also very open-minded and

handled criticism well. As someone who was family-oriented, she felt she often went out the way to help others. She could be self-sacrificing and liked to put the needs of others before her own. As a spiritual, African American woman, she felt strongly about her role in society and felt an obligation to serve as a role model for other members of her family.

Eva had warm eyes, was very approachable, and cared very much about the clients she served. She was hyper-responsible, proactive, and a "perfect fit" for employment in helping professions. Her personality was one that constantly strived for success and was meticulously organized, especially if something was related to meeting the goals she set for herself. Eva had to take care of her grandmother when she was diagnosed with Alzheimer's and watched how difficult it was for her family to navigate through the many different organizations that were supposed to provide care and assistance to special needs families. This experience translated into a passion for helping others. Eva worked in a home that has all women clients.

Summary of DSPs behaviors and perceptions. The results of the video observation forms indicated overall the comfort levels of the DSPs during the interview process were very positive. DSPs made direct eye contact and exhibited no physical signs of being defensive or uncomfortable. They were friendly, cooperative, forthright, open, and confident. They expressed their acceptance of client rights to be sexual and affectionate and their body language seemed to agree with the positive acceptance they expressed verbally. Each DSP expressed how important it was to them to help others and how protective they were of their clients. Once again their body language seemed to support their verbal expressions. The most common unusual behavior exhibited was confusion, particularly in regards to the policies, procedures, and protocols for behaviors that could be considered sexual in nature. Negative body language was typically only expressed during the interview process when talking about other staff members who did not treat

the clients as well or when discussing a new supervisor. Frowns, shoulder struggling and more movement in their chairs was observed when these topics were discussed.

The results of the video observation forms in regards to perceptions observed from the interview videotapes were mostly positive. DSPs expressed a willingness of the staff to work together to solve problems and the willingness of administration to work with DSPs to solve problems. Their body language, tone, and voice inflection seemed to support those verbal expressions. The DSPs stated they felt they were not recognized enough by the organization for the amount of training they do for each other within the CILA homes, especially with new staff members and new supervisors. Their body language, tone, and voice inflection seemed to support those verbal expressions. Frowns, shoulder struggling and more movement in their chairs was observed when these topics were discussed.

Not a lot of new information was learned by completing the video observations forms. However, the most helpful aspect of the process was the identification of impactful statements that were not viewed as important in the initial precoding and coding stages. The audio/videotapes aided in the emotion and value coding portion of the data analysis because the DSPs used tone, inflection, and passion to emphasize the topics, issues, and problems they were most passionate about during the interview process. The information in the transcript did not seem as impactful or important simply by reading the transcripts. Listening to and observing the audio/videotapes allowed for the identification of additional important stories and for the identification of additional topics that needed further follow-up and exploration. This occurred because of the passion in which the DSPs presented their stories and examples of incidents in the workplace on the audio/videotapes. This aided in the identification of what they cared about and viewed as important.

Research Question #1: How do employee training and training materials help guide staff behavior in regards to sexuality and affectionate behaviors of residents?

Several sources of information were used to answer this research question. First, document analysis was conducted on a selection of agency materials given to new DSP employees such as the employee handbook, the agency DSP training notification and registration form that outlines the mandatory training that must be completed by new DSPs, the agency volunteer information packet and application, the agency DSP job description, and the DSP code of ethics.

Pertinent policies and procedures from these documents were summarized to provide the context and background for the work environment of the DSPs, as well as the agency training provided to inform them of the agency rules and regulations. The structure in which they work is important as it directly influences the choices they make in their day-to-day jobs. Next, document analysis was conducted on the mandatory training modules prepared by the Department of Human Services and the mandatory on-the-job training materials also required by the Department of Human Services. A detailed explanation of the DSP training requirements was provided to give a detailed and in-depth understanding of the range of work activities involved in being a DSP and to provide an understanding of the diverse skills required to be a DSP. In order to consistently evaluate the different training materials from the various organizations, a language usage analysis form was developed. Review of the documents revealed a pattern in word usage, with the same words used over and over.

Repetitive words were written down and counted as each document was analyzed. Once a definite pattern was identified, those dominantly used words were included on the language usage analysis form. Next, the repetitive words were divided into two groups—negative and

positive. Words that could have a negative connotation, such as abuse, were labelled negative. Words that could have a positive connotation, such as advocate or recovery, were labelled positive. This distinction is important because this study looked at how the agency, the regulatory agencies, the mandatory training, and the training materials portrayed human sexuality and affectionate behaviors in populations with ID to the DSPs. The Language Usage Analysis form was completed for all the documents included in the document analysis. The negative and positive words appear in the Label column of the form. Each label was counted in each document and the number of times it appears in the document was tabulated on the form. In most cases, the negative labels were utilized much more than the positive labels. Finally, DSP interview responses to training questions were provided for the categories of positive feelings/experiences, negative feelings/experiences, and little or no memory of training topics.

There are three primary concerns after completing the document analysis. First, the negative language choices influenced the experiences and attitudes of DSPs in the workplace in a negative way. Specifically, existing human sexuality training was geared towards preventing negative behaviors and materials appear to be negatively skewed for not only the way the information was presented but also with the emphasis on enforcement and potential penalties if the "wrong" behaviors" took place in the workplace. Negative language was the prevalent type of language used in all the training materials reviewed.

Second, while the training schedule required by the DHS was intensive and required a minimum of 120 hours of training in the first 120 days of employment, it included little training on the topic of human sexuality. The sexuality section of the DHS Human Growth and Development Module consisted of one page which asked the DSP to "match the terms penis, vagina, testes, genitals, clitoris, intercourse, masturbation, ejaculation, scrotum, foreskin, uterus,

and anus with the correct description on the other side of the page" (DHS, 2013, p. 17). The Module did include one additional page of information on menstrual care. All other human sexuality education provided or required by the agency or DHS covered sexual abuse prevention; no positive sexuality training was provided. A lot of mandated training topics existed for DSPs but no regulatory agency required training specifically addressing human sexuality. Third, most of the DSPs did not remember the specifics of their mandated training program once on the job.

Training Materials Document Analysis

All documents included in the study were read in their entirety. Next, the document analysis form was completed for each set of materials (see Appendix H). Agency documents used for document analysis were the Agency Employee Handbook, the Agency DSP Training Notification/Registration Form, the agency website, DHS Mandatory Training Modules, SACIS Employee Training Session Handouts, the Agency Volunteer Information Packet and Application, Agency DSP CILA DSP Job Description, DSP Code of Ethics, and Agency on the Job Training Materials. Training materials were created by multiple agencies: Department of Human Services (DHS), Office of the Inspector General (OIG), the agency, and SACIS. Training topics are mandated by DHS and the OIG. All DSP training must be documented in employee files and be made available during site inspections for licensing and accreditation purposes. Each document was reviewed first for content and then for language usage.

Training DSP Training Notification/Registration Form

The Training DSP Training Notification/Registration Form informed new DSP of both the agency and DHS mandatory training requirements. It was actually a packet that included the informative checklist, the registration form, and a brief description of each of the required trainings. The agency provided training that included mandatory in-services, training,

certification, and/or licensure for its employees depending on position, department, and work requirements. The agency also had periodic, mandatory staff meetings with employees in order to communicate with employees, to provide training on safety-related matters, and to ensure quality services are being provided to individuals (Agency Employee Handbook, n.d.). DHS mandated employees with direct care responsibilities must complete DSP certification training, including OJT within 120 days of employment. The training included the following modules: Introduction to Developmental Disabilities, Human Rights, Human Interactions, Individualized Service Plan (ISP), Abuse/Neglect, Health & Safety I, Health & Safety II, Crisis Prevention Institute (CPI), CPR/First Aid, Medication Administration, On the Job Training (OJT) (See Table 7.)

Table 7

Mandatory DSP Training Topics

Training Topic and/or Requirements	Regulating Agency	Type of Training
Intro to Developmental Disabilities	Department of Health & Human Services	Mandated class
Human Rights	Department of Health & Human Services, DOJ	Mandated class
Human Interactions	Department of Health & Human Services	Mandated class
ISP	Department of Health & Human Services	Mandated class
Abuse/Neglect	Department of Health & Human Services, DOJ	Mandated class
Health & Safety I	Department of Health & Human Services	Mandated class
Health & Safety II	Department of Health & Human Services	Mandated class
Crisis Prevention Institute (CPI)	Department of Health & Human Services	Mandated class
CPR/First Aid	Department of Health & Human Services	Mandated class
Medication Administration	Department of Health & Human Services	Mandated class
Literacy Testing	State Law	Mandated test
TB Test with results	Department of Health & Human Services	Mandated test
Hepatitis B Inoculation Series	Department of Health & Human Services	Company Benefit
On-the-Job Training (OJT)	Agency	Agency OJT
Driving Requirements/Clearance	Agency	Agency Policy
Background Check	Agency	State Requirement
HIPAA Training	Department of Health & Human Services	Federal Requirement
Dress Code	Agency	Agency Policy
Ethical Standards	Agency	Agency Policy
Professional Conduct	Agency	Agency Policy
No Smoking Policy	Agency	Agency Policy
Safe Work Environment Policies	Agency	Agency Policy
Alcohol & Drug Policies	Department of Health & Human Services, DOJ	Agency Policy
No Cell Phone Policy	Agency	Agency Policy
Special Topics	Outside Agencies	OJT

Adapted from Human Resource Training Schedule & Agency Employee Handbook

Licensing Agencies Mandatory Learning Modules

Language used in various training materials was analyzed for either a negative or positive power influence in regards to the topics of sexuality and affectionate behaviors. The analysis of

language was an unanticipated research focus of this study. The researcher began a preliminary examination of the documents to be included in this study with the review of a one-page, back-to-back brochure on the topic of prevention of sexual abuse. The negative language prevalent throughout the document impacted the researcher both emotionally and intellectually. A cursory review of the other documents resulted in an overwhelming amount of negative terms and phrases using the same core language and expressions. At that point in the study, additional analysis tools were developed starting with the core language and expressions to analyze all of the documents in the study for use of language as well as the original subjects included in the study.

The language usage analysis form was created and used to analyze the DHS Human Rights Module, DHS Abuse Module, DHS Human Interaction Module, DHS Health Module, and The Office of the Attorney General's Abuse Module. The DHS Abuse Module used the word abuse 112 times, the word inappropriate 12 times, the word stigma twice, and the word perpetrator eight times, for a total of 134 negatively powered words through the document. In contrast, it only used 29 of the positively powered words. Also in contrast, the DHS Human Interaction Module only used four of the negatively powered words but used 68 of the positively powered words (See Table 8).

Table 8

DHS Training Materials Analysis – Language Usage Analysis

Type of Influence or Power	Label	Required Human Rights Module # of Appearances	Required Module Abuse # of Appearances	Required Module Human Interaction # of Appearances	Required Module Health # of Appearances	OIG Abuse Training # of Appearances
Negative	**Abuse**	14	112			35
Negative	**Assault/Sexual Assault**					
Negative	**Crisis**					
Negative	**Harassment**					
Negative	**Inappropriate**	1	12	4		
Negative	**Perpetrator**		8			
Negative	**Rape**					
Negative	**Sexual Exploitation**	1				3
Negative	**Sexual Violence**					
Negative	**Stigma**		2			
Negative	**Trauma**					
Negative	**Victim**					3
Negative	**Victimization**					
Positive	**Advocate/Advocacy**	14	4	14		
Positive	**Confidential**	16				
Positive	**Healthy Relationships**	12	2	34		
Positive	**Help/Helping**	8	9			
Positive	**Reclaim**	1				
Positive	**Recovery**					
Positive	**Prevention**	4	8	10		2
Positive	**Respect/Sensitivity**	16	6	20		1
Positive/Negative	**Survivor(s)**					

On the Job Training

On the job training (OJT) is required by the regulatory agencies. The DHS required OJT includes 73 packets of training materials, forms, activities, and worksheets that must be

completed and be kept in each DSP training folder. Using the term "on-the-job-training" was misleading because the agency really had very little input or control over these OJT training required by DHS. DHS had mandated the topics, the materials used to document the trainings, and the worksheets that must be completed as part of the required trainings. Topics ranged from an introduction to the People First Terminology to how to help a resident on and off a toilet. Human sexuality and affectionate behaviors were not covered in any of the OJT activities. One packet did cover injury reporting but it was geared more towards first aid scenarios. Another packet covered how to recognize and report maltreatment, which was further review of the OIG guidelines and requirements about reporting physical abuse in any form. The segment on "Creating & Maintaining a Trust-Producing, Healthy, Engaging Environment" covered the physical environment and how to be an active listener.

Prevention strategies included recognizing individual employee attitudes, emotions, and vulnerabilities; reduce negative and increase positive as part of prevention; and self-awareness. Communication training included non-verbal, verbal, and sign language. Additional training topics included grief training and typical OSHA training topics such as bloodborne pathogens, first aid, cardiac pulmonary resuscitation, automatic external defibrillator, disease prevention, general health, basic nutrition, food safety, hygiene, and disaster planning and response. As necessary, additional site specific training was developed by the agency as a response to the needs of the DSPs, other staff, clients, or agency.

Minimum training required was 40 classroom hours followed by at least 80 OJT hours. The training must be completed within 120 calendar days of hire date and each employee must receive at least 80% accuracy on the classroom portion of the training. Classroom hours may not include breaks or lunch time. Each module must have a completed checklist on file in each

person's training record. The training topic requirements included in the 40 classroom hours and the 80 hours of OJT are:

Module 1 – Introduction to Developmental Disabilities – 5 hours

Module 2 – Human Rights – 5 hours

Module 3 – Abuse, Neglect & Exploitation Recognition, Prevention & Intervention – 5 hours

Module 4 – Human Interaction & Communication – 5 hours

Module 5 – Service Plan Development & Implementation – 5 hours

Module 6 – Basic Health & Safety – 20 hours

Agency Selected OJTs – selected from DHS approved trainings – 35 hours

DHS Training Modules pertaining to sexuality and affectionate behaviors included:

Module 1, Section 2, Psychosocial needs of individuals

Module 1, Section 3, Basics of human growth and development

Module 2, Section 5, HRC's role in preventing abuse, neglect and exploitation

Module 2, Section 8, Principles of advocacy

Module 2, Section 12, Agency Policies

Module 3, Sections 1-8, Prevention/Recognition/Intervention of Abuse/Neglect/Exploitation

Module 4, Section 10, Types of relationships

Module 6, Section 18, Role of bodily functions

Module 6, Section 19, Dimension of human sexuality

Agency Website

The agency's website was one of the first thing prospective employees see. It included employment opportunities as well as the job descriptions for the different positions available within the agency. In addition, the agency's mission statement, vision statement, and philosophy towards client services and abuse prevention are focal components. The agency's website was well designed and provided compressive information about the multiple programs available through the state. It was eye-appealing and easy to maneuver. It contained a positive focus and included many graphics that aid in the overall positive appeal of the webpages. Contact information for the staff responsible for each program was readily available, as well as basic information on the eligibility requirements to obtain or utilize the different services for populations who are disabled.

Agency Job Application and Employee Handbook

Agency job application. Applicants looking for a job with the agency typically visited the agency website and/or picked up potential employment materials at the Human Resource Office, including an agency job application. The job application for the DSP position was a multiple-page document. The document included information about liability and confidentiality requirements as well as the agency's philosophy about how to treat the clients served by agency programs.

Agency description. The agency employee handbook was one of the first phases of new employee training provided by the agency. Each employee must sign that they read the handbook and they received a copy of the employee handbook for their future use. The agency's rules, regulations, and policies are clearly stated in the handbook. The agency emphasizes the fact that it was accredited in five programs by the Commission on Accreditation of Rehabilitation

Facilities (CARF), was accredited by the State Department of Human Services (DHS), and is a member of the State Association of Rehabilitation Facilities (ARF). The agency was a participating agency in a state-wide self-advocacy initiative, funded by DHS and designed to "empower people with developmental and other disabilities to make their own decisions, stand up for their rights and speak for themselves based on their strengths and desires" (Agency Employee Handbook, p. 1). This was important because the handbook clearly stated that DSPs are expected to live up to the professional standards of both the profession of DSPs and the accrediting bodies of the agency.

The mission of the agency was to "empower individuals with developmental disabilities through services and programs that help them reach their potential in an environment that fosters respect, dignity, and success for each individual" (Agency Employee Handbook, p. 2). The agency expected each employee to maintain high standards of conduct, professionalism, and appearance during all scheduled work periods. It was the philosophy of the agency that the success of the agency depended on the treatment of people, and considers it was every agency person's responsibility to treat individuals receiving services, stakeholders, visitors, vendors, and one another with respect and understanding (Agency Employee Handbook, n.d.). DSPs were held to the code of ethics for their profession and the code of ethics for the agency. DSPs were expected to uphold the agency mission, goals, and objectives; conduct personal and professional activities with honesty, dignity, integrity, equity, social justice, competence, and good faith manner; to take adequate steps to prevent personal issues from interfering with their professional duties; respect the need for discretion and confidentiality; and to respect the cultural attributes of individuals receiving services and others (Agency Employee Handbook, n.d.).

Confidentiality was further mandated by compliance with the Health Insurance Portability and Accountability Act of 1996 (HIPAA), which governed the way DSPs use and share protected health information (PHI) (Agency Employee Handbook, n.d.). DSPs must take reasonable steps to safeguard protected health information, whether it was electronic, written, or spoken (Agency Employee Handbook, n.d.). The agency recognized the importance of employees being active citizens in their communities by volunteering for civic boards and working with community service organizations. The agency supported such involvement as long as confidentiality was maintained (Agency Employee Handbook, n.d.). This was important because the handbook was the first agency training document that spelled out the requirements for the new DSPs and sets the standard expected by the agency for the new DSP employee.

Qualification & selection of employees. How the agency selects DSPs was important because it gave an in depth explanation of the qualifications expected of DSPs before they are allowed into the CILA homes to work with clients. It spoke to their qualifications and skills for working with clients who were ID. Employees were selected based upon their qualifications and the ability to meet the requirements of the position for which they were hired. All employees must have been at least 18 years of age to serve in a position that provides direct care to individuals, which included DSPs. The agency was required by law to submit a criminal background check to the state police for each employee (Agency Employee Handbook, n.d.). The agency was required to contact the State Department of Public Health's Health Care Worker Registry regarding applicants and employees to ensure no disqualifying condition existed before any applicant was hired (Agency Employee Handbook, n.d.).

Employees who worked an average of 30 to 40 hours a week were considered to have been employed full-time. Employees who worked an average of less than 30 hours per week

were considered to have been employed part-time (Agency Employee Handbook, n.d.). Employees in direct care positions such as DSPs were required to provide proof of education no later than the third day of employment or the employee will be suspended or terminated (Agency Employee Handbook, n.d.). DSPs who would be supervising medication administration must have demonstrated functional literacy equivalent to an eighth grade reading level as required by state regulations (Agency Employee Handbook, n.d.). Employees who failed to demonstrate this competency were not eligible for further medication training and did not receive their supervision of medication administration certificate (Agency Employee Handbook, n.d.).

Employee support & value. The agency philosophy was "the individuals we serve are the core of our organization. The individuals we serve are the most important members of our organization, and the employees who serve these individuals are highly valued" (Agency Employee Handbook, n.d.). According to the agency employee handbook (n.d., p. 3) "employees should never feel that their concerns are too small to deserve management's attention. Further, the best employment relationships result from open communication between the employee and the employer." This is important because DSPs were frequently working in the CILA homes without direct supervision, with a supervisor on-call if they are needed. Perceived support from supervisors and administration directly influenced DSPs perception of their abilities to do their jobs as well as how much they enjoyed working for this particular agency.

Abuse, neglect, misconduct & disciplinary procedures. All agency employees were responsible for knowing and adhering to protocols for reporting allegations of abuse, neglect, or exploitation of individuals receiving services in accordance with agency policies, procedures, and in accordance with the requirements of the Office of the Inspector General (OIG) (Agency Employee Handbook, n.d.). According to the OIG, all allegations of mistreatment, abuse,

neglect, or exploitation of individuals receiving services were mandated to be thoroughly investigated. The results of the investigation were mandated to be reported to the agency's compliance officer at the conclusion of the investigation. Applicable sanctions, including termination and/or reporting to the appropriate authorities were mandated to be invoked if an allegation is substantiated. Authorities to which the agency may be mandated to report the incident may include the local and/or state police, DHS, DPH, and OIG (Agency Employee Handbook, n.d.).

Misconduct was defined by the agency as "as serious infraction or violation of agency policies, procedures, or protocols governing employee behavior and work performance (Agency Employee Handbook, n.d.). According to the agency employee handbook, examples of misconduct included:

- Insubordination, sleeping on the job, or theft
- Possession, use, sale, or purchase of non-prescribed drugs or intoxicants on company property or during work hours
- Working under the influence of alcohol, illegal drugs, or intoxicants
- Verbal or physical threats or fighting on company property or during work hours
- Destruction, abuse, or misuse of company property
- Falsification or improper alteration of records, including employee time sheets
- Abuse, neglect, or exploitation of individuals receiving services
- Disclosure or misuse of confidential information.

The agency employee disciplinary procedures were designed to identify and correct problems that might affect an employee's work performance or the services provided to individuals. These procedures provided employees and their supervisors with a system to discuss

specific problems, determine when and how these problems can be corrected, and to set goals and follow-up actions. When a supervisor determined that an employee is not meeting performance or conduct standards, disciplinary action and/or termination may follow. Potential disciplinary procedures included counseling, verbal warning(s), written warning(s), unpaid suspension, or termination (Agency Employee Handbook, n.d.). This background of the system in which DSPs work is important because DSPs reported how much they rely on each other in the CILA homes when problems arise and how much it hurt both the staff and the clients when a substandard employee joined their house staff.

One topic covered specifically in the Agency Employee Handbook was sexual harassment. Sexual harassment was defined as "unwelcome and/or unsolicited sexual advances, requests for sexual favors, and other verbal, written, or physical contact or sexual nature or otherwise nature" (Agency Employee Handbook, n.d.). Further, the conduct involved the behaviors being made a condition of employment, either stated or implied or the conduct unreasonably interfered with the employee's job performance or created a work environment that was intimidating, hostile, or offensive (Agency Employee Handbook, n.d.). No other reference to sexuality or affectionate behaviors appeared in the Agency Employee Handbook.

Agency Volunteer Application & Training Packet

Anyone who visits a CILA facility as volunteer must go through a volunteer screening process. Potential volunteers must have completed the application process, passed a background check, completed mandatory trainings, and signed all required forms before volunteering at any CILA home. Potential volunteers must have also met with a member of the management staff and completed a screening interview. The Volunteer Application and Training Packet consisted of the following documents:

1 copy - Agency Welcome Letter from Human Resources Director
2 copies - Volunteer Agreement
1 copy - Agency Volunteer Program Handbook
1 copy - Social Network Policy
1 copy - Agency Volunteer Information Form
2 copies - Background Check Acknowledgement Form
2 copies - Declination of Abuse and Healthcare Worker Background Check
2 copies - Important Notice to Volunteers about Prior Criminal Convictions
2 copies - Procedure for Reporting & Investigating Allegations of Abuse/Neglect/Mistreatment
1 copy - Office of the Inspector General Reporting Abuse & Neglect Training Booklet
1 copy - HIPAA Training for Volunteers

Agency DSP Job Description

New employees were given a job description and an employee handbook. The job description included a very specific summary of the tasks and obligations required of DSPs. The employee handbook provided details about each job task—including the potential consequences if the task was not completed according to agency standards and regulations. The language used in various training materials was analyzed for either a negative or positive power influence in regards to the topics of sexuality and affectionate behaviors (See Table 9).

Table 9

Agency Documents – Language Usage Analysis

Type of Influence or Power	Label	Agency Website # of Appearances	Agency Employee Handbook # of Appearances	Agency Volunteer Application Packet # of Appearances	Agency DSP Job Description # of Appearances	Agency Job Application # of Appearances
Negative	**Abuse**		11	48	1	1
Negative	**Assault/Sexual Assault**			5		4
Negative	**Crisis**		2			
Negative	**Harassment**		10	9		
Negative	**Inappropriate**		2			
Negative	**Perpetrator**					
Negative	**Rape**					
Negative	**Sexual Exploitation**		1	8		2
Negative	**Sexual Violence**		2	4		
Negative	**Stigma**					
Negative	**Trauma**					
Negative	**Victim**			3		
Negative	**Victimization**					
Positive	**Advocate/Advocacy**	22	8	4	9	1
Positive	**Confidential**		10	27	4	2
Positive	**Healthy Relationships**	22	4		1	
Positive	**Help/Helping**	12	2	3	5	
Positive	**Reclaim**	1				
Positive	**Recovery**	4				
Positive	**Prevention**	9			4	
Positive	**Respect/Sensitivity**	26	8	8	5	
Positive & Negative	**Survivor(s)**					

Sexual Assault Counseling & Information Center (SACIS) Workshop Materials

Brochure. According to the brochure, SACIS was committed to changing attitudes that foster violence toward others. Services were available regardless of age, gender, race, disability, spiritual preference, ethnicity, or sexual orientation. SACIS training was available to cover topics

on sexual victimization issues. SACIS worked with various institutions to help reduce the stigma associated with being a victim of sexual assault and to help improve recovery conditions for all victims within their service area.

PowerPoint presentation slides. The presentation was geared to women victims. Disability was defined as "not what someone has, but occurs within the environment, outside the person" (SACIS, 2012, pg. 2). Environment could be the physical environment, communication environment, information environment, and/or social and policy environment. According to SACIS, a new way of looking at disability helped our society understand that it is a matter of degree (2012). SACIS considered one was more or less disabled based on the intersection between one's self, one's functional abilities, and the many types of environments with which one interacts (2012). The experience of disability was minimized by designing environments to accommodate varying functional abilities and providing individualized solutions when needed (SACIS, 2012).

In 2001, the World Health Organization (WHO) established a new definition of disability, declaring it an umbrella term comprised of several components:

- impairments to include a problem in body function or structure;
- activity limitations to include a difficulty encountered by a person in executing a task or action;
- and participation restrictions to include a problem experienced by person in involvement in life situations.

This definition was based on human rights and social models that focused on the interaction of a person with a disability of any kind and their environment (WHO, 2001). The civil rights model of disability said that the disability was a social construct, meaning that it was a society that is

not set up to support and empower people who had disabilities (SACIS, 2012). Historically, issues related to sexual behavior and persons with disabilities have been avoided.

People first language presentation. People first language focused on the individual rather than the disability. The preferable term to use was “people with disabilities” instead of disabled people. It was considered more sensitive and respectful to use appropriate terminology. People first language diminished the impact of negative labels (SACIS, 2012). The point was to see each individual as a person first and respond to them with dignity and respect in all circumstances.

Discussion guides & workshop handouts. The issue of consent was considered to have been complicated. Guardians were not always available, or may have had interests that were adverse to those of the victim. This could have become an issue in regards to releases of information, treatment, and attendance at counseling sessions. The current law did not require the consent of a guardian, health care surrogate, or health care power of attorney in order for a victim with a disability to receive health care or release forensic evidence following a sexual assault (SACIS, 2012). If a victim with a disability was unable to consent to the release of evidence, and the victim’s guardian, health care surrogate or health care power of attorney was unavailable or unwilling to release the information, an investigating law enforcement officer may release the evidence. A physician, not a team of professionals, decides whether the victim with a disability has “decisional capacity,” or the ability to make decisions about her own health care and releasing evidence. The physician makes a decision after having a conversation with the victim and exercising professional judgment. Effective January 1, 2012, the Sexual Assault Emergency Treatment Act (SASETA) was amended to protect the personal autonomy and choice

of a sexual assault victim with a disability in receiving emergency health care services and releasing forensic evidence (SACIS, 2012).

Language used in various SACIS workshop materials was analyzed for either a negative or positive power influence in regards to the topics of sexuality and affectionate behavior. Brochures, PowerPoint slides, discussion guides, and handouts were evaluated. Materials were furnished by several DSPs who attended the workshop (See Table 10).

Table 10

SACIS Workshop Materials –Language Usage Analysis

Type of Influence or Power	Label	SACIS Brochure # of Appearances	SACIS PowerPoint # of Appearances	SACIS Discussion Guides # of Appearances	SACIS Handouts # of Appearances
Negative	**Abuse**	2	3	10	1
Negative	**Assault/Sexual Assault**	5	10	4	36
Negative	**Crisis**	1	1	3	11
Negative	**Harassment**	1		1	1
Negative	**Inappropriate**		1	1	
Negative	**Perpetrator**		2	3	
Negative	**Rape**		1	5	12
Negative	**Sexual Exploitation**		1		1
Negative	**Sexual Violence**	3	10	38	
Negative	**Stigma**	1		2	
Negative	**Trauma**		6	17	
Negative	**Victim**	1	6	1	10
Negative	**Victimization**	1	1	2	1
Positive	**Advocate/Advocacy**		1	5	1
Positive	**Confidential**	1		1	
Positive	**Healthy Relationships**	1		8	
Positive	**Help/Helping**	2			
Positive	**Reclaim**	1		1	
Positive	**Recovery**	1		3	
Positive	**Prevention**	1		1	
Positive	**Respect/Sensitivity**		5	3	
Positive/Negative	**Survivor(s)**	4	7	2	2

Codes and categories were developed for the interview transcripts. From these codes and categories, themes were developed. The constant comparison method was used to develop the

categories and themes. Throughout the coding process common and less common categories were formed. These categories were developed from the responses from the interview question responses from the DSPs. Specific details about the common categories appear below. The overall themes were Employee Training and Development, Socialization Needs (Affectionate Behaviors, Sexuality, and Relationships), and Language Issues (Positive, Negative, and First Person).

The common categories developed for types of training were sexual abuse prevention, confidentiality, First Aid and Cardiopulmonary Resuscitation (CPR), and how to disperse medications. The need for more human sexuality training was also mentioned by all DSPs but little or no training on this topic was already in existence. Less common categories were CPI, crisis management, disease transmission, human rights, online daily reporting case management system, personal liability, state and federal laws, and self-protection from weapons.

The common categories of affectionate behaviors were females flirting with others, males flirting with others, female friendship, male friendship, female socialization, male socialization, females holding hands with others, males holding hands with others, female hugging, males hugging, female use of media, female use of technology, and males use of technology. Less common categories of affectionate behaviors were female attention seeking behaviors, male attention seeking behaviors, female ego, male ego, female dating, male dating, female problematic affectionate behaviors, male problematic affectionate behaviors, affectionate behaviors safety versus privacy issues, female other types of behaviors, and male other types of behaviors. The common categories of sexuality and masturbation behaviors were male groping, public male masturbation, private male masturbation, female problematic sexual behaviors, and male problematic sexual behaviors. Less common categories of sexuality and masturbation

behaviors were female groping, public female masturbation, private female masturbation, female sexual intercourse, male sexual intercourse, sexuality safety versus privacy issues, female problematic sexual behaviors, female marriage, and male marriage. The common categories of influences on sexuality/affectionate behaviors were policy, consent, guardianship, communication, and privacy. Less common categories on sexuality/affectionate behaviors were setting and functional level.

Categories were developed for the concept of choice. The most common category in regards to choice and sexuality/affectionate behaviors was the perceived lack of choice due to medical or physical reasons. The identified level of ID was included in this category as being viewed as impactful by the DSPs.

Less common categories developed for choice were has the ability to make an intellectual choice, does not have the ability to make an intellectual choice, or choices are made for the client by the guardian, parent, or case manager. Gender categories were developed from the interviews but very little data about gender was generated through the interview process. The categories developed were gender bias against females, gender bias by females, gender bias against males, and gender bias by males. The most common category in regards to the ability of the resident to give consent for participation in sexuality/affectionate behaviors was the unknown category. Less commons categories developed for consent were lack of ability to give consent due to medical or physical reasons, lack of ability to give consent due to legal reasons, client had the intellectual ability to give consent, and the guardian/parent/case manager made the choices for the client. An analysis code summary was prepared to identify emerging themes. In addition, research questions were evaluated to measure how and if the data collected were sufficient to answer the research questions. The results are presented in Table 11.

Table 11

Interview Analysis Code Summary

Developing Theme	Category/Code	Research Question 1	Research Question 2	Research Question 3	Research Question 4
Perception of Training	Positive Feelings/Experiences	√			
Perception of Training	Negative Feelings/Experiences	√			
Perception of Training	Little or No Memory of Training Topics	√			
Socialization/Affectionate Behaviors	Attention Seeking/Ego		√		
Socialization/Affectionate Behaviors	Dating		√		
Socialization/Affectionate Behaviors	Flirting		√		
Socialization/Affectionate Behaviors	Friendship & Socialization		√		
Socialization/Affectionate Behaviors	Holding Hands & Hugging		√		
Socialization/Affectionate Behaviors	Media & Technology		√		
Socialization/Affectionate Behaviors	Other		√		
Socialization/Affectionate Behaviors	Problematic Behaviors		√		
Socialization/Sexuality Behaviors	Dating & Marriage		√		
Socialization/Sexuality Behaviors	Groping		√		
Socialization/Sexuality Behaviors	Masturbation - Females		√		
Socialization/Sexuality Behaviors	Masturbation - Males		√		
Socialization/Sexuality Behaviors	Sexual Intercourse		√		
Socialization/Sexuality Behaviors	Other Related Behaviors		√		
Socialization/Sexuality Behaviors	Problematic Behaviors		√		
Feeling Prepared	Positive Feelings/Experiences			√	
Feeling Prepared	Negative Feelings/Experiences			√	
Perceptions of Influence	Policies, Procedures, & Protocols				√
Perceptions of Influence	Affectionate Behaviors				√
Perceptions of Influence	Sexuality Behaviors				√
Perceptions of Influence	Serving as Sex/Health Educator				√

Participant Perceptions of Training

For research question one, each participant was asked the following questions and follow-up questions about training and training materials at their work site:

1. Describe the training you had to complete for your job, and
2. What type of training did your employer provide to help prepare you or help you deal with work issues?
3. What training topics do you remember?
4. What was your favorite type of training?
5. What can you remember about your training for sexuality and affectionate behaviors?

A summary of the findings from this section of the interview data analysis indicates the DSPs have some problems with the current training provided by the agency and mandated by DHS. First, too much training is required at once on too many different topics. According to Ana, "the training doesn't really stick with you because there is so much of it so fast." This was also the opinion of Claire and Darius. Staff felt the training was comprised of too many worksheets and not enough of the video scenarios. Most of the DSPs remembered the video training scenarios but less than half of them could name most of the required DHS training topics. Next, the DSPs would like to see additional trainings be made available to the staff. The most requested types of training were sexuality education for both the staff and the clients and sign language courses to allow for better communication with the clients. Additional training requests were for more in-depth first aid and CPR training (including choking), relationship basics for the clients, health education, policies for sexuality for the clients, and how to help clients develop their social skills.

DSPs felt bombarded with negative concepts and word choices in regards to sexuality and affectionate behaviors in the CILA setting. The training materials implied all such behaviors

were a crime or strictly forbidden. Gia stated: “When I look at the training, it is no, no, no. So if I was 18 and I just took 12 to 25 hours of training that said no, it’s bad, it’s bad, it’s bad, you must call in and report it right away, I wouldn’t necessarily know that I was supposed to be supportive of clients having normal needs and normal relationships.”

Two training topics were particularly liked by the DSPs. One was the CPI training, a passive restraint training program that helps staff protect both themselves and the clients when they are having a meltdown. The other was an agency course provided to the staff on how to groom an African American person’s hair. DSPs expressed a need for and an interest in more training on the topics of client socialization, human sexuality, and the identification of what each level of functioning meant in regards to client behaviors and abilities.

Participant Perceptions of Training – Positive Feelings/Experiences

The personal DSP description narratives for perceptions of training appear below.

Ivy. “We had about 40 hours of classroom training. My class met some mornings, some evenings. Then we had OJT that was very laid back, and probably changed from site-to-site. Topics I can remember are OIG – Abuse & Neglect, Medication Pass Training, Crisis Prevention Intervention, CPR/First Aid, Epi-Pen, Risk of Falling/Gait Belts, Hand-Washing, and Intro to Disability.”

Henry. “The training was about teaching and conducting productive meetings, coordinating health and medical services, creating an abuse-free environment, maintenance, public relations, networking in the community, general safety, site safety, personal issues, staff training and development, things like that.”

Claire. “My training was held in an agency center away from the clients. We covered abuse, diet, health and safety, documenting, CPR, CPI, first aid, med administration and HIPAA.

It was done in a classroom setting with handouts of the PowerPoint slides. There was limited role playing. Training was held during normal business hours over three weeks. Most days we covered one topic."

Eva. **"**It is like, when a new staff is hired, the staff that is currently on the job with the new staff, basically, has to train the new staff. So if, like, anything out of the ordinary goes wrong, out of the ordinary meaning for the new staff that they are not used to, then that is where we step in and say, this is her behavior. This is what she does. Just keep her calm or redirect her into another activity."

Ben. "Some training is to benefit both of us-the staff and the consumer. The CPI training is actually for us to help us protect ourselves but also to protect the consumer—because we are not trying to hurt them, we are just trying to get out of a bad situation. If you are cornered, you have to figure out a way to get out of it without harming the consumer and without harming yourself too."

Darius. "I remember them showing us a few video clips on everything like how to just talk to them about stuff. Like if a client asks us what a body part is, we should just sit down with them and it explain to them the best way we know how. I remember the instructor saying they have had clients who had sex and that we should say that is okay because they have the right to it because they are human. They have rights with what they can do. They just said they have to go in a room. I remember that they said some of them might be on birth control or that you might catch them masturbating or anything like that. It was nice training that was really helpful. I really liked the scenario training. I think we really remembered it. There was a scenario with a specific situation, and then the opportunity to talk through it and figure out what is the right versus the wrong choices. I really liked that kind of training. What I remember most was the class about

preventing sexual abuse. I don't remember what it was called but we did go over and over it. I can't remember most of the training we had. I know some of the topics we talked about but I cannot remember any of the training names. I know we talked about outings, communication, medications, and how to answer questions."

Henry. "You know, some of our OJT, like one of them, they have to learn how to groom an African American person's hair because there was an issue where white people didn't know how to do it because they didn't have that kind of hair so they had an OJT here where they learned how to groom somebody."

Eva. "Nothing has ever happened that caught me by surprise. Specifically a situation where -- we have one higher functioning. She tried to attack me. It wasn't that I didn't know how to handle the situation. Because when hired, you actually get trained to handle those type of situations. And luckily for me, there was other staff there to intervene. So that was the one incident that I encountered where the training was very beneficial."

Claire. "I tried teaching my ladies about breast cancer for Breast Cancer Awareness month. They didn't understand the concept so if I were to attempt sex education I don't think it would work. Maybe good touch/bad touch but that is about it."

Participant Perceptions of Training – Negative Feelings/Experiences

Ana. "I can remember having medication training, first aid/CPR, and CPI training. We have on-going training as needed but it is usually as a reaction to something that has happened in one of the houses. The training doesn't really stick with you because there is so much of it so fast. For instance with the medicine certification if you make so many errors you have to be re-trained to keep your certification. The agency takes it very seriously."

Claire. "I don't think all the information from the mandatory training is absorbed. I would say our training classes are pretty much we sit in a classroom for eight hours a day. You just sit and do worksheets and stuff. A lot of people space out during their training."

Ben. "I think they need more training for emergency situations like choking. I remember the med certification training, CPI, CPR. It seems like most of the training is to prevent harm to the consumer. You do learn basic stuff like what to do if they bite you. There are different kinds of appropriate reactions—like if they were to choke me you have to figure out a different way to get out of that without harming them. If you harm them, there is a liability for you. You can be sued, you can be fired—there are tons different things. If I give the wrong medication I can be sued. That is why we have so much training."

Claire. "I wish we had more training in communication. My job would be better if I could communicate better with my ladies. Our house is all one sex. Most are co-gender. We had SACIS training but it was just about abuse prevention—being able to understand it, how to handle it, and how to help the individuals. As far as affectionate behaviors, we see lots and lots of hugs and kisses. Mostly they copy the behaviors they see in others. They see other people do it so they do it."

Darius. "I would really like to learn sign language or the type of communication they (my clients) use. I am getting to know how some of them communicate but the more I know the more I can have full conversations with them. I wish we had more training like communication. They try helping us understand our clients but I feel we should have had a class in sign language since so many of our clients do use it. Some are really, really into sign language and they are always signing something to me. Sometimes I don't understand and that offends them or upsets them because they want you to understand what they are talking about. It makes me feel bad

because they are really trying to interact with me. They have their own ways of communicating and we all try to catch it. If we figure it out we share it with all of our co-workers. We sort of train each other to help out the client. If we know what he wants, we can help him better."

Ana. "The supervisors need better training when they are promoted, especially about how to schedule staff, how to interact with employees, having empathy for the staff, and how to remember how it feels to be at the bottom. The wages are low so being treated with respect by management really matters. She frequently posts the schedule at the last minute, she hasn't taken the time to get to know the guys (clients) in the house, and she doesn't like to come in when called. She is a little young to be a supervisor and her lack of maturity is obvious to the staff. She behaves emotionally and is viewed by the staff as being unfair."

Ben. "I feel like training is reactive because if something bad happens they bring people to train again. We also have mandatory training that we have to do every year so the training never stops."

Darius. "I think they should tell us how to go about working with the clients in regards to sexuality—like what's the right way to about it if you see clients interacting with each other. I think that's the best thing they can do. It's important because the clients are still free; they have their rights. At the end of the day that is what matters. You know, you can't just tell them no—he's grown. He's not in jail; he's not in prison. You know, he is free. So I think the best thing can do is teach us what we can do."

Gia. "There is a need for sexuality programs for both our clients and our staff. Yeah, there is a real need for it."

Ivy. "The training provided to use did not really help in regards to sexuality and affectionate behaviors and how to find the right balance between personal space, appropriateness

and the client needs for affectionate and pseudo-family support. We got a lot of mixed replies when asking those types of questions. Clients are allowed to make their own choices but we cannot let them do x, y, and z. Even things like hygiene. We are not allowed to force them to do anything, but then staff would get in trouble if a client hated to take a bath so we strongly encouraged a shower instead. Our OIG Abuse and Neglect training was the only sort of training on sexuality that I can recall."

Finn. "I think the basics of relationships for the clients needs to be built into the training. I didn't see anything but abuse prevention in the training. Nothing about how to teach them to hold hands or ask for consents or kissing or how to ask someone for a date."

Ben. "I actually believe that we need more sexuality training because you don't know what to do. We have to learn what to do because I really don't know. If there is any existing training—and I honestly don't know if there is, it would be in the CPI or the abuse training. It is an 8 hour class and it is the only thing I can remember. I believe there should be a sexual class because it trains you how to react and how to talk about it without being awkward or being bad at it. There is good training for prevention of abuse but not good training for Sex Ed or communication."

Ivy. "I think there is sexual health education that could be conducted on a broader level, including individuals who might not have the ability to consent to a sexual relationship. I mentioned that one woman liked to put things in different orifices, and the company responded by providing a dildo of some sort. Their reasoning for it, from my knowledge, was a safety concern. It is safer for someone to put something that is clean and designed for that reason (use of a clean dildo) than to find random objects around the house to satisfy that need (inserting whatever she finds in the house and inserting them in her body). While I did not work at the

company when this was an issue, my co-workers have expressed their concerns about the appropriateness of those actions, and how they were not sure exactly how to approach that situation."

Finn. "I had this guy who brought a girl home who was not disabled. I think I handled it well but I am not sure. Without the proper sex education for the disabled people, like, I don't know if I did do it the right way, but I think I did. I mean I went in there when they were alone in his room when they were not supposed to be. I just said I don't know if this is appropriate or not. I told them I would have to ask some other people. I called my supervisor and she didn't know either. I think we need some sex education classes for the clients on different levels so they can get something out of it."

Gia. "The DSPs are the one size fits all and then with all of that mandatory training, I was like, well, where is the sexuality? When I looked at the training, it is, like, no, no, no. So if I were 18 and I just took 12 to 25 hours' worth of training that said no, it's bad, it's bad, it's bad, call in and report it right away, I wouldn't necessarily know what I was supposed to be supportive of the clients having normal needs and normal relationships. It's all bad, or at least it seems that way from the training. It's just easier to say no. It's all bad. Then who gives these people their hug, you know, and where do they get their affection?"

Ivy. "I guess I would like to add to what I feel needs to be addressed or things that I feel need to be added to the sex education. I think staff needs education on how to react in certain situations when working with individuals who need assistance in very personal areas of their lives. Our individuals may not have the ability to consent to sex, or have a healthy romantic relationship, but they still have health-related issues related to sex and personal areas of their lives."

Finn. "I really feel like the sexuality of our residents is chosen for them. They are rarely left all alone and they have limited opportunities to meet someone to date. We spend more time talking about and training about how not to let them get abused instead of how to help them have happier lives and normal relationships."

Henry. "There is a need for sexuality training, no doubt about that. Some of the governing bodies --everybody has a different opinion about this topic. Just about every topic anymore. Public health sees it another. And it is like a tug-of-war. You don't know who, you know, the federal government, the federal people, can have different opinions on things. So there is just training scattered all over the place I think."

Ben. "I had a patient when I was just passing out meds—I am med pass certified, so I was passing her medication and she started choking on her medication and you really can't do anything because she was in a wheelchair and she is low functioning. So I really did not know what to do. So it had nothing to do with me, but like it was kind of ridiculous because I was on the phone with 911 as I was giving her the Heimlich Maneuvers because everybody else was crying because they didn't know what to do. So I believe they need more training in emergency situations because no one knew what to do."

Ana. "The number one thing that would make my job better is if they would train all their supervisors how to treat their employees with respect."

Finn. "Some of our clients make a lot of noises and stuff and that will make people mad when we are at the movies or when they are in the grocery store and they are yelling. Some of our clients have a lot of problems with personal space. It makes people mad sometimes when we are out in public. I really think we need more training in how to help them with their social skills."

Gia. “I can tell you, special education doesn't focus on adults. I mean, they focus on – on, you know, children and that kind of thing. So, when you have a special education degree and you come work at an agency like ours, typically, those are the people that don't make it in our world. They really aren't prepared.”

Participant Perceptions of Training – Little or No Memory of Training Topics

Ivy. “We did receive training about good touch/bad touch and health proximities. But when I was thinking about it more, I realized a lot of the lessons that were taught were directed towards higher functioning adults. All of the classes were integrated with all of the different positions, so most of our lessons were taught with the assumption that our clients were higher functioning. (This is why I cannot recall a lot of what was learned.)”

Claire. “I can’t remember any training we received in sexuality. Their chart does include if they have the ability to give consent. Each client has an ISP, an individualized service plan. It also includes who has guardianship over the client, which also influences consent. Some clients have a state guardian assigned to them. For our ladies, most of them have the same lady from the state. She is pretty open-minded and very easy to talk to about issues such as sexuality. The only thing I can remember to do with sexuality in our initial training was mandatory reporting and how we handle any type of abuse.

I think it was mentioned that our clients masturbate and that some clients engage in sexual activities. I think they covered the policy that as long as it is in an appropriate setting we allow it. I believe it was part of the initial orientation. We also have to report it if it is not appropriate. I wish I had taken the human sexuality course in college. I don’t think our schools do a very good job preparing us for sexuality in the real world.”

Research Question #2: How do DSPs in CILA settings experience residents' sexuality and affectionate behaviors?

Each participant was asked the following questions:

1. Describe for me a typical word day in your CILA home.
2. When I say the word sexuality, what comes to mind?
3. Tell me about your experience with sexuality issues at work.
4. Participants were also asked have you ever been uncomfortable because of something that happened at work.

Themes addressed in this section are Employee Training and Development, Socialization Needs (Affectionate Behaviors, Sexuality, and Relationships), and Language Issues (Positive, Negative, and First Person). The behaviors that were identified as occurring the most often were dating, flirting, friendship and socialization, obsessing over staff or television stars, holding hands and hugging, the use of media and technology, masturbation, fighting over who was the most popular, lack of fear of strangers, groping, changed behavior after return from homes visits, confusion about choice and consent issues, and male staff having difficulties dealing with periods and cramps. DSPs expressed difficulty in being able to tell the difference between coping or self-soothing behaviors and sexual behaviors. Actual sexual intercourse was reported as rare for most residents in any of the CILA homes. Communication issues were identified as the primary barrier to socialization for most residents.

Theme One – Employee Training & Development

A summary of the findings from this section of the interview data analysis indicates the clients engage in affectionate behaviors on a regular basis and engage in sexuality behaviors as well. For the first theme of employee training and development, DSPs expressed a need for more

sexuality education for both staff and clients. DSPs also requested more first aid and CPR training, more training how to use the client case files and social plans, training in regards to grief counseling and death, and training on how to increase and enhance client socialization. These topics are incorporated into the next three research question responses as well in more detail.

Theme Two – Socialization Needs

The second theme to be discussed will be Socialization Needs. Socialization needs for the clients were identified in the homes through the use of a client plan that was developed by the case manager, working with the agency nurse. Personal goals and social stories were included in the plan were individualized for each client. The DSPs are responsible for implementing the goals and charting the client progress each day in an online reporting system. Many different types of affectionate behaviors were identified through the interview process and are summarized below. However, DSPs reported they were often confused as to what behaviors were allowed and not allowed in the plan. Many reported that the plan and case file did not contain a section for sexuality and affectionate behaviors or a section informing the staff if the client had the ability to give consent for these types of behaviors. DSPs felt they should have a more active role in creating the social plan but most of all they felt the social plan should be explained to them more thoroughly and repeated to them more often.

Further, DSPs felt there was an issue with the consent of choice for the residents to participate in sexual and affectionate behaviors. Field trips, dinners in local restaurants, and activities at sister houses within the agency were held to help expand the social activities of the residents. Even so, residents had little interaction with others outside of the CILA home except

for other residents and staff. Both the issues of consent and individual choice were reported as confusing and problematic in the experiences of the DSPs.

DSPs reported affectionate behaviors were much more prevalent than sexual ones among residents. DSPs were concerned with the lack of role models for the residents in regards to sexual activity and affectionate behaviors. Media, such as television shows, and social media, such as texting and Facebook were viewed as the primary sources of exposures residents had to sex and dating behaviors. Residents were reported as lacking in basic socialization skills such as asking someone for permission to hold hands, asking someone for permission to kiss them, how to ask someone out for a date, have a long-term relationship with a member of the opposite sex, or how to ask someone for consent to have sex. Communication issues were identified by the DSPs as the primary barrier to socialization for most residents.

The two most interesting experiences shared in the opinion of the researcher had to do with what occurred in a resident chose to have sex and the DSP perceptions of sexual and affectionate behaviors as a form of communication. DSPs reported if a resident chose to have sex, a staff meeting was held after the fact with the resident and several staff members to make sure the act was not any form of sexual abuse. In addition, the meeting was held to make sure the resident had the knowledge to protect themselves from sexually transmitted diseases, pregnancy, and abuse in the future. This is not a natural approach to sexuality and sexual intercourse. An unexpected issue identified in this study was how important language and communication became in regards to the perception and control of human sexuality and affectionate behaviors. DSPs reported having difficulty determining what was a sexual behavior and what was the client "just acting out" in a behavior chosen to manipulate, express anger, or as a coping mechanism. Behavior is communicative. Sexuality is communicative. However, a behavior (even one that

seems sexual) that occurs may not necessarily be negative but seemed to be perceived to be so by the DSPs. DSPs felt the obligation after their training (primarily negatively focused) to manage unexpected behaviors and to label them as unacceptable or something to be stopped. DSPs admitted when they were unsure about what to do in certain situations or they had not been trained on a specific behavior, they erred on the safe side and just told the client to stop the behavior entirely.

Both positive and negative behaviors were identified from the experiences of the DSPs. Positive Behaviors identified were:

- Dating – two male residents have girlfriends (although no one has seen either one).
- Dating – a male resident has a girlfriend who has no special needs.
- Dating – a male resident has a long-term girlfriend who lives in another CILA home.
- Dating – several residents from "sister houses" call themselves boyfriend and girlfriend and hold hands at social events.
- Dating – a female resident expresses her interest in dating Dr. Phil.
- Dating – a male resident has his girlfriend over for dinner.
- Flirting – when on field trips clients like to sit by their "favorite" person and they flirt while on the field trip or at dinner.
- Friendship & Socialization – female clients go to the senior center for a spa day, have pizza parties, and have craft day.
- Friendship & Socialization – some clients have close relationships with their families.

- Holding Hands & Hugging – many clients hug friends or staff if they are happy.
- Media & Technology – many clients use cell phones and social media to communicate with others.
- Masturbation is acceptable behavior as long as it is completed in private and not in common areas of the house.
- Clients capable of giving informed consent are allowed to make their own choices in regards to sexuality and sexual relationships.

The negative behaviors identified were:

- Two female residents constantly fight over who is the most popular in the house.
- Female residents flirted so much with male staff the house staffing schedule had to be changed to only include female staff members.
- Media & Technology – clients have to be taught appropriateness when using technology and social media.
- A young, attractive female is very outgoing with people and no knows fear of strangers. She has to be protected from potential social dangers.
- Clients act very differently after they return from home visits. It can be difficult to figure out what happened during their time away.
- Some male clients obsess over the female staff members; some clients actually attack staff members physically or exhibit other inappropriate behaviors such as groping, public masturbation, or flashing body parts in public places.
- Not all clients have the ability to give consent to sexual behavior. This can be confusing to staff as to who can and cannot engage in sexual intercourse with their significant other. In addition, sexually active clients require a team meeting

of staff that meets with the client to make sure their rights and health are being protected.

- Male staff seems to be uncomfortable dealing with female clients' periods and cramps.
- Some female clients exhibit behaviors that can result in self-harm, such as pulling and pinching their nipples until they bleed.

Participant Experiences – Affectionate Behaviors – Attention Seeking/Ego

The personal DSP description narratives for perceptions of affectionate behaviors appear below.

Eva. "We have two ladies who constantly fight over who is the most popular in the house. They will flirt with any of the male staff who comes into the house. They each try to out-do the other in the number of hugs or kisses they can get from staff. They want to be the first to get food or a snack. They both act like prima donnas of the house."

Participant Experiences – Affectionate Behaviors – Dating

Ben. "There are a lot of different people I work with all of the time. We have some really old clients that we do not have to worry about. We do have a teenager that is my age actually. He is 21 years old and he talks about his girlfriend all of the time but we have never seen his girlfriend so we do not know if she really exists. He has a cell phone because he talks to his child. His girlfriend does call the house because you cannot make outgoing calls you can only take incoming calls. So it does kind of cut into their freedom. He is high-functioning. I believe he is considered physically disabled instead of ID. Our house has a mixture of disabilities. He can't manage his money or his bills."

Eva. "One of our female clients is interested in dating. When the Dr. Phil Show comes up she likes to yell 'Oh, he could get it!'"

Claire. "We do have one guy at our sister house that is pretty high functioning. He really doesn't even need to come to us but he does. He lives with his girlfriend and she has no developmental delays or anything. I'm not really sure why he comes to us."

Ben. "We have the younger guy in our house who says he has three kids. I don't know if it is real because it is hard to believe sometimes. He complains that he has no freedom. He says he has no right to do anything in the house. He wants to move out because he doesn't believe he belongs here. However, I believe the court system was involved in his case because he was living in a hotel. Evidentially he was addicted to some drug. It is just one of the things he has claimed. There are a lot of things he has claimed so it is difficult to tell what actually the truth is. I don't believe he has the power to leave or move out. He does go to workshop all the time, which is like schooling. I know he has had a girlfriend from the workshop before. Again, I never met her either."

Ana. "One of the men does have a girlfriend from another house. He talks about her all the time; not so much lately so I don't know how they are doing. He will tell us he saw her at work today or they shared cookies or took a picture together. He really enjoys those kinds of things from the relationship."

Darius. "I have run across clients who do call themselves boyfriend and girlfriend—usually between the sister houses. I have never seen them get into any sexual activity, but they do hold hands, sit by each other, and do stuff with each other. It's really kind of sweet actually. I feel like that is part of that mentoring I was talking about."

Finn. "One of my guys has a girlfriend and he brings her over for dinner. They hold hands. They will kiss, but they really never talk about sex between a man and a woman. I think there needs to be more teaching about human sexuality for the clients. We actually had a workshop a few weeks ago. It was basically about how to train women on sexual abuse prevention. Some of the information was still helpful for working with men—especially about what is wrong. However, it is obvious they still do not understand what it means to have a relationship between a man and a woman."

Participant Experiences – Affectionate Behaviors – Flirting

Finn. "When we take the clients on field trips they like to sit by their favorite person, either from their house or their sister house, or their favorite staff. We see them talk to each other and interact on outings and they also talk about flirting with each other while at work."

Ana. "Sometimes the female clients flirt with the male DSPs. In one house it became such a problem, only female workers were scheduled to work there. The clients frequently hug."

Participant Experiences – Affectionate Behaviors – Friendship & Socialization

Finn. "We try really hard to give them a "normal" life. We work at getting them out into the community. But when they go to a party, it's usually at another house. I mean they are interacting but it's not the same really."

Henry. "We have a woman who keeps a cardboard picture of a movie star in her bed and refers to this as her 'boyfriend'. She has numerous male acquaintances she also refers to as her 'boyfriend'."

Claire. "Almost everybody is a college student of some sort, except my supervisor who is a little older. I am very protective of my clients. I think it is kind of a parental role to keep

them safe. Some of my co-workers don't like me because I insist they do things correctly. My ladies frequently go to the senior center for spa day, they have pizza parties, they have craft day. An issue with sexuality for people with ID is their ability or inability to understand the consequences of their actions and their choices."

Gia. "What I think is sometimes a case of those that have the verbal capability to express the desire to have an intimate relationship with somebody, it has been engrained in their head for so long that that is not what disabled people do."

Eva. "Some of the clients have close relationships with their families. It depends on their family members. Like if they call and check on them, want to talk to them, skype. Like one of my girls skype her mother. Visits, they either come to the home or they come pick up the resident and take them back to their homes. So it just depends on the family."

Participant Experiences – Affectionate Behaviors – Holding Hands & Hugging

Ivy. "One client would hug if she was happy. She had no problem jumping on top of a staff member who was sitting on the couch, or patting a staff member's head or back. She would also kiss the staff and other client's cheeks."

Eva. "Our clients have social goals that are called social stories. So like when they come home or any time throughout the day, really, you can run their goals. They are social stories. It can be from eating to going outside to like I was telling you about the lady who likes to hug and be affectionate. She has goals too. Like, don't just hug. Don't squeeze really hard and stuff like that. So social stories, they have those. And yes, I know -- it is like half and half in my house. Some of them have guardians and then the other ones their guardian is by the agency."

Ivy. "Some of our clients would show affection through hugging. One client would only hug when she was trying to make the staff not be mad. For example, she would grab a staff

member's neck. Then when she calmed down she would hug the staff and say "sorry" and ask that staff to take them out for a snack."

Ana. "They guys are very affectionate because we have been there a while. So, they have learned to care for us as well. If they are having a bad day, they may request a hug. One guy in particular gives out hugs to everybody. He has certain staff he likes more than others but he still likes to hug everyone."

Ivy. "One client would only hug to go out on an outing. She hugs a staff, and then brings her shoes so that staff could help her put them on."

Henry. "A young, attractive female is very outgoing with people she knows, as well the people she is just meeting. She has no fear of strangers in public. She introduces herself and hugs anyone and everyone no matter where she is."

Participant Experiences – Affectionate Behaviors – Media & Technology

Ben. "We have a guy who texts a lot to others on his cell phone. The 21 year old who tries to hit on all the females. He likes to think he is a lady's man. I don't blame him for asking the questions he does. That is the thing; people think that he is like a pervert. They think he is weird. And I am just like, you known, it is not like that. He is 21 years old. He has no one to talk to. Who is he going to ask that stuff? Some of the staff gets offended because he talks to them like he dates them. He talks down to the female staff. He tries to hit on the girls like he is some big player. Basically, he is acting like what he thinks any other 21 year old would do. So it is no big deal. I think it is funny when he hits on girls because that is what any 21 year old would do. But it is just different because he has a disability. He just has a diagnosis of mild ID. That's the only difference."

Finn. “I don’t think the clients get to see many positive role models when it comes to dating and affection. My girlfriend works here too but they have a really strict policy of no fraternization. We can’t even work in the same house or be around each other at work. So most of the role models for our clients are TV shows.”

Ben. “You have to type a report each day into the online system. It includes what their day was like and if they caused any problems, if they are different, if their bowels moved, and everything. It’s called CASPER. You have to type everything in and let everyone know. The nurses and case managers look it over to make sure everything is the same. It’s another safety tracking mechanism. It tracks behavior trends. Everything goes into the report—if you forget to put it into the daily report, you can get into trouble.”

Participant Experiences – Affectionate Behaviors – Other

Finn. “We have a guy in a wheelchair who just sits outside to enjoy the day. People will walk by and talk to him. He knows most of the people in the neighborhood. He has a lot of friends.”

Darius. “Clients act very differently when they come back from home visits. I guess they really want to be at home but they can’t so they come back with an attitude. They have a hard time dealing with the changes of rules and location. It agitates them.”

Finn. “We go on a lot of field trips. But when we go to the store, we all stay together. When we go to the movie theater, we all sit together. I mean, there are some people who just stare. It seems like people are still very phobic of the disabled. It is socially isolating for them.”

Finn. “I really feel like the sexuality of our residents is chosen for them. They are rarely left all alone and they have limited opportunities to meet someone to date. Even on field trips or sister house activities; they see the same people over and over.”

Participant Experiences – Affectionate Behaviors – Problematic Behaviors

Eva. "It is kind of the policy to remain calm as the DSP and then to talk to the client so that they understand what they did is outside of limits of acceptable behavior."

Ana. "We had guy who became a problem so they wouldn't give him a female staff member. He would obsess over female staff and fantasize about them. It created issues so they always give him a male staff member to work with. I felt the administration acknowledged both the individual and the staff and took actions to protect them both."

Eva. "With the one that is higher functioning, which I implemented the rule of -- this is actually the one that tried to attack me. If you are going to hug me, we have a three second rule and you are going to count it out. So one, two, three, and then we are done. And then she has to ask, can I hug you. And then we say yes, and then, okay, count 1, 2, 3. And then after we are done hugging I say, all right. Give me a high five and we are on our way."

Gia. "We actually have a house that for the safety of some people had to go to a completely no-touch policy, like not even, like, handshakes or anything, because they seem to -- you would allow something and they would all seem to not understand. But the staff there is all female then, so, the clients found them very attractive."

Henry. "A young male who lived out in the community before coming here flirts with the staff to the point it becomes a behavioral problem because he won't accept "no" for an answer. His reaction to the situation begins to take on the characteristics of sexual harassment."

Eva. "Most inappropriate behaviors are already in their plan with the kind of action of how to deal with them. Because it says in their plan, this is what she does. It says things like I like to do this. I don't like to do this. And, like, this is my reaction. So from mine clients like to go shopping. It might say I do not like to be asked a lot of questions. Say, if I am asked a lot of

questions, I might start screaming or something like that. So it says what they like, what they don't like, and how they react to different situations."

Henry. "A young male wants to give "hugs" to female staff, but the hug goes on too long as inappropriate time/place/person, he takes the opportunity to come up behind the staff, puts his arm around her, and forcefully puts pressure on her as if he is laying on her shoulders. This can cause the staff person to lose their balance when they are standing."

Eva. "We set boundaries and then redirect them to another activity. We don't talk baby talk to them. Oh, no, no. Don't do that sweetheart. No, we don't. We call them by their name and talk to them like they are adults. I mean, some of them respond and some of them don't."

Participant Experiences – Sexuality Behaviors – Dating/Marriage

The personal DSP description narratives for perceptions of sexuality behaviors appear below.

Henry. "A young woman asked her female peer, "Will you marry me?" The peer said "Yes." And then they kissed on the mouth."

Participant Experiences – Sexuality Behaviors – Groping

Eva. "Just saying a resident may be hitting or, in my own experience, when I first started, a resident actually grabbed my breast and I wasn't used to that. I wasn't offended, but I was shocked because I know their situation, meaning like their mental status, so I didn't take it offensive at all. I was shocked but not offended. But they just told me how to deal with it and to chart it. I was being trained at the time. An experienced staff member just told me that I need to talk to her and say that is not what you do. Do you want to do something else or do you want to eat something else. Just trying to redirect her in another direction."

Ana. "The older men in the house will frequently grab at the breasts of the female staff. Some just push their hands away and say no. But the giggle while they say no, and act like it is "cute" that the clients grabbed them. They think the clients don't know what they are doing but I am pretty sure they do."

Eva. "I expect my clients to behave at whatever level they are on and I adapt my behavior to meet their needs. You adapt to their needs and their level of functioning. Like when I got my chest grabbed, like I said, I didn't take that offensive. I just took it as, this is someone who she sees me as, oh, she is someone new. I don't know her. I don't know what she is trying to do. I don't know what she is doing here. What is she talking about? Why is she talking to me? A lot of questions like that because she never seen me a day in her life and here I am new coming in her space and she don't know what is going on. So that was just her first reaction. But it wasn't offensive at all. It really wasn't sexual, she just grabbed. It is just almost an instinctive kind of reaction--she was just out of her comfort zone and grabbed and happened to grab that part of my anatomy."

Participant Experiences – Sexuality Behaviors – Masturbation – Females

Claire. "When asked how she felt about her experiences with client sexuality, specifically the masturbation she mentioned, her response was 'Meh, it's part of life.'"

Gia. "I think we have less female masturbation in the houses than male masturbation because it is easier for the males to get access. We see female masturbation the most in the bathroom, just because they have better access then and don't have the clothing getting in the way."

Claire. "It's (sexuality) not a big issue in my house because they don't understand what it is—well, one sort of does. She masturbates a lot. She will do it anywhere but mostly in the

bathroom or where there’s not clothing blocking her way. She is very opportunistic. I am very accepting of her behaviors. The only time I would try to divert her or try to stop it was if it was an inappropriate situation. Like, if we were at a store and she tried to do it, then I would try to stop it because it needs to be done private. I don’t care if she masturbates; it just needs to be in an appropriate setting.”

Ivy. “Most of the clients were low functioning and did not express sexuality. We did have one client who liked to stick things up her rectum. We have a few other clients who would masturbate by rocking back and forth or sticking their hand down their pants.”

Eva. “Toilet time is the most popular time for masturbation for our women.”

Participant Experiences – Sexuality Behaviors – Masturbation – Males

Darius. “I feel like because they are just human beings they are equal to us. They have a right to touch their body as much as I have the right to touch my own body. So if I want to touch my own body, I would touch my own body—that’s just how they feel. They feel it’s my body so I can do what I want. It doesn’t bother me because, you know, it’s human. People do it. People do it. It’s a basic human need.”

Finn. “We have guys so biology is taking place and they obviously had happy dreams, you know, but they really don’t talk about it a lot.”

Ben. “If someone is masturbating or someone is doing something that is sort of in the bathroom or in the shower or in their room, I believe we are just taught to let them do what they want to do until they are done. And then I think we actually have to clean up the mess.”

Ana. “We just direct the men to their rooms if they want to masturbate. We try to remind them to not do it in public. The worst part is staff is responsible for helping them cleanup afterwards. We see more body fluids than we want to.”

Henry. “We have guys who get visibly excited when looking at magazine pictures of attractive women.”

Darius. “One time I had to put an individual in the tub because he likes to get in the tub because it is one of his sensory things. He likes how the water feels; it calms him down. So I put him into the tub and walked out. I returned to check on him and to make sure he was okay and he was having, you know, touching on him. I was like...hmmm. So I’m, like, okay. And I was, like, I don’t think that is appropriate you know, even though he was in privacy, but he kept doing it while I was right there. So I was, like, I don’t think it’s appropriate since I’m standing right here. And he just looked up at me, like, huh? I’m like, I don’t think it is appropriate—could you please stop? I mean, it’s okay to do it, but can you just wait until I leave? Because he understands, you know, what’s right from wrong. You know, so he can understand right from wrong. So I just have the conversation with him and tell him, no. You need to wait until I leave the room. I try to, you know, school him like what’s right and what’s wrong. You know, when you see people walk in, you should stop because that’s the right thing to do. You shouldn’t just keep going. He needs to learn what is socially acceptable. So he stopped and I left right back out after that. He was able to retain that lesson, which I appreciated.”

Ben. “It is more about prevention for your own safety and also the consumer safety but we are never taught about it—I remember one thing. If someone is caught masturbating or anything like that we just let them be—whatever they do, we have to clean it up. We have to finish the process by cleaning up after them but we are not to bother them. It is more like a custodial relationship—like being their Mom or something.”

Darius. “Another client, he likes to just be touching himself, so we tell him to try to only do that in his room. He doesn’t really understand the concept of privacy. He understands kind of

but he doesn't really understand. We tell him you really shouldn't do that in the front room. It seems like the more we talk to him the more he does it. He's not very caring whether he does it in front of us or not. They told us in training if we see some inappropriate things that we know they shouldn't do we should try to talk them out of doing it in public. We try to teach them appropriate social skills. They (management) warned us ahead of time these types of things would happen and they are always there if we need help dealing with a situation."

Ben. "There are a lot of different rumors that spread because the consumers talk to the other staff and the staff starts talking to other people. Gossip spreads like wildfire."

Eva. "I haven't seen anything in the houses. It is just what I've heard happened in other houses. The ugliest is the male house. I have heard that those men play with themselves so. I've heard a lot about it from the other women I work with. They never use any names or break confidentiality but they say those men play with themselves all the time. They say just, like, oh, my gosh. They do this a lot. Or, oh, my goodness--I didn't know they did this so much."

Ben. "It is really difficult because if someone sees someone masturbate, they are going to run out and tell the other staff and the staff is going to start talking and it is a big ordeal when it doesn't need to be a big deal. I mean they are adults—they have the right to do what they want to do. However, it does go into the CASPER report so everyone knows about it. If another staff member says something about it and you didn't put into the CASPER report, you can get in trouble for not writing it down."

Participant Experiences – Sexuality Behaviors – Sexual Intercourse

Ben. "One guy had a girlfriend that would come to the house. She would come over and they would just hang out but they were never allowed in their room by themselves, which is another thing I think that should be allowed. I think if you are a higher functioning person you

should be allowed more rights and freedom. I mean, they understand what is going on—they are not going to hurt people. I mean if they were going to do something, we would walk in and do what? We are taught if they are masturbating to let them finish. What are we going to do if they are having sex? Can't walk in there and say stop. What are we going to do? I've never been in that situation but it would be a really good situation to be put in because it would be great for the guy. Not a lot of people have anybody. I don't know what the policies are for sex. They don't have a lot of social interaction with the rest of the world. When we go out on field trips everyone looks at us. They don't usually want to talk to our clients because they don't want to be put in a situation that is awkward."

Gia. "How normal is it to have a safety plan if you want to have sex? Or a group of staff that meets afterwards with you to discuss the entire situation? That's what happens to our clients. We had a resident that we found out had sex last weekend. We had to have a meeting with her and several staff members to make sure she has enough knowledge to protect herself. She's already had sex and it was consensual. Now she has to talk about it, discuss birth control options, and share intimate details of her life in order to make sure she is protected emotionally and physically."

Ana. "We have another guy who is actually married but his wife is actually in another town. He goes back and forth to visit her. He goes through a lot of staff as well because he refuses to work with a lot of them. That means staff have to switch off when he refuses to work with someone, making the scheduling of the staff more complicated."

Gia. "I had a young lady who was sexually active. She was open about it. She had asked me, you know, so I am in the kitchen with a banana, you know, teaching how to use a condom. A couple weeks later, she came over and said, you know, I need your help. She had discussed sex

with her boyfriend and said he wanted her to give him oral sex. So I'm – like, here are things you need to think about to protect yourself and also to enjoy yourself. You are the sex educator for these people because you are in the parental role. We are the most available for advice."

Participant Experiences – Other Related Behaviors

Claire. "The ladies that did still have a period regularly would go through PMS as usual. We also documented how long it lasted each month and if there was anything unusual about it. I had a couple of ladies who were going through menopause and their cycles were all over the place. Staff would document and contact the nurse as necessary for Tylenol. Because most of the staff was female, we knew what we were doing. We would offer hot showers and heated rice bags for cramps. Also, we made sure they had comfortable clothes to wear. All of my ladies used sanitary pads as they required assistance in keeping them changed. Anyone wearing an incontinence product was already on a toileting schedule of every two hours and staff would simply change the pad as needed. For the ladies who had cycles but did not need incontinence products, would simply be helped to the bathroom to be assisted as needed.

I did have one lady going through menopause that did not require an incontinence product regularly, but wore them on her period because her flow was extremely heavy and regular pads just didn't cut it. Teaching the male staff what to do was probably the biggest challenge. Female staff would take care of everything as much as possible, but occasionally a male the short straw. Basically, all I ever did was the same thing I would do for myself. I would make sure there were sanitary products available to use and to keep the ladies as clean and comfortable as possible."

Ben. "We are taught that our clients are consumers because they want to be just like everyone else. They want to be known as people too."

Gia. "I think I find those employees with an alternative life style, like an alternative choice, don't have the toughest time accepting disabled people as being sexual beings as much as, you know, your traditional. I have found them to be more open-minded."

Participant Experiences – Sexuality Behaviors – Problematic Behaviors

Henry. "We had a young man ask his peer if it was okay to touch his 'pee pee'".

Eva. "One of our female clients came back from a home visit and climbed on one of the therapy balls. She kept "humping" the ball and yelling 'Oh Daddy! Oh Daddy!'"

Ana. "We have two men in particular that have troublesome behaviors. For example, we have a guy who if he hugs you will make sure his head is lying right on your breasts. We have another guy who is blind but if you have to get close enough to give him something or feed him, he will grab for your breasts. He seems to know just where they are. Most staff just laughs it off, move his hand, and move forward. We do tell them to stop doing it as well. I am not sure what kind of training the clients get but they repeat the same behaviors over and over. We just get to the point we ignore it and go on. They do know what they are doing though because they laugh. I think we let them get by with it because they are older. If they were younger guys, we would react differently. I think they are definitely trainable. The clients don't exhibit the same behaviors with the male staff. I think they are taking advantage of the female staff being young and attractive. I guess it is part of life no matter what age they are."

Claire. "One of my ladies has made comments about 'open your legs and lie on the bed and lay on the floor.' She has issues with men. We have no proof but our thought is that she has probably been molested in the past. She has echolalia; she repeats everything word for word. We think she is just copying behaviors that she has seen other people do."

Eva. **“**We have a lady that when she gets frustrated, she pulls on her chest, specifically she pulls at her nipples. She will just reach in her shirt and grab her breasts. Sometimes she just raises up her shirt and scratches her nipples. She does it, sometimes, when she has a trigger and, sometimes, it is just -- she just does it. And she likes to really scratch them. Make them bleed. She cannot be given Band-Aids -- I forgot what the reason, but she is not allowed to get Band-Aids for some reason. That is in her social story as well. Social story usually go, like, such and such or so and so will have quiet hands, meaning you are not going to hurt the staff; you are not going to hurt your housemates; you are not going to hurt yourself. So and so will be nice. So and so will speak good words, or say good words and stuff like that. This social script is written by everyone that comes together. That is what the ISP is for--Individual Support Plan is all about. And with the goals, we just usually write a plus or a refused or a minus. A minus is not bad. It just means that it didn't get accomplished. Like, for example, the snow days, they weren't able to go to the day program because it was -- the weather was just so bad. So for instance, one goal is so and so will go out and review street signs. Well, I will put a minus because it wasn't accomplished, considering the weather, but a minus isn't bad. Now if it is a good day and you refuse, then I will put a refuse and write it in your contact notes.”

Ana. “There is a lot of inappropriate touching, which we frequently ignore. We cover good touch/bad touch but the clients do it anyway, even when they know it is wrong to do so. They get by with it. The guys are mostly an older population and some of the staff thinks it is funny, cute, or that they do not know what they are doing so they allow the guys to get by with it. They do normal guy things. They do masturbate and things like that. We are supposed to just let them do it but have them go to their room and close the door.”

Ben. "I think the clients do not always understand about showers and bathing. I am not sure they understand they are receiving a shower because sometimes I think they think it is sexual abuse or that the staff is trying to come on to them sexually when they are just trying to help them with personal hygiene. This is a hot point with the staff from the liability point of view. Also, some clients use bath time as a way to manipulate the female staff. The 21 year old will pretend he doesn't know how to shower himself so he can hang out with the female staff while he is naked and so he can get showered by a female. I think he is not only manipulative but that he is desperate for a female touch. He is really smart. I am not sure the training really prepares the female staff to work with people like him. They seem to fall for it a lot, even when I tell them that he is just playing his game. He gets mad at me for it too. So he knows what is going on. He knows exactly what is happening."

Eva. **"**One our female clients will flash people. She just raises her shirt, flashes her breasts and makes noises with her tongue."

Research Question #3: How prepared do DSPs feel to deal with workplace issues regarding sexuality and affectionate behaviors?

Each participant was asked the following questions:

1. Describe your typical work day in your CILA home.
2. When I say sexuality what comes to mind?
3. Tell me about your experience with sexuality issues at work.
4. How do you feel about your experiences?
5. What is the most stressful thing about your job?

The themes addressed in this section were Employee Training and Development and Socialization Needs (Affectionate Behaviors, Sexuality, and Relationships). A summary of the

findings from this section of the interview data analysis indicated that most DSPs loved working at this agency. Further, they liked forming relationships with the people they worked with, including the clients. They did express a desire for more training about human sexuality in general; human sexuality issues that might come up in the institutional setting, human sexuality issues that might come up in CILA settings, and policies, procedures, and protocols that impacted human sexuality in CILA homes. DSPs expressed difficulty in understanding where to draw the line in regards to sexuality behaviors.

Many DSPs mentioned the additional stress on the staff as a whole when a new supervisor is hired—particularly one who was promoted from another house who previously worked as a DSP. The DSPs indicated more training needed to be provided for new supervisors, particularly on how to schedule staff and resource management. Several DSPs recommended that only people who planned on a career in disability services should be promoted because otherwise the new supervisors seemed to lose focus and prioritize their personal obligations (such as attending college) instead of the needs of the workplace.

One of the most stressful things experienced by a DSP in the workplace was the death of a client—this resulted in the fear that a DSP might react too slowly and not be able to help a client in time. It also resulted in a request that the staff receive more first aid and CPR training adapted especially for the different situations that frequently occur in the residential setting such as choking and falls. DSPs also suggested grief counseling for both the residents and the staff because it was felt that residents who passed away were viewed as easily replaced by the administrators when they were viewed as a loss of a family member by the DSPs and the residents.

The lack of maturity of some staff members was viewed as a problem by the DSPs interviewed. However, the tendency for staff to get embarrassed was mentioned more than once. In addition, it was stated that the clients get flustered when the staff turns red because the clients think the staff person is angry. DSPs expressed a concern about where the line is drawn between sexual harassment and personal care. The possibility of being accused of sexual abuse or assault was of great concern to all the study participants. DSPs expressed a concern for their personal safety, particularly when working in a CILA home with violent clients. However, the most irritating aspect of the job was working with other DSPs who did not take their job seriously or who stole things from the house, such as food. They did mention supervisors and administrators acted quickly when DSPs informed them of problem staff and those people were quickly removed from working at the agency. Finally, the lack of respect shown to DSPs by some supervisors was a concern to the DSPs. DSPs expressed the desire for more recognition of their accomplishments within the homes, where they frequently work independently with the supervisor available to them on an "on call" basis.

Participant Experiences – Positive Feelings/Experiences

The personal DSP description narratives for perceptions of how prepared DSPs feel to handle workplace issues in regards sexuality and affectionate behaviors appear below.

Eva. "My job -- my job doesn't stress me out at all. When I was in high school, when I was a junior, I volunteered at two nursing homes. I knew that nursing was what I wanted to do, which is why I came into college, knowing I wanted to be a nursing major. But then when I came here and found out about CILA jobs, I went for it. Unfortunately, I did not get the job with the agency when I first did the application, but I tried it again and I got the job."

Ben. "I love working here. I believe that it helps a lot. I understand that I am a role model for them. But I feel like sometimes they get upset that it is more like they feel I am staff and I just work there and I am not their friend when I feel like I am becoming friends with everybody in the house while I am working."

Eva. "I like forming relationships with the people I work with. The best part of my job is talking to them (the clients) and engaging with them, like, activities. Even though they don't like it, they'll probably scribble scrabble on a coloring sheet and be done. But I mean they did a little bit. So I just think going to work and just seeing them. And then one lady, she knows our name. Well, two know our name. But she like, Eva come to work. Come to work, Eva. And it just helps me. It helps. Like, she cares."

Darius. "Overall, I really think the company is really good to work for. I never thought in a million years I would be working for the people I work for or working with the people I work with—trying to better them on their everyday life and stuff. But, I really love it."

Eva. "I love my job, actually. I feel like I was well trained; I am happy and well supported. I work with really nice people. I think my personality might have something to do with the fact that I love my job and working with the clients. I am pretty easy-going and I really like helping people."

Participant Experiences – Negative Feelings/Experiences

Ben. "A lot of the staff does get embarrassed. Like a staff just walked up to me and asked me a question about what to do about so and so. They don't know how to answer the questions. They get really embarrassed. Now the consumers get confused because if the staff turns really red in the face, they don't know how to tell the differences in the faces between embarrassed and mad. Usually if they are embarrassed, I just go and handle it for them. I just go redirect the

conservation and they typically forget and move on. However, sometimes they ask over and over and over again and don't forget. They remember things more than you think. Sometimes it is just a bad situation turning into a worse situation. If they act on their ideas it is more like a worse situation getting even worse. If they get stuck on a topic and you do not answer their questions they will get violent, they can start getting mad at you; they can start treating you like you are a bad person for not answering those questions when you are really just doing your job."

Claire. "I don't think the staff handles things very well that come up in the houses. I think some of them need to be older and more mature. We have an issue with maturity."

Ivy. "We also had a situation where a client's mother has guardianship over her. Her mother said that her daughter's anus was hurting her and she needed ointment. Staff did not notice any discomfort or redness. Many DSPs worried about the line between sexual harassment and personal care."

Ben. "It is really more like being emotionally afraid. Because you get attached to these people and then they just pass away. I think it would be similar to how it must feel like to work in a hospice system because I feel like we get connected to them and they pass away. I understand that everyone is just living their life but still I feel like no matter what, everyone is going to pass away. It seems like it is just shorter for them. As I said, I had one person pass away on me and then another person choked in their sleep and they died. You get emotionally attached to them. When they pass away, you get afraid that it is going to happen more often. You get to know them so well. You cook for them, clean for them, and they tell you stories. They act like your grandma I guess. It is hard to not get connected with the people. It is the hardest part about the job—trying to not get connected when you shouldn't, I guess.

It’s challenging—you are supposed to be professional and be the employee and not their friend but you have to be their friend to be a good employee. It is almost like they are your family. That is how emotionally attached you get to these people. It also feels a little weird because when someone dies, their spot in the house is replaced within the week. It just feels like they can be replaced so easily. That transition is stressful because while this really is a business it doesn’t feel like a business to staff. That’s where you kind of get stuck because you don’t’ know exactly how you should feel in the business end or in the friendship end because the roles and the parameters get blurred and blended together. You are supposed to be friendly but not too friendly—it’s confusing.”

Ivy. “Some of the clients were very violent and there were not always easy solutions. I worked overnight shifts for four months or so, and I had one client try to choke me. There were several others who liked pinching, scratching, and hitting the staff. It was incredibly stressful thinking that there were no other staff, or even clients that would be able to communicate what had happened. I was afraid me or the other client would get hurt, and I would be the only person who would be able to explain what happened. But there is only so much funding, and they cannot have two people there each night.”

Ben. “I personally have never felt I was in danger but I have felt more scared because I don’t want to react too slowly. Sometimes you do just react too slowly because you really don’t know what is going on. We had one consumer who had a lobotomy so he doesn’t remember anything after that time. He asks about his family members and they have all passed away and he doesn’t remember that so he gets mad. He will get mad at you and walk into the kitchen. There are knives, there is a fork, and there is a bunch of different things in the kitchen. So I get scared sometimes. You don’t know what anyone is thinking.”

Participant Experiences – Other Related Feelings/Experiences

Ana. "I am cautious of where I draw my personal line of what is appropriate and what is not, because with each client it could be different."

Claire. "What I hate the most is other staff, things like stealing holiday dinner food or their overall immaturity. The most stressful thing was working with people who did not do their jobs properly."

Finn. "My job would be better if some of the staff were not so lazy. They take it as a job and nothing more instead of actually coming to work not to just do a service but to help make people's lives better that are not able to do it for themselves. That's the thing—it's not the guys that live there, it is sometimes the workers. They are getting worse and worse I feel like."

Eva. "It is frustrating to you when you work with people who don't take the job seriously. Well, not necessarily as serious, but at least just show that you care. Like poking them is not okay. You be treating everyone with respect. That is very important to me."

Ben. "The most stressful part of my job actually, I believe, is death because I have worked with clients that are consumers that have passed away, and they passed away on me actually. I had a patient I was just passing out meds—I am med pass certified, so I was passing her medication and she started choking on her medication and you really can't do anything because she was in a wheelchair and she is low functioning. So I really did not know what to do. I told someone to call 911 and I gave her the Heimlich maneuver. That is all I could think of. So I did it and luckily I saved her life. She lived for about two weeks and then she passed away. So it had nothing to do with me, but like it was kind of ridiculous because I was on the phone with 911 as I was giving her the Heimlich Maneuvers because everybody else was crying because they didn't know what to do. So I believe they need more training in emergency situations

because they didn't no one knew what to do. I just kind of believe I lucked out because I gave her the Heimlich maneuver."

Ana. "We got a new supervisor who took the place of someone who was promoted who worked there a long time. She does not know how to do scheduling and frequently breaks her word or promises when she makes the schedule at the last minute. Dealing with the recent turnover rate due to this supervisor is very stressful. The house is being influenced by the constant change of staff. This transition from a good boss to a bad boss is the most stressful thing at my job right now. She frequently forgets to give the staff the sheets and the forms they need to do their jobs. She leaves them locked in her office and forgets about them until she gets called in to unlock her office. The supervisor or the nurse is supposed to do the colostomy bag but she hasn't wanted to learn how to do it or she is unavailable. It seems like she doesn't want to. Not all the staff is trained to do it so it makes it complicated to take care of the guy."

Darius. "The most stressful thing about is when you don't know what the clients or anything want and you just keep trying everything that you know to fulfill what they need but you just can't understand or you just don't figure it out. We have clients on so many different levels that each have different levels of abilities to communicate. It makes it difficult to try to figure out what they need and how to prevent the same thing from happening the next time. It is like being a parent trying to figure out what they need. They want to calm down just as much as we want them to calm down. It is just a matter of learning how to communicate with them and learning what they need to help self-soothe. One guy we have likes to listen to music so I have learned to ask him if he wants his radio. He will always say yes because it helps keep him calm. It can really get me down because I want to help them out with things."

Darius. "Sometimes I feel like we don't have the things we need. For example, we have so many wheelchairs in our house we need a bigger kitchen table or they need to make the living room a little bit bigger to accommodate the wheelchairs. I think with a little construction things would be better. We can't do a family style dinner if everyone won't fit at the table. I think the changing rooms could be a little bigger as well. They need larger bathrooms because more space would let us help change the individual clients better."

Research Question #4: How do DSPs perceive their influence on the sexual expression of Residents with ID in the CILA setting?

Each participant was asked the following questions:

1. Do you think your personal attitudes and experiences influence how you interact with your residents?
2. Have you ever served as a sex educator at work?
3. Have you ever served as a health educator at work?
4. How did that make you feel?

Themes addressed in this section were Employee Training and Development, Socialization Needs (Affectionate Behaviors, Sexuality, and Relationships), and Language Issues (Positive, Negative, and First Person). A summary of the findings from this section of the interview data analysis indicates that staff is very aware and intimidated by the strict policies about no fraternizing (or dating) between staff and clients—almost to the point of being afraid of being viewed as too nice to the clients. DSPs voiced their preference for supervisors who are making a career out of working with populations with ID and who have experience with the agency for an extended period of time. DSPs felt they had a lot of influence on the behaviors of their residents.

Staff at the different houses was confused by the current system that is in place to address client sexuality and affectionate behaviors. They do not know where to find the information in the client's ISP record and some staff was not aware at all of any current policies or procedures in regards to sex or sexuality. DSPs feel the topic is further complicated by the different levels of understanding exhibited by the clients they serve and by the issue of informed consent. Staff is further concerned about their legal liability due to gossip and/or false accusations that may occur in the CILA workplace. DSPs strongly felt that a strong team of workers in the house and the strong support of the agency supervisors and administrators are vital to the quality of life for both the clients and the staff. DSPs worked together to figure out solutions to social issues when supervisors were not actually in the house when sexuality behaviors came up.

The issue of how to identify if residents were LGBTQIA or were just acting opportunistically since most houses only served males or females was asked by DSPs. This is an issue that merits further study. Society as a whole is evolving with understanding sexuality and gender identification and it is important to study these populations in the institutional as well. However, these issues were not a focus of this particular study and the few results generated on those topics were not included. It is important to note the open-minded philosophy of the agency and its staff was not reflected in its written policies and procedures or the language used in the mandatory training materials in regards to sexuality and affectionate behaviors in any population with ID, either populations who are considered heterosexual or LGBTQIA.

Most DSPs shared they felt like they served in the roles of health educator, sex educator, parent, big sister, or big brother when it came to giving information and advice to the residents. While the client files included an area directed towards client social goals, little training or guidance was recalled by the DSPs in regards to where to find information about the ability to

give consent on behalf of the client or where to find the client sexual goals with the client file. DSPs felt reluctance on the part of supervisors and management for DSPs to serve as health and sex educators for the clients. DSPs felt this was an issue of liability but also felt like no one within the organization was serving in the role of health and sex educators for either the staff or the clients. Some DSPs did not identify themselves as a sex or health educator but shared that they were the one who provided the information to the residents in their home in regards to sex, dating, and socialization skills.

Participant Experiences – Serving as Sex/Health Educator

The personal DSP description narratives for perceptions of serving as a sex or health educator appear below.

Gia. "I definitely served as both a health educator and health educator while working in the different homes during my career here. I've had to teach male residents how to put on a condom and female residents how to take the birth control pill. I've had to teach female residents what a vibrator is and how to care for it and how to use it so as to not cause them any harm. A lot of the DSPs are hesitant to talk about sex with the residents so someone has to do it."

Ivy. "I did sometimes feel like I served as a sex educator or a parent in regards to teaching the clients about sexuality. It was mostly things like "it's not appropriate to put your hands down your pants in public" types of things we had to tell them. I really didn't mind doing those things because our clients would not have sat through a sexual education lecture, or listened to anyone (even their staff) for the most part. They only responded to 'No No No! No Thank You!'"

Darius. "I don't think I am their go-to-person for sex education. I probably feel like any one of my co-workers who catches them in the act might be better at the education, even though

I think they'll treat the situation just like I treat it. We have a lot of collaboration between our team members on the staff."

Ben. "When other staff in the house is hesitant to address something they come to me. I think it is because they know I am a health major. I usually work with the same people so they know I am pretty good with it and most of them do not have any health background. Most people get promoted if they have been their over four years so I help the newer employees out quite a bit."

Darius. "I don't really think I serve as a sex educator—I just help teach them right from wrong. I accept their rights as human beings and the only time I intervene is when it's in a public place or when I am trying to teach them."

Ben. "I believe we are the sex educators for these consumers because they don't have much in the way of role models or family support. Once in a while there is a family member that comes by but a family member is not going to visit and talk about sexual activity or the birds and the bees, I guess. So they are not going to talk about sexuality in the half hour they have of time to visit. Some people don't even stay for ten minutes. They will just see them and leave, after they make sure they are all right. I think we are the only people they have and that are why they become so close to us. I do feel like we are like their mom or something."

Claire. "I do think I serve as a health educator in my house. I get called on weekends, at night—I get calls or texts. Staff will not only ask what to do but what is proper procedure within our company or what would you do if this happens. Sometimes it is the pill is missing, what do you do? The answer is to call the nurse. That kind of thing. Most of our clients stay in the public schools until age 21. It is assumed they are getting some sex education there.

I think our staff could use more specific information about both sex education in general and what to expect for population s with IDs. I feel like I am educated because of my health education training but the rest of the staff isn't. I feel for the most part our supervisor deals with the sex education duties and issues. I probably did serve as a health educator at work because I tend to speak my mind on a variety of topics. I was fine in that role because someone needed to do it, and of the people I worked with or for I was probably the most qualified."

Ana. "I don't feel like I serve as a sex educator but I do feel like I serve as a health educator in my house. I think the number one health concern we work with is feces and possible disease prevention. We also deal with a lot of body fluid issues. I try to be very careful. I wear gloves but we have a lot of exposure to body fluids of different types."

Participants Experiences – Policies, Procedures, & Protocols

The personal DSP description narratives for perceptions of policies, procedures, and protocols appear below.

Claire. "There are very strict policies about no fraternizing or dating between the staff and clients. Consent is not an issue—it is just strictly not allowed even if it is consensual. Informed consent does not matter in this type of situation if it involves staff."

Eva: "There are specific procedures for getting help from supervisors. First, we are supposed to call the "on call" cell phone number. Supervisors share the phone, with each one being on duty for one week at a time. Each supervisor is responsible for two homes when on call—their main home and their "sister" home. If no one answers, then we are supposed to call their personal cell phones. If the police need to be called, staff is required to call the police first and then call the supervisor using the on-call phone number."

Ana. “Our staff gets along very well and we work together to help the guys as much as we can. Typically the supervisor is the glue that holds the team together. Our new supervisor is more interested in her nursing school requirements than her job. I think the supervisor should be focusing on a career working with populations who are ID. Our previous supervisor served as the mother of the house—both for the clients and the staff.”

Eva. “When I have a problem at work that I can’t figure out, I talk to other staff. If we can’t figure it out, I call the supervisor. I have never had a situation where the supervisor couldn't help me. They are both good. They are pretty helpful.”

Gia. “You know, I think we have pretty good policies or procedures. I feel really supported by our organization. There is also a section in the ISP for sexuality. I’m not sure how many staff pays attention to it but it is there.”

Ben. “It is confusing because we really do not know what the policies are regarding sexuality. No one has ever said “Don’t answer those questions” but all of us staff feel like it is discouraged.”

Ivy. “One of our high functioning women developed bumps on her private area from not bathing properly. Her ISP states she is able to bathe herself, so staff was not checking in or her while the shower was going. She mentioned she had these bumps and had a doctor look at them. From then on we were required to monitor her bathing habits. Still, we were never told whether it is our job to make sure the bumps are disappearing, or if that is an invasion of privacy.”

Ana. “As a staff, I don’t think the issue of consent comes up. It is in their ISP who their legal guardian is but the goals seem to be more social within the community than sexual. I don’t think there is even a place on the ISP for sexuality. It is not really geared towards sexuality or anything like that. We don’t really even know who is in charge of the issues of consent.”

Finn. "I am not aware of any policies about sex or sexuality. There may be some but I am just not aware of them. Many of our houses are all male or all female. Each house has a sister house that they socialize with for parties or dinner. I think they should take the time to go over the policies more often."

Finn. "It is policy that they cannot take anyone back to their rooms. I don't know if it has anything to do with only some of them have the right to give consent. Most of them have guardians so they cannot legally make their own decisions. Maybe that applies to sex too. It's really hard because we have clients on so many different functioning levels."

Ben. "So it is like I would talk to them about sexual activity but no one really asks much. Once in a while I have gotten that one person that has asked me if I am sexually active. You are not even supposed to answer that question. There is a policy that you are not supposed to talk about yourself at all. You are supposed to ask another question to get rid of that last question. You are supposed to ask a yes or no question to them to get their mind off of that question they just asked. I don't think we are allowed to talk about sex at all, period. I feel like we are encouraged to discourage them to even think about it."

Gia. "It can be a complicated situation—trying to figure out sexuality rights for our clients. It depends on their ability to understand their actions. Also, guardian approval is an issue. It is their right to be alone with another person. However, if their guardian disagrees with being able to be alone, staff has to be trained accordingly. If they can be alone with other people, we have to create a "safety plan" as part of their ISP. Some safety plans include requiring a verbal contact though a closed door every 30 minutes, or checkpoints like that to make sure we protect the client from certain types of abuse or situations that might cause them some type of harm."

Ben. "It is also stressful to figure out what is the truth and what is a rumor. The clients will go over staff's head if they do not get their way. There are a lot of rumors spread. You don't know whether to listen to the clients of the employees because employees can lie too. However, if a staff person is not working out with the existing group, upper management tries moving them to another house. We do have to click as a staff because we are a small group working with a small group of adults. Management is quick to step in to resolve any issues or problems with staff. I would like to see a little more attention on finding staff that are the right fit for each house. You get connected to the clients but also to the staff in the team."

Ivy. "We also had a client who went on a home visit, and when she came back her mother announced she had a bite mark on her inner thigh. Because of previous concerns about bruises on other areas of the body, a staff and supervisor inspect the woman for bruises and scratches before she leaves the house, and there was no indication of a bruise or bite mark before she left the house. Staff notified the supervisor of the claims, but did not hear about it again."

Eva. "When an incident occurred, I had received training that such a thing could happen, my co-workers had received the same training, so we all responded per protocol and I was fine."

Ana. "It is also stressful because sometimes you have a client who has been in the system for so many years they know the ins and outs very well. They also know things that you can do and the things that you cannot do as an employee and the things they can and cannot do as clients. So they push and play upon those things in a manipulative manner."

Ana. "We have a guy who frequently hits the employees and likes to use them as a human punching bag. There are no consequences to the clients for their inappropriate behaviors, which is very stressful for the coed staff. The behavior management plan is reactive instead of

proactive so it takes time to get new tools to deal with new behaviors in place. The clients can be too friendly and frequently invade the personal space of staff."

Ben. "Our house has multiple disorders. There are so many of them we are not even really told what the disorders are. I think that this is kind of ridiculous too because it says on the sheet. It typically says ID and says mild or severe. It says different kinds of stuff. I just feel like that is really not a right way to put it. Why don't you just tell us what they have? What is the disorder instead of mild ID? What does that mean? We never really had training that made what that means clear to us. They explained the forms and the information sheets but that doesn't really tell us what it means.

Having a better idea of the different types of disabilities, what they are, what they entail, what they mean, and how I can adapt my job around them would be helpful. I mean then you would realize what is wrong. You don't see mild ID. You don't see severe ID. You see a person. For example, when they have allergies, the chart says everything. It doesn't just say mild allergies or severe allergies. The ID diagnosis doesn't ever say what their actual problem is. I mean the chart says all their meds. They could be taking medication for seizures. That makes sense. They may be taking medication for depression. That makes sense. But what does ID really mean? You don't really see the disability and so it is kind of difficult to work with that."

Ana. "I don't like changing the colostomy bag. Frequently feces will spill while you are changing the bag. One time I went home and smelled something. I looked down and I had poop on my shoe. Another thing that is very stressful is how good at multi-tasking you have to be when you are there by yourself at night. There could be a fire or something—I hope that never happens but the fact that it could is very stressful when you are by yourself. Someone could have to go to the ER and then what would you do? Anything could happen."

Ben. "It is also stressful to figure out what is the truth and what is a rumor. The clients will go over staff's head if they do not get their way. There are a lot of rumors spread. You don't know whether to listen to the clients of the employees because employees can lie too. However, if a staff person is not working out with the existing group, upper management tries moving them to another house. We do have to click as a staff because we are a small group working with a small group of adults. Management is quick to step in to resolve any issues or problems with staff. I would like to see a little more attention on finding staff that are the right fit for each house. You get connected to the clients but also to the staff in the team."

Eva. "This is interesting because me and my co-workers were just talking yesterday that a previous employee that was in my house was not caring and, in this job, you have to care. You have to have compassion. We take them by their hand. We call them by their names and we talk regular to them. Not baby talk. We talk to them like they are adults and he just didn't do none of that. He didn't touch them. He poked them. And that just -- you cannot do that in this job. You have to care. He is gone now. Management moves quickly when we tell them there is a problem. We appreciate that."

Ana. "Choosing the right staff is really important because in this business you really have to have a soft heart and some people are not—not that the clients even need sympathy, I'm not saying that. Rather, they need to be treated with empathy and I don't think some people understand. We have a system to report staff members who are not treating the clients well or with respect and they usually do not last long. Upper management reads the daily reports and takes action as necessary to protect both the clients and the staff."

Darius. "If the supervisor is there I just ask them. What are the dos? What are the don'ts? How should I react if a certain situation comes across during the work day? Sometimes I

just ask my co-workers if they have ever been in this situation or predicament before and if so, what did they do? Sometimes you just go off of your feeling because I should know what is right or wrong about the situation. I should know what to do or how to prevent it or how to go about it and how to do it. Hopefully they can retain what I told them and realize, that no, he told me not to do this here in public.

It's sort of like being a big brother or a parent or mentor because the parents tend to baby them. I can't baby someone who is actually older than me, even that the situation may call for it; they are still older than me. I wouldn't baby them because that is not how they should be treated. They shouldn't be treated as babies. They should be treated as healthy adults like they are. So I wouldn't baby them at all—I would probably be more like a big brother or a mentor, you know, and try to keep them as happy as possible."

Participants Perceptions of Influence – Affectionate Behaviors

The personal DSP description narratives for perceptions of their influence on affectionate behaviors appear below.

Ana. "I think we have a lot of influence on our client's behaviors because we are around them the most. Only one of my clients has a regular relationship with his mother. She comes around all the time."

Ivy. "Personal attitudes and experiences absolutely influence how staff interacts with the residents. If you let a client hug you once, then sometimes they want hugs each time you walk past them in the hall. I realize that sometimes I start off with the clients a little more reserve and personal space than I used to."

Ana. "I think I have a lot of impact on the decisions the clients make. I know they listen to me. They enjoy when we have a good time together but of course when they have behaviors it

can be little rougher to calm and settle them down. But overall, I think we have been around a while so they have grown to connect to us and see us as their mentors or parental role models. Management always tries to remind us that we are not their parents but honestly that is how I feel. It feels like I have eight children."

Participants Perceptions of Influence – Sexuality Behaviors

The personal DSP description narratives for perceptions of their influence on sexuality behaviors appear below.

Ivy. "Most staff considers it all part of the job. Some experiences were more uncomfortable than others. Sometimes there were contradicting information about what is okay and what is not (i.e. hugging or clients kissing staff on the cheek). Staff were told to keep things professional, then told this is their home and that we are the closest thing to a family that some of the clients have. Most of our clients had state guardianship."

Claire. "I do think I probably did influence the ladies quite a bit in regards to sexuality. I never admonished them for sexual activity except to say it needed to be done in private. I don't understand why an adult with a disability should be treated any differently than everyone else."

Ben. "The agency lets the clients be who they are. Like they have their privacy, but it is like if you want to go in their room, you just walk in their room. They don't have locks on their doors. It is more of a safety issues I believe. I feel they don't have the privacy they should have. It's more like you have got to keep their minds occupied so they do not think of stuff like that I guess. I believe that everybody has their own freedom. They should have their own freedom just like everybody else does. The only difference is, for their own safety, we have to work with them just like we work with anyone else. We need to give them freedom but we need to keep them safe."

Ben. "Media influence—they are allowed to watch whatever they want. Some clients have their own TV and they will ask questions from the shows. The young guy was watching an "R" rated movie and a sexual question came up. He asked me what it was. It wasn't like I could not answer because he understands. He knows about sex. He knows about that stuff. He has done everything. He knows about sex. It is more like you have to kind of just answer the question and turn it back. It is hard to explain with him because he understands it all. But with others, you can just ask another question to re-direct them easily."

Finn. "Choice for the clients is a really big deal. Choice is provided for the clothing they wear, the field trips they take, the restaurants they chose for dinner trips, the friends they make, and more."

Summary

This chapter summarized the results found during the data collection process. In this chapter, I explained that qualitative research design and interview methods were used to collect data about the sexuality and affectionate behaviors experiences of DSPs in the CILA workplace. Purposive sampling techniques were used to select participants who were interviewed using an in-depth, semi-structured interview process. Interviews were transcribed verbatim, and analyzed by organizing constructs into codes, categories and developed into themes. Trustworthiness was established using a combination of triangulation, researcher reflexivity, member checking, adequate data collection, reflective journaling, peer reviewing, and using multiple sources for value coding (field notes, interview transcripts, and documents). Information was presented from the analysis of training materials from regulatory agencies, training materials from the agency, agency marketing materials, agency employment documents, and a SACIS Workshop held during the research period for DSPs. In chapter five, I will summarize and synthesize the main

results of the study and link them to literature, discuss the implications to policy and practice, and make recommendations towards meeting the workplace training needs of DSPs in the CILA workplace.

CHAPTER 5

Conclusions, Discussions, & Recommendations

Purpose of the Study

Presented in this chapter are my study conclusions; my recommendations for future research, the preparation of DSPs, and the profession of health education; my final thoughts on my research results; and the summary. The primary purpose of this study was to explore DSP workplace experiences, preparation, employee training, emotions, and perceptions in regards to types of sexual and affectionate behaviors exhibited by adults who are intellectually disabled in their care in the CILA setting. For this study, human sexuality was defined as the constitution of an individual in relation to attitudes or acuity. This was a broad concept that included aspects of the physical, psychosocial, social, emotional, and spiritual makeup of an individual (*Miller-Keane Encyclopedia and Dictionary of Medicine, Nursing, and Allied Health, 2003).* It was not limited to the physical or biological reproductive elements and behavior, but encompassed the manner in which individuals used their own roles, relationships, values, customs, and gender. For this study affection was defined as a positive feeling or emotional disposition toward another that did not necessarily include the expression of those feelings (Mikkelson & Floyd, 2013).

The study focused on analyzing what DSPs experienced in the CILA workplace through in-depth, semi-structured interviews, observation of behaviors on interview video tapes, observation of emotional verbal cues on interview audio tapes, document analysis, and field notes. This analysis provided an understanding of what ideas and values DSPs brought to their roles of guiding the sexuality and affectionate behaviors of those residents in their care and identified additional training needs from their perspective to help them better do their jobs. If the basic level of sexuality experiences for working with populations with ID by DSP was

identified, training programs could be developed to build skills in regards to sexuality workplace issues to enhance the CILA experience for both DSP and their residents in the future.

Summary of the Study

It is widely acknowledged within the field of services for populations with IDs that human sexuality is integral to clients' quality of life and overall wellbeing (Brashear, 1978; Esmail, et. al., 2010; Isler, et. al, 2009; Rembis, 2009; Wiwanitkit, 2008). While incorporating aspects of sexuality into client services was viewed in the research as imperative to overall quality of life and wellbeing, the model, or lack thereof, upon which this could be enacted, may be inherently exclusionary. Considering that sexuality is a relatively recent addition to the rehabilitation repertoire (Esmail, Darry, Walter, & Knupp, 2010; Rohleder & Swartz, 2012; Schulz, 2009) services for populations with ID, which strive towards an integrative/social model, have yet to comprehensively integrate this aspect of human experience within pedagogy or practice (Dune, 2012b). As such, rehabilitation staff may use the medical model of sexuality, popularized within typical populations, to address the "problem" of "limited" sexual performance and functioning in an effort to 'help' the client achieve near typical levels of sexual participation (Mckee & Schover, 2001).

Sexuality as constructed by people with ID cannot be dissected and explained within the confines of public, interactional or private sexual schema. The findings of this study emphasize that people with ID are agents in the construction of their sexuality. Bandura's social cognitive theory (1986, 1997, 2006), which highlights people as social agents, may therefore be a better theory to apply to constructions of sexuality with populations who are ID. Research which employs Bandura's social cognitive theory and constructions of sexuality with disability would be beneficial in further understanding of agency and sexuality with disability.

Little research has been conducted pertaining to the sexuality and affectionate behavior needs of people with ID or to the subsequent sexuality training needs of DSPs working with populations who are ID in CILA settings. Most of the research that has been completed was done so in countries other than the United States. Even less research has been conducted focusing on the experiences of the CILA DSPs in regards to sexuality and affectionate behaviors of their clients and how those behaviors influence the overall workplace experiences of DSPs (Rapanaro, Bartu, & Lee, 2008). More research to document the need for additional employee training to assist DSPs in dealing with sexuality issues within populations with ID in CILA settings should be conducted to better meet the needs of ID adults and the staff that work with them. Better trained DSPs would result in better experiences for ID adults, as well as a reduction in the number of sexuality incidents within the CILA setting due to DSPs not understanding the various sexuality needs of their residents.

The most cited research for identifying how DSPs experienced 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 DSPs who work with people with disabilities (SexKen-C). The SexKen-C has still only been used once and has not been updated since my initial literature review or since its use in the original study. The original data has been lost and the original instrument is extremely out of date.

The Perception of Sexuality Scale is one of the only instruments used in studies conducted in the United States. It was developed for use in a Master's Thesis. The purpose of the descriptive study was to determine the perception of DSPs 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 developed for use by college students instead of actual staff working in the CILA setting (Scotti, Slack, Bowman, & Morris, 1996a). With little or no research found examining the direct experiences of DSPs in CILA homes regarding the sexuality and affectionate behaviors of populations with ID, I decided to conduct in-depth discussions with DSPs regarding their experiences, their training, and their recommendations for improving their preparation to deal with the sexuality and affectionate behavior issues that came up in their daily work duties.

The research methodology utilized in this study was based on the creation of a descriptive case study. Bandura's Social Learning Theory was used as the guiding theory throughout the data collection process to explore what influence DSPs had on the sexuality and affectionate behaviors of the clients they supervised. Four research questions were answered in the study:

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

Nine individuals working as DSPs in CILA homes were selected to participate in this study. The purposeful sample consisted of five Caucasians, and four Black/African Americans.

The educational level of the participants ranged from a high school diploma to a Master's Degree. Most of the participants were employed full-time and worked the second shift—the shift where all residents with ID were in the houses and were awake. The participants ranged in age from 22-30.

Data collection included eight sources of data—participant demographic information questionnaire, semi-structured interviews, observation of behaviors on interview video tapes, observation of emotional verbal cues on interview audio tapes, document analysis, language usage analysis, reflective summaries, and field notes. Each participant was asked all the questions on the interview script as well as any additional questions that came up during the interview process. The interviews were audio and video-taped and transcribed by a court reporter. Field notes were written during and after each interview. Once the transcription report was received back from the court reporter, the transcripts were read by the researcher and initial codes were written in the margins. The transcripts were compared to the field notes made by the researcher during the actual interview and a file folder was created for each participant. Each participant met with the researcher again in person to review their interview transcript and add any additional information or experiences they wished to share.

Audio and video-tapes were reviewed by two independent raters using a video observation report form developed using the same language found to be prevalent from the mandatory training materials from CILA regulatory agencies. The researched collaborated with a tenured faculty member from a local university to independently evaluate the audio/videotapes to create codes and categories for emotional and value coding. Results from both evaluators was compared and contrasted to assist in increasing the project's reliability. The same collaboration process was used to independently evaluate the interview transcripts to create codes and

categories for interview data. After codes, categories, and themes were identified a summary report of all the data was prepared for review by the project participants.

The summary report was sent to each participant and each participant reviewed the data analysis summary and suggested any additions or clarifications to the data. The constant comparison method was used to develop the categories and themes. Throughout the coding process common and less common categories were formed. These categories were developed from the responses from the interview question responses from the DSPs. Data analysis included sorting the data into evolving categories and themes according to the research (See Table 11). The common categories of affectionate behaviors were females flirting with others, males flirting with others, female friendship, male friendship, female socialization, male socialization, females holding hands with others, males holding hands with others, female hugging, males hugging, female use of media, female use of technology, and males use of technology. Less common categories of affectionate behaviors were female attention seeking behaviors, male attention seeking behaviors, female ego, male ego, female dating, male dating, female problematic affectionate behaviors, male problematic affectionate behaviors, affectionate behaviors safety versus privacy issues, female other types of behaviors, and male other types of behaviors. The common categories of sexuality and masturbation behaviors were male groping, public male masturbation, private male masturbation, female problematic sexual behaviors, and male problematic sexual behaviors. Less common categories of sexuality and masturbation behaviors were female groping, public female masturbation, private female masturbation, female sexual intercourse, male sexual intercourse, sexuality safety versus privacy issues, female problematic sexual behaviors, female marriage, and male marriage. The common categories of influences on sexuality/affectionate behaviors were policy, consent, guardianship, communication, and

privacy. Less common categories on sexuality/affectionate behaviors were setting and functional level.

Gender categories were developed from the interviews but very little data about gender was generated through the interview process. The categories developed were gender bias against females, gender bias by females, gender bias against males, and gender bias by males. The most common category in regards to the ability of the resident to give consent for participation in sexuality/affectionate behaviors was the unknown category. Less commons categories developed for consent were lack of ability to give consent due to medical or physical reasons, lack of ability to give consent due to legal reasons, client had the intellectual ability to give consent, and the guardian/parent/case manager made the choices for the client.

Transcripts were reviewed and coded by two independent raters to develop codes and themes, which were organized topically. Rich, thick descriptions from the transcripts were utilized to give meaning to the findings and to develop recommendations. I used triangulation, researcher reflexivity, member checking, adequate data collection, reflective journaling, peer reviewing, and using multiple sources for value coding (field notes, interview transcripts, and documents) to ensure trustworthiness for this research. Common categories under the affectionate behaviors were dating, flirting, friendship/socialization, holding hands/hugging, media/technology, and problematic behaviors. Common categories under sexuality behaviors were groping, masturbation/females, masturbation/males, and problematic behaviors. Less common categories, appearing at least once were affectionate behaviors-attention seeking/ego, sexuality behaviors – sexual intercourse, and sexuality behaviors – dating and marriage. Once data were categorized, each category's responses were sorted to identify overarching theme areas of recommendations. Based on this analysis, three overarching themes and many

recommendations emerged. The themes were Employee Training and Development, Socialization Needs (Affectionate Behaviors/Sexuality/Relationships), and Language Issues (Positive/Negative/First Person).

Conclusions

Primary strengths identified included thinking of residents as family, the feeling of strong management support, and lack of significant conflict within the CILA homes. Elements that detracted from the DSP experience included low rate of hourly pay, employee turnover among DSP supervisors, lack of specific sexuality education for both staff and residents, limited retention of mandatory training topics, and lack of communication of sexuality policies and procedures. The following conclusions can be drawn from the findings of the interviews and document analysis:

1. There is a need for additional training for DSPs and staff on the topics of human sexuality and affectionate behaviors in CILA homes.
2. While DSPs and staff complete all the state-required, mandatory training in the first few months of their employment, they retain very little of it, especially in regards to the specific topics of human sexuality and affectionate behaviors. What they do remember is negative and results in a reluctance to discuss or acknowledge sexuality issues for the clients in their care. The DSP training process needs to be examined further for methods of training, topics included in the training, and how to increase knowledge retention in the staff.
3. DSPs are confused when it comes to the policies, procedures, and protocols regarding sexuality and affectionate behaviors that pertain to how situations are handled in CILA homes. Policies and practices within CILA organizations need to be developed that

affirm socialization, sexuality, and affectionate behaviors for populations with ID. The philosophies of the agency and the DSPs expressed in the data collection process did not match what's written about existing policies, procedures, and protocols. This should be addressed through the adaptation of current existing policies, procedures, and protocols and the creation of new ones to enhance the socialization, sexuality, and affectionate behaviors for populations with ID.

4. DSPs need a better understanding of what the label mild intellectual disability, moderate intellectual disability, and severe intellectual disability mean and how those different levels of abilities influence the behaviors and abilities of the clients they serve.
5. While many health educators have limited, if any, experiences in advocating for health issues, an active effort should be undertaken to inform and educate regulatory agencies for CILA homes and DSP training on the need for the inclusion of quality human sexuality training programs and materials in the required DSP training schedule.
6. Even professionals working in the field with populations who are disabled or families who have a family member who are disabled used first person language sporadically. Even more alarming are people who were trying to create programs to help people with disabilities had pre-conceived intentional or unintentional notions that negatively impacted the resources they created. Person first language should be required for use in all new and updated training materials provided by regulatory agencies, agencies, and outside vendors who provide training to DSPs.
7. Every effort should be made to balance the use of positive and negative language word choices when creating new and updated training materials to provide training for DSPs,

especially materials developed by regulatory agencies, agencies, and outside vendors who are supposed to be the experts in the field of disability services or human sexuality.

Discussion

In this study, DSPs cared very much about the residents in CILA homes who were under their care and supervision. They considered the residents to be like members of their own family. However, there was a basic lack of understanding of what it meant to be an adult with ID and the impact having ID had on the residents' abilities and life choices. There were so many different disorders in each CILA home DSPs found it confusing to comprehend how all of them should be dealt with by caretakers such as DSPs. DSPs expressed a desire to understand exactly what the label attached to the different disorders means and how it impacts both the employee and the resident.

DSPs are confused about the sexuality rights of the residents. Human sexuality plays a major role in everyone's life. Regardless, whether we are young or old, man or woman, it is an integral part of what we do and who we are. There has been much done by way of research and scholarly writing examining human sexuality in general (e.g., Abramson & Pinkerton, 1995; Beach, 1977; Diamond, 1997; Reinisch et al., 1990; Tiefer, 1995). Human sexuality is the way in which we experience and express ourselves as sexual beings (Rathus et al., 1993). Human sexuality is constructed via public, interactional and private sexual scripts (Simon & Gagnon, 1986, 1987, 2003). The relatively recent inclusion of sexuality in disability services is based on the theory that all people have a right to sexual education, intimacy and intimate relationships (Rathus, Nevid, & Fichner-Rathus, 1993; Parker, 2007). According to the World Health Organization (2012) sexual rights include "the right of all persons, free of coercion,

discrimination and violence," to attain the highest possible "standard of sexual health, including access to sexual and reproductive health services".

A lot of the research about sexuality and populations with ID was very dated but similar themes were stated, whether from the 1960s, 1970s, 1980s, 1990s, 2000s, or if the research was considered to be more recent and up-to-date. Each decade the right to sexual expression by people with ID was considered to be a new, upcoming and important topic. Each decade recommended new and additional training in human sexuality issues for direct staff working with residents in institutions, group homes, or in the CILA setting. However, I could find no evidence of experts working in the field of human sexuality for populations with ID or training materials for either DSP or residents living in CILA homes. Repeating information from the literature review conducted for this study, little or no research existed in the United States about sexuality issues in group homes at all. Many researchers agreed there was a need for human sexuality programs and training materials for staff and residents but there appeared to be little or no follow-up to address those recommendations.

Foremost, sexual rights encompass "the right to have one's bodily integrity respected and the right to choose—to choose whether or not to be sexually active, to choose one's sexual partners, to choose to enter into consensual sexual relationships, and to decide whether or not, and when to have children" (Parker, 2007). In addition, research has shown that sexuality is a key component for psychosocial wellbeing (Grov, Parsons, & Bimbi, 2010; Niet et al., 2010). According to the Parker (2007, p. 973) "sexual health is more than the absence of disease. Sexual pleasure and satisfaction are integral components of well-being and require universal recognition and promotion". Considering these conventions sexuality would be well placed within disability services as it can address potential sexual issues. It could provide a better understanding of

sexuality topics for DSPs through education about sexual choices, sexual health, sexual negotiation, as well as acknowledge the need and/or desire for satisfying sexual relationships.

The issues of sexual choices and consent were indicated as issues of concern in the experiences of DSPs. As health educators we need to follow through with the development of training programs that assist frontline staff such as DSPs to understand and address the concepts of choice and consent in regards to populations with ID. In addition, these new programs need to be written with positive, people first language that is based on respect and the awareness that people with ID are autonomous adults who have the right to make autonomous adult choices in regards to their sexuality and affectionate behaviors.

One of the most controversial social policy issues that remains underdiscussed in scholarly literature is the sexual autonomy of persons with ID, especially those who are institutionalized (Sabatello, 2014). This population is typically infantilized—the process of thinking of them as not being capable of having the same range of sexual desires, needs, and expectations as persons without disabilities (Sabetello, 2014). Although attitudes about the abilities and capabilities of persons with ID are changing for the better, it remains true that "many people still struggle to accept that individuals with ID engage in sexual activity" (McIntyre, 2007, p. 1303). The literature surrounding sexual autonomy and issues of sexuality people with ID continue to confront remains remarkably silent on this issue in general, especially when such individuals are institutionalized (Gilmour, Smith, & Schalomon, 2014; McCann, 2012; Perlin, 2005, Perlin, 2011). DSPs identified that often times behaviors such as groping, or inappropriately touching staff was overlooked or let go because the resident was viewed as not knowing what they were doing or behaving like a child by the staff. DSPs frequently exhibited an absence of a real understanding of what it meant for the resident to be ID or to also have

several other types of diagnoses that might impact their behavior or ability to make behavioral choices. This needs to be better addressed in DSP training and preparation programs.

In the United States, the law has followed this trend, with very little attention being paid to the legal rights of person with disabilities to exercise their autonomy, especially in the institutional setting. Many critical questions remain unanswered in the law, leaving hospitals and community treatment facilities to decide for themselves how to best deal with these issues, often with no clear guidelines (McCann, 2012). A closed institution, by its nature, places substantial limits on an individuals' mobility and freedom of action. In considering how best to allow individuals to express their autonomy, it is important to consider all aspects of a relationship, including issues indirectly raised by sexual intimacy (McCann, 2005). Although an institution may need to restrict some privileges based on safety or treatment concerns, it will be critical for institutions to consider a "least restrictive environment" approach when dealing with clients' sexual autonomy (Perlin, 2011).

Even if a written policy on sexual activity is put in place, the fear of litigation by institution administrators may still lead to the "policing" of such activity in case some form of harm may be taking place. The threat of litigation may therefore lead to staff members erring on the side of caution in relation to sexual activity among those in institutions (McSherry & Somerville, 1998). The nature of this topic makes it a contentious point among the various groups that debate it, legislate it, and implement it. Beliefs and values beyond law and legislation are intertwined with attitudes towards sexual activity (McCann, 2012).

The issues of consent, choice, and sexual opprtutnites need to be clarified in policies and training to enable DSPs to better support the sexuality of residents with ID. The positive and supportive philosphy of the agency and staff in regards to sexuality and affectioante behavior

does not match the written policies and procedures within the organization. As health educators we need to actively solicit a change in the DHS materials and advocate for future materials to be written by a collaborative team consisting of representatives from human sexuality educators, special educators, and disability specialists. Health educators also need to increase their understanding of persons with special needs of all sorts (disease, developmental functioning, and age) within their academic preparation programs, especially for populations who may reside in assisted living or residential facilities.

Social norms are the “prevailing codes of conduct that either prescribe or proscribe behaviors that members of a group can enact” (Lapinski & Rimal, 2005, p. 129). However, interpretations of norms are subjective, so people may act on them in different ways. In a review of the literature on gender differences, Oliver and Hyde (1993) found that women are more likely than men to report negative feelings in response to sexual behavior. Social norms can be communicated either directly, by interpersonal communication and direct observation, or indirectly, wherein people infer norms without observation. For my study, female DSPs participated in the study longer, and were more active in the follow-up emails and texts. Men and women were equally accepting of sexuality and affectionate behaviors of their clients. However, several female DSPs reported a hesitance of the male DSPs to deal with female clients during their monthly periods or with personal hygiene associated with them being women.

The use of social norms often excludes individuals with disabilities and their experiences of sexuality (Guildin, 2000). If people with disabilities are excluded from public (i.e. popular culture) portrayals of sexuality they may subsequently be excluded from sexual opportunities and be perceived (by themselves and others) to be unviable sexual partners (Dune, 2012a; Overstreet, 2008). Thus sexual participation and negotiation as mediated by public and interactional sexual

scripts may discourage sexual behavior with people with a disability. Without an appropriate model for sexuality with disability to inform staff, people with ID may be relegated to expressing their sexuality within the confines of typical institutional policies and procedures.

In addition, people with ID often do not acquire adequate knowledge regarding sexuality, even though sexuality is a universal human trait (Sweeney, 2007; DiGiulio, 2003). The findings of my study indicated a need for further human sexuality training for both the staff and the clients. Educators and program administration need to recognize that comprehensive human sexuality education is more than the sum of facts or definitions of body parts and biology (Sweeney, 2007). Important goals of any human sexuality program are the promoting of a positive self-image through the use of materials that uses positive language and positive imagery (Sweeney, 2007). DSPs identified that the negative language of the existing training materials served as a barrier for their comprehension of the intent of the training and limited their willingness to positively support the sexuality and affectionate behaviors of their clients.

My study found it is not only important to use positive language in regards to sexuality and affectionate behaviors but to make sure that all training and training materials use "person first" language. According to Blaska (2013), "the words or phrases people speak and write, plus the order in which they are sequenced greatly affects the images that are formed about individuals with disabilities and the negative or positive impressions that result." Language is a reflection of how people in a society see each other. Stereotyping sex, race, and disability through language usage is very pervasive and can have a negative effect on society's and staff's perceptions of persons with disabilities, as well as affect the self-image of individuals with disabilities (Blaska, 2013). The results of both the in-depth interviews and the document analysis found negative language was prevalent in existing DSP training and training materials. DSPs

reported their own behaviors and how they reacted to resident behaviors were impacted by the overuse of negative language in these materials.

Discussion of Participants

The strength of this project is the participants and their honest, detailed stories they so willingly share. The participants in this study were committed to both their employer, their clients, and to helping me with this study. They donated the requested hour of their time for the initial interview and remained active in the study throughout the entire data collection and data analysis process. Most participants asked to see me again to follow up on their initial interviews as well as kept in contact on a regular basis via phone, text messaging, or email as they remembered additional information or had new experiences in the workplace. Each participant actively checked their transcripts during the member checking phase of the study and added richer, descriptive detail to their answers during the process. In contrast to the many of the existing studies, all the participants in the study liked their job, liked their employer, and liked the clients they worked with in their CILA home. The only complaints were the low hourly wage, other employees who did not do their jobs or treat the clients with the respect, and the need for more training for new supervisors. All of the study participants stated that the administration listened to the DSPs and those employees were quickly removed from the staff. I was surprised by the commitment of the study participants, how positive they were, and how much they cared about the clients and the clients' quality of life.

Limitations

The study was limited for several reasons. First, the participants in the study were more educated than expected. Many of the employees came to the area to study at the local university. Once they graduated with the Bachelor's Degree, they chose to stay both in school to work

toward a graduate degree and to stay employed with the agency. For this reason, local DSPs are more educated than the average DSPs who may work at other CILA facilities. Having disabled family members and/or planning a career working with adults with ID enhanced motivation to participate in the study, which could have resulted in bias. The participants were not as representative of the local community as expected. The DSPs over the age of 30 typically work at the adult daycare also ran by the same organization, which was not included in the study. It was anticipated that the age range of participants would have included DSPs of all ages—instead the age range was more indicative of the local university population instead of the community as a whole.

Recommendations for Future Research

Specific recommendations for future research include the following:

1. Since residents use cell phones and social media on a regular basis, a study about the use of technology in CILA homes needs to be completed (text, instant messaging and online chat). The use of technology may create additional risk factors for the safety of the clients and additional liabilities for the staff. Training programs and materials may need to be adapted to address any potential issues found as a result of this technology study.
2. This case study needs to be repeated with all levels of the staff, training officers, and management to identify additional training needs and potential sexuality and affectionate behavior issues within other levels of the organization.
3. This case study needs to be repeated at additional CILA organizations to identify additional training needs and potential sexuality and affectionate behavior issues within other organizations.

4. Using the topics identified in this study, an instrument needs to be developed to enable large scale data collection of sexuality and sexuality training issues in CILA agencies.
5. An assessment to see what training DSPs actually remember should be conducted. The types of training methods that would be more beneficial to the DSPs to enhance their retention of the training topics should be studied. Many DSPs stated they did not remember their mandatory training because it was mainly worksheets and it was so much training taking place is such a compacted timeframe.
6. A study should be conducted of the pre-professional preparation and training materials of health educators in regard to the inclusion of populations who are special. It is anticipated this study will find little if any inclusion of populations who are special currently exist in these preparation programs or academic textbooks. Specific information about these populations should be included to increase health educator understanding of populations who are special in general as well as how there is a need to adapt traditional training methods and materials when working with populations who are special in some way due to disease, aging, or functional level.
7. An instrument needs to be developed to identify and measure the functional development levels of human sexuality that can be used by DSPs and other laypersons, with little training, to guide and enhance their interactions with clients in regards to sexuality and affectionate behaviors. The instrument should not only identify levels of human sexuality behaviors but also provide guidance on how to handle those behaviors and levels of human sexuality in the CILA setting.

Recommendations for DSP Training

Specific recommendations for future research include the following:

1. To aid in DSPs being able to better communicate with their clients, adding a training unit in sign language should be explored as part of the OJT training program. The development of this module should be done in collaboration with sign language experts. Not only was this type of training specifically requested by DSPs, numerous examples of frustration were mentioned during the interviews about how not knowing sign language interfered with the ability of the DSPs to communicate with their clients. Additional training in sign language would help the DSPs prevent negative client behaviors in the workplace and during community events.
2. New materials should be developed for training based on the results of the training methods study. My analysis determined DSPs remembered best training based on video scenarios and the subsequent discussion, which is visual learning. The current literature supporting learning styles and methods needs to be used to guide the development of any new materials.
3. The need for education on the topics of sexuality and affectionate behaviors is continual and it should be relevant, current, inclusive, accurate, developmentally appropriate, and culturally sensitive. The training materials should be prepared collaboratively with representatives from the fields of health, special education, and disability studies in order to be the most effective.
4. Human sexuality training should be made available to staff on all levels, including policy makers.

5. When working with populations who are ID, it is important that professionals from all fields of study (such as sex educators, law enforcement officials, medical staff, and mental health counselors) realize people who have ID are not children in adult bodies. This is important because they are adults, with all the rights, responsibilities, and respect entitled to an adult citizen. To treat them like children is demeaning and disrespectful.
6. Experts who develop training materials and programs for staff working with populations who are ID need to take the time and effort to screen their work product(s) for inclusiveness and the over use of negative language or word choices that may prohibit staff from exhibiting positive behaviors and/or skills from the training.
7. DSPs reported that they frequently rely on each other for support and problem-solving. A system to recognize the importance of this type of "on-the-job" training needs to be created and implemented. DSPs reported they would like to be recognized more by the organization for serving as the "unofficial" trainer or lead staff when they serve as the one everyone goes to for answers in a specific CILA home.

Recommendations for Health Educators

1. Health educators and other professionals who create marketing and training materials need to be aware of the power of the language and word choices they use on their target populations and how word choice may influence human behavior. When creating materials either for people with disabilities or the people who work with people with disabilities great effort needs to be made to use First

Person Language. These items need to be addressed in the training and preparation programs for health educators.

2. Health educators and other professionals who create marketing and training materials need to be aware individuals with disabilities, particularly ID, are not children in the bodies of adults. Therefore, the need to prepare materials carefully with the awareness of the power of language and word choices they use and how those word choices may influence human behavior needs to be addressed in the training and preparation programs for health educators.
3. Health educators and other professionals who create training materials for sexuality and affectionate behaviors in populations with ID need to be aware individuals with disabilities, particularly ID, are not children in the bodies of adults. Therefore, the pictures and graphics used for these training materials need to be age-appropriate and show examples of adult bodies. A review of current sexuality training materials for individuals with ID resulted in only finding materials adapted from use with children with childlike graphics.
4. Pre-professional training programs for health education and special education, among others, should include specific training on working with special needs adult populations. According to DSPs, current professional training programs for special education focus only on graduates working with children. Several DSPs stated that special education majors do not adapt well to working with adults and typically quit working as DSPs in the first few weeks. DSPs feel that this results in the loss of valuable training that could be retained if special education training programs included preparing for working with adult populations as well.

5. A study should be conducted of the pre-professional preparation and training materials of health educators in regard to populations who are special. As part of the literature review for this study, multiple textbooks and training materials were reviewed as part of the process of looking at populations who are special from the health educator's perspective. Most textbooks only included one or two paragraphs in the entire book. Too often populations who are special were thought to be the responsibility of special education or medical fields of study. This needs to be examined further to allow for better collaboration between health education and other fields of study and to better prepare health educators to work with people who are ID or who have special needs for any reason.

Final Thoughts

Far too often the message sent is not received. Far too often the meaning of an educational program or training is not retained. The trick is in creating a compelling message. A gloom-and-doom message does not actually work. Negative words can have long-lasting results that spread far beyond the person to whom they were given. In fact, just seeing a list of negative words for a few seconds will make a highly anxious or depressed person feel worse (Waldman, 2012). If you vocalize your negativity, or even slightly frown when you say "no," more stress chemicals will be released, not only in your brain but in the listener's brain as well (Waldman, 2012). As health educators, we need to educate others on how to communicate their messages in ways that cannot only be received but retained. When trainers turn negative thoughts and worries into positive affirmations, the communication process improves (Waldman, 2012).This is especially important when other agencies and fields of study are creating programs that deal with human sexuality and affectionate behaviors—topics that are essential to us as human beings.

Educators can unintentionally influence the process through the language and word choices they use, or the order they present them.

When working on the final coding and presentation of the interview data, I noticed a similar unintentional flaw in my data summary. Educators like things to be organized and typically use traditional methods of organization and layout such as alphabetization when presenting topics or information. My first primary code was affectionate behaviors. The more specific sub-code was affectionate behaviors – aggression. The first sub-code for sexuality behaviors was sexuality behaviors – aggression. After spending years investigating this topic and working with the best way to neutrally present topics that might make staff uncomfortable, I began my reporting process with an alphabetized organizational method which resulted in negative topics being presented first—just because it allowed the sub-code labels to be presented in alphabetical order.

I never noticed that I was beginning the dialogue with impactful, negative thoughts, stories, and experiences. Setting the tone in a negative way is often how health educators begin programs to change behavior. We want to build the consensus there is a problem that needs to be resolved. However, we often unintentional give the impression there is a problem or set a negative tone or mindset, when in reality we just want to present information or training materials about a particular topic. No actual problem may actually exist. In my organization of topical codes, changing the focus from negative to positive at the beginning could easily be changed simply by changing the term aggression to problematic behaviors for both sub-codes. This simple change moved those negative DSP experiences down the list and allowed for positive stories about sexuality and affectionate behaviors to be presented first. This is a subtle

method of influencing human opinion and behavior but an important aspect to be aware of when creating educational and training materials.

Importance of person first language. This research project is the first phase of my original plan, which was to create an instrument for the frontline staff to use to aid them in understanding stages of sexuality and human growth and development, specifically for individuals with ID. Doing so would hopefully reduce the stress levels of DSPs and enhance the sexuality and affectionate behaviors of the populations with ID that they serve by increasing the acceptance of their basic right to human needs. Further, it would move the identification of sexuality issues from the psychologist through the use of expensive traditional testing and psychological instruments to the frontline staff that see and work with the residents every day.

One psychologist I worked with on another project for a state institution for populations who are ID shared she was not a health educator, not a sex educator, and while she had money to purchase supplies and materials for the residents and staff, she had no idea even where to start when choosing appropriate materials and no time to research the topic. I met with training officers, institution directors, human resources directors, psychologists, special educators, and licensed counselors from outside the study area and outside the network of local service agencies when trying to narrow down the focus for this project. They all thought I was "on to something" that would be beneficial, practical, save time and money, and that was needed. However, in all of those conversations with all of the professionals and me the language that was used referred to populations with ID as adults who behave or function like children. This was a very important concept to note because many, many of these people were experts who work in the field with populations who are ID. These were the "experts" that educators would or have contacted when there was a need to create new program materials. These materials would be used to train

management personnel who write the policies and procedures that govern the lives of those with ID on a daily basis, as well as the frontline staff that work with them.

I created this project to serve as the needs assessment for the development of a scale to identify the sexual and affectionate behaviors exhibited in the CILA home setting and convert those to a scale based on age-appropriate behaviors in children that DSPs could more readily understand. The plan was to create a checklist that allowed DSPs to observe and chart client behaviors. Potential behaviors would appear in different columns and be associated with developmental milestones typically exhibited in our society by children. For example, if a male client stuck his hands in his pants or constantly touched his genital area he might be exhibiting the exploratory sexual behaviors of a three-year old child. Once enough behaviors were identified to indicate a particular level, recommendations and suggestions on how to work with a client at that sexual/affectionate behavior level would also be on the checklist. Only very late in the research project when I was putting together the final overriding concepts did I notice that I had not intended to use first person language in the development of my potential instrument (scaled checklist) or training materials. My entire project to enhance the lifestyles of populations with ID and to enhance how society treats them with respect and dignity included a fatal flaw—comparing individuals with ID to children. To be truly compliant with First Language, no age specific level of development should be associated with behavior levels or used for comparison.

The scale can simply be developed into functional levels of sexuality and affectionate behaviors, such as Level 1, Level 2, and so on. Seems like a very simple concept but one that I missed after years of research until the end of the project. This particular realization also indicates the need for collaboration between fields of expertise when developing educational training materials and programs for populations outside the traditional target areas. Too often

health educators create programs and materials that teach disease statistics and concepts and forget to equate those programs and materials to the actual human beings they are actually serving. Collaboration between the fields of health education, disabilities studies, psychology, and special education in the development of human sexuality training materials for DSPs would allow for a more comprehensive work product that was more respectful, functional, and beneficial to both the DSPs and the clients they serve.

The first person who pointed out that I was inconsistent with my use of First Person Language was a member of my committee whose area of expertise is Special Education. Ironically, even the initial title of my research project was not in First Person Language, even though I have been the mother of a person with a disability for over 25 years. This is important for several reasons.

If people who advocate for those with disabilities to be treated with respect and to not be discriminated against do so through lack of awareness or knowledge, how often does it happen from those who have no experience with populations who are disabled? I believe that every parent who has a child who is disabled has a lot of stories to share that relate to this topic. One of my favorite examples is the biology teacher who could not understand why I was upset that my son failed a biology test. The fact that my son is legally blind and the test he failed was comprised solely of visually identifying different objects submersed in dark pond water had no relevance to the situation from her perspective. She said she expected him to fail and he only had to do the best he could, just like the rest of the class. How often do we create materials, services or programs that are submersed in pond water from the perspective of individuals with ID or individuals with disabilities in general?

The very basis for communication is that the message is sent and that the message is received, as well as understood. Educators and service providers must be clear in their use of language when working with populations who are ID and disabled in general to be inclusive, respectful, and non-discriminatory. Collaboration between fields of studies and working with "experts" with different focused points of view are imperative when health education programs are being created for populations with special concerns such as ID. Further, educators who create learning materials and programs about sensitive topics such as sex abuse need to balance their language choices. The materials should not be so heavily based on negative language, labels, and subliminal messaging as existing materials used to currently train DSPs. Collaborating with representatives familiar with people first language would minimize a lot of the language problems identified in DSP and other training materials evaluated in this study. Such collaborative work would be suggested for programs and programs materials as they are updated in the future or in the creation of new programs and subsequent new training materials.

Summary

This project analyzed the experiences and training preparation of DSPs working in CILA homes. The overriding purpose of this study was to explore the workplace experiences and training of DSPs, with types of sexual and affectionate behaviors exhibited by adults who are intellectually disabled in their care in the CILA setting. Extensive interviews with DSPs were conducted and an in-depth analysis of training materials required by both the agency and regulatory agencies were conducted. Related to that effort, it became necessary to reach an understanding about the nature of regulatory compliance and its influence on the DSP training process. In addition, it became necessary to gain an understanding of the affectionate and sexuality behaviors of the clients with ID in order to understand how DSPs' apply in a practical

manner the information gained through the training process. The findings and conclusions incorporated these concepts into the recommendations in the hope that any resulting training and resource materials developed as a result of this study will improve the quality of life and work issues in CILA homes for both the DSPs and the clients who they serve.

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APPENDICES

APPENDIX A

From: epkingsley@aol.com
Date: September 21, 2014 at 9:55:31 PM CDT
To: alsego@eiu.edu
Subject: Re: Welcome to Holland

On Sep 6, 2014, at 4:47 PM, epkingsley@aol.com (former email address--no longer valid) wrote in an email (edited for personal information):

Hi Anita!

I'm so glad you persevered and were successful in tracking me down! I'm sorry (and disappointed) that Sesame Street didn't forward your request to me. They're usually pretty good about that. But here I am and I'm delighted to hear from you and gratified that Welcome to Holland has been helpful to you personally and that you would like to use it in your dissertation.

Yes, of course you have my permission to reprint it.

Usually I go through a lengthy ritual in which I send people a correct authentic version of WTH to make sure that they have an accurate version. Welcome to Holland has been reprinted so many times (as I'm sure you're aware) that it has been changed, cut, amended, butchered and rearranged to fit many people's personal agendas. I have to make sure that people promise to print it exactly as written, without any changes, cuts or additions. But I see that you have a correct version already so I am not worried about that.

I need to ask that you give a proper attribution and somewhere affix a copyright notice: Copyright ©1987 by Emily Perl Kingsley. All rights reserved. Used with permission of the author.

My own son, Jason, is now 40. He has Down syndrome and is living in a small group home in the community with two roommates. He works in the mailroom of our local Arc. If you are not familiar with Jason, you might want to check out his wonderful book (COUNT US IN: GROWING UP WITH DOWN SYNDROME by Jason Kingsley and Mitchell Levitz, available at Amazon).

I am most interested in the topic of your dissertation! While sexuality didn't impact Jason's life in the workplace all that much, it certainly has been an important topic of interest in his growing up and maturation.

Best of luck with your dissertation. I'd love to have a copy of it when it is finished. If you need to reach me, I am at ***(contact information available as needed with permission of the author.)***

Warm regards,
Emily

Emily Perl Kingsley

APPENDIX B

Human Subjects Approval Form

EIU

From: EIU IRB
Sent: Wednesday, January 14, 2015 3:57 PM
To: Anita L Sego
Subject: IRB Study Approval - Sego, #14-168

January 14, 2015

Anita Sego
Health Studies

Thank you for submitting the research protocol titled, "Sexuality Workplace Issues among Direct Service Personnel Working with Populations who are Intellectually Disabled in Community Integrated Living Arrangements: A Case Study" for review by the Eastern Illinois University Institutional Review Board (IRB). The IRB has approved this research protocol following an expedited review procedure. IRB review has determined that the protocol involves no more than minimal risk to subjects and satisfies all of the criteria for approval of research.

This protocol has been given the IRB number 14-168. You may proceed with this study from 1/14/2015 to 1/13/2016. You must submit Form E, Continuation Request, to the IRB by 12/14/2015 if you wish to continue the project beyond the approval expiration date. Upon completion of your research project, please submit Form G, Completion of Research Activities, to the IRB, c/o the Office of Research and Sponsored Programs.

This approval is valid only for the research activities, timeline, and subjects described in the above named protocol. IRB policy requires that any changes to this protocol be reported to, and approved by, the IRB before being implemented. You are also required to inform the IRB immediately of any problems encountered that could adversely affect the health or welfare of the subjects in this study. Please contact me, or the Compliance Coordinator at 581-8576, in the event of an emergency. All correspondence should be sent to:

Institutional Review Board
c/o Office of Research and Sponsored Programs
Telephone: 581-8576
Fax: 217-581-7181
Email: eiuirb@www.eiu.edu

Thank you for your assistance, and the best of success with your research.

Richard Cavanaugh, Chairperson
Institutional Review Board
Telephone: 581-6205
Email: recavanaugh@eiu.edu

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 people who are intellectually disabled before you became employed with this agency?
Yes
No

21. <u>Job Appointment Level – Please circle how your agency classifies your job with the organization:</u>
Full time
Full time < 9 months
Part time
Prefer Not to Answer

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

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

24. <u>How long have you worked in this agency?</u>

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

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

27. <u>Please list any additional training or workshops you have attended that have to do with human development, sexuality, or affectionate behaviors:</u>

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 residents with ID 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

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

APPENDIX F

Interview Audio/Video Observation Protocol

DESCRIPTIVE NOTES	REFLECTIVE NOTES

APPENDIX G

Video Observation Report
Page 1 – Overall Behavior

Participant evaluated ____

Date of Video ___________________   Observer: ______ Anita Sego _______ Misty Rhoads

Purpose: The purpose of this participant observation is (1) to provide a more accurate and in-depth picture of the participant's comfort level with the research topics (2) to improve the researcher's description of the participant and non-verbal communication behaviors.

Instructions: Please consider each item carefully and assign a score of 1 to 5 with 1 being the lowest level of attribute observed and 5 being the highest level of the attribute being observed. If attribute is not observed, check the 0 column for the behavior interval.

Topic	Behavior Intervals	0	1	2	3	4	5	Additional Comments
Behaviors Exhibited	Accepting							
	Animated							
	Attentive							
	Blushes							
	Bubbly							
	Comfortable							
	Confident							
	Cooperating							
	Crosses Arms							
	Defensive							
	Direct and/or Forceful							
	Direct Eye Contact							
	Eye Movement - Increases							
	Fidgets and/or Bobs Head							
	Forthright							
	Friendly							
	Frustrated							
	Helping Others							
	Independent							
	Open							
	Outgoing and/or Passionate							
	Parental							
	Quiet/Private							
	Trustable							
	Uncomfortable							
	Uncooperative							
	Voice Change in Tone and/or Inflection							
	Walled Off							
	Warm							

Comments:

Video Observation Report
Page 2 – Resident Sexuality

Topic	Behavior Intervals	0	1	2	3	4	5	Additional Comments
Resident Sexuality	Accepting							
	Appropriate							
	Attentive							
	Competing							
	Comfortable							
	Cooperating							
	Demanding							
	Dependent							
	Disruptive							
	Exploring							
	Frustrated							
	Helping Others							
	Imitating							
	Inappropriate							
	Independent							
	Initiates Activity							
	Intent							
	Knowledgeable							
	Making Choices							
	Requesting Help							
	Shocked							
	Uncomfortable							
	Uncooperative							
	Unsafe Activity							
	Using Appropriate Manners							

Comments:

Video Observation Report
Page 3 – Resident Affectionate Behaviors

Topic	Behavior Intervals	0	1	2	3	4	5	Additional Comments
Resident Affectionate Behaviors	Accepting							
	Appropriate							
	Attentive							
	Competing							
	Comfortable							
	Cooperating							
	Demanding							
	Dependent							
	Disruptive							
	Exploring							
	Frustrated							
	Helping Others							
	Imitating							
	Inappropriate							
	Independent							
	Initiates Activity							
	Intent							
	Knowledgeable							
	Making Choices							
	Requesting Help							
	Shocked							
	Uncomfortable							
	Uncooperative							
	Unsafe Activity							
	Using Appropriate Manners							

Comments:

Video Observation Report
Page 4 – Perceived Support by Co-Workers

Topic	Behavior Intervals	0	1	2	3	4	5	Additional Comments
Support By Co-Workers	Accepting							
	Appropriate							
	Attentive							
	Competing							
	Comfortable							
	Cooperating							
	Demanding							
	Dependent							
	Disruptive							
	Exploring							
	Frustrated							
	Helping Others							
	Imitating							
	Inappropriate							
	Independent							
	Initiates Activity							
	Intent							
	Knowledgeable							
	Making Choices							
	Requesting Help							
	Shocked							
	Uncomfortable							
	Uncooperative							
	Unsafe Activity							
	Using Appropriate Manners							

Comments:

Video Observation Report
Page 5 – Perceived Support by Supervisors & Management

Topic	Behavior Intervals	0	1	2	3	4	5	Additional Comments
Support By Supervisors & Mgmt.	Accepting							
	Appropriate							
	Attentive							
	Competing							
	Comfortable							
	Cooperating							
	Demanding							
	Dependent							
	Disruptive							
	Exploring							
	Frustrated							
	Helping Others							
	Imitating							
	Inappropriate							
	Independent							
	Initiates Activity							
	Intent							
	Knowledgeable							
	Making Choices							
	Requesting Help							
	Shocked							
	Uncomfortable							
	Uncooperative							
	Unsafe Activity							
	Using Appropriate Manners							

Comments:

Video Observation Report
Page 6 – Attitudes about Training

Topic	Behavior Intervals	0	1	2	3	4	5	Additional Comments
Training	Accepting							
	Appropriate							
	Attentive							
	Competing							
	Comfortable							
	Cooperating							
	Demanding							
	Dependent							
	Disruptive							
	Exploring							
	Frustrated							
	Helping Others							
	Imitating							
	Inappropriate							
	Independent							
	Initiates Activity							
	Intent							
	Knowledgeable							
	Making Choices							
	Requesting Help							
	Shocked							
	Uncomfortable							
	Uncooperative							
	Unsafe Activity							
	Using Appropriate Manners							

Comments:

APPENDIX H

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:

Types of Language (+/-):

APPENDIX I

Description of Concurrent Coding Methods

	Concurrent Coding Methods	**Tool**	**Action**
Throughout Entire Project			
	Pre-Coding	Interview/Field Notes	Notes in margins
	Descriptive Coding	Reflective Summaries	Identify Ideas, Concepts, Themes
	Emotion Coding	Interview Transcripts	Create Initial Codes
	Value Coding	Document Analysis	Create Categories/Sub-Categories
	Focused Coding		
			Compare Themes
			Compare Categories
			Adapt Categories as necessary
			Adapt Sub-Categories as necessary
Reliability Check	Bias Check	Self-Reflection	
	Coding Review	Member-Checking	Check for bias
		Independent Rater Review	Compare Themes & Categories
			Adapt Categories/Sub-Categories
End of Project	Final Coding		

APPENDIX J

Final Code Sheet

Affectionate Behaviors

S-ROLE – S, BB, BS, E, P, G	Staff Role (Staff, Friend, Big Brother/Big Sister, Educator, Parent, Gatekeeper)
F-ATT	Female Attention Seeking Behaviors
M-ATT	Male Attention Seeking Behaviors
F-EGO	Female Ego
M-EGO	Male Ego
F-DATE	Female Dating
M-DATE	Male Dating
F-FLIRT	Females Flirting with Others (Staff, Residents, Strangers, Friends, Boyfriends)
M-FLIRT	Males Flirting with Others (Staff, Residents, Strangers, Friends, Boyfriends
F-FRIEND	Female Friendship (Real and Imaginary)
M-FRIEND	Male Friendship (Real and Imaginary)
F-SOCIAL	Female Socialization
M-SOCIAL	Male Socialization
F-HANDS	Females Holding Hands with Others (Staff, Residents, Strangers, Friends, Boyfriends)
M-HANDS	Males Holding Hands with Others (Staff, Residents, Strangers, Friends, Girlfriends)
F-HUG	Female Hugging Others (Staff, Residents, Strangers, Friends, Boyfriends)
M-HUG	Males Hugging Others (Staff, Residents, Strangers, Friends, Girlfriends)
F-MEDIA	Female Use of Media
M-MEDIA	Male Use of Media
F-TECH	Female Use of Technology
M-TECH	Male Use of Technology
F-AFF-PROB	Female Problematic Affectionate Behaviors (Aggression, Self-Harm, Danger to Staff,
M-AFF-PROB	Male Problematic Affectionate Behaviors
AFFSAFE	Affectionate Behaviors Safety versus Privacy Issues
F-OTHER	Female Other Unexpected Results (Males Staff Refusing to Deal with Periods, Sign Language, New Supervisors, Memory of Training Topics, Staff Conflicts, Residents as Family, Lack of Impact, Unknown Power of Consent, Unknown Influence of ID & Physical Disabilities, Fear of Medical Emergencies)
M-OTHER	Male Other Unexpected Results (Death, Sign Language, New Supervisors, Memory of Training Topics, Staff Conflicts, Residents as Family, Lack of Impact, Unknown Power of Consent, Unknown Influence of ID & Physical Disabilities, Fear of Medical Emergencies)

Sexuality & Masturbation

F-GRP	Female Groping
M-GRP	Male Groping
PUBF-MASTB	Public Female Masturbation
PUBM-MASTB	Public Male Masturbation
PRIF-MASTB	Private Female Masturbation
PRIM-MASTB	Private Male Masturbation
F-SEX	Female Sexual Intercourse
M-SEX	Male Sexual Intercourse
SEXSAFE	Sexuality Safety versus Privacy Issues
F-SEX-PROB	Female Problematic Sexual Behaviors
M-SEX-PROB	Male Problematic Sexual Behaviors
F-MAR	Female Marriage
M-MAR	Male Marriage

Types of Training

ABUSE	Abuse Prevention (Physical & Sexual)
CON	Confidentiality
CPI	Bites, Holds, CPI
CRIS	Crisis Management
DT	Disease Transmission, Bloodborne Pathogens, Airborne Pathogens
CPR	First Aid/CPR
RIGHTS	Hunan Rights
MED	How to Disperse Medications
ODR	Online Daily Reporting – Case Management Software
LIAB	Personal Liability
SEX	Sexuality
LAW	State & Federal Laws
WEAP	Weapons – Self-Protection

Overall Behaviors Observed From Videotaped Interviews

ACC	Accepting
ANI	Animated
ATT	Attentive
BLUSH	Blushes
BUB	Bubbly
COM	Comfortable
CONF	Confident
COOP	Cooperating
CA	Crosses Arms
DEF	Defensive
DIR OR FOR	Direct and/or Forceful
DEC	Direct Eye Contact
EMI	Eye Movement Increases
FID OR BOB	Fidgets and/or Bobs Head
FORTH	Forthright
FRIEND	Friendly
FRUS	Frustrated
HOTR	Helping Others
IND	Independent
OPEN	Open
OUT OR PAS	Outgoing and/or Passionate
PRTL	Parental
Q OR P	Quiet and/or Private
TRUST	Trustable
UNCOMF	Uncomfortable
UNCOOP	Uncooperative
VCT OR VCI	Voice Change (Tone and/or Inflection)
WO	Walled Off
WARM	Warm

Overall Perceptions Observed In Videotaped Interviews

P-ACC	Accepting
P-APP	Appropriate
P-ATT	Attentive
P-CMPT	Competing
P-COM	Comfortable
P-COOP	Cooperating
P-DEM	Demanding
P-DEP	Dependent
P-DISR	Disruptive
P-EXP	Exploring
P-FRUS	Frustrated
P-HOTR	Helping Others
P-IMI	Imitating
P-INAPP	Inappropriate
P-IND	Independent
P-IA	Initiates Activity
P-INT	Intent
P-KNOW	Knowledgeable
P-MC	Making Choices
P-RQH	Requesting Help
P-SHK	Shocked
P-UNCOMF	Uncomfortable
P-UNCOOP	Uncooperative
P-UNSA	Unsafe Activity
P-USAM	Using Appropriate Manners

Prevalence of Positive/Negative Sexuality and Socialization Language

L-ABUSE	Abuse
L-ASSLT	Assault/Sexual Assault
L-CRIS	Crisis
L-HAR	Harassment
L-INAP	Inappropriate
L-PERP	Perpetrator
L-RAPE	Rape
L-SEXEXP	Sexual Exploitation
L-SEXV	Sexual Violence
L-STIG	Stigma
L-TRAUMA	Trauma
L-VIC	Victim
L-VICMZ	Victimization
L-AA	Advocate/Advocacy
L-CONF	Confidential
L-HR	Healthy Relationships
L-HELP	Help/Helping
L-RECLM	Reclaim
L-REC	Recovery
L-PREV	Prevention
L-RESP	Respect/Sensitivity
L-SURV	Survivor(s)

Influences on Sexuality/Affectionate Behaviors

POLICY	Policy
CONSENT	Consent
GUARDIAN	Guardianship
FUNCTION	Functional Level
SETTING	Setting
COMM	Communication
PRIVACY	Privacy

Bias/Gender

F-GENBIAS	Gender Bias Against Females
GENBISBYFEMALES	Gender Bias By Females
M-GENBIAS	Gender Bias Against Females
GENBISBYMALES	Gender Bias By Females

Concept of choice in regards to sexuality/affectionate behaviors

NOCHOICE	Lack of Choice Due to Medical/Physical Reasons
YES_CHOICE	Yes Has Ability to Make Intellectual Choice
NO_CHOICE	No Does Not Have Ability to Make Intellectual Choice
GUARDCHOICE	Guardian, Parent, or Case Manager Makes Choices for Individual

Concept of consent in regards to sexuality/behaviors

UNKNOWN	Who Has The Power to Give Consent Unknown
NOCONSENT	Lack of Ability to Give Consent Due to Medical/Physical Reasons
NOLEGALCON	Concept of Lack of Ability to Give Consent Due to Legal Reasons
YES-CON	Concept of Intellectual Ability to Give Consent
NO-GUARCON	Guardian, Parent, or Case Manager Makes Choices for Client

Major Themes

EMPDEVTR	Employee Development & Training
SOCIAL	Socialization (Affectionate Behaviors/Sexuality Behaviors/Dating & Relationships)
LANG	Language (Positive/Negative/First Person)

VITA

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Special Honors and Awards:

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Sexuality Workplace Issues Among Direct Service Personnel Working With Populations Who Are Intellectually Disabled In Community Integrated Arrangements: A Case Study

Major Professor: Dr. Roberta Ogletree

Publications:

Rhodes, M., Kittleson, M., Ratanapradipa, D., Sarvela, P., Ritzel, D., Chaney, D., Walker, B., Sego, Al., and Magoc, D., Phillips, K. (2013). The effectiveness of oral vs. podcasting reviewing techniques: A comparative analysis approach. *Illinois Journal for Health, Physical Education, Recreation, & Dance, Spring*, 34-41.