

Individuals with Intellectual Disabilities Engaging in Peer-to-Peer Safety & Sexuality

Training: A Case Study

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Natalie F. Williams

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This dissertation titled  
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Training: A Case Study

by

NATALIE F. WILLIAMS

has been approved for  
the Department of Counseling and Higher Education  
and The Patton College of Education by

Mona C. Robinson

Associate Professor of Counseling and Higher Education

Renée A. Middleton

Dean, The Patton College of Education

## Abstract

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Director of Dissertation: Mona C. Robinson

Individuals with intellectual disabilities (ID) are at a greater risk for victimization when compared to individuals without disabilities (Petersilia, 2001; Sobsey, 1994) and individuals with other types of disabilities (Harrel & Rand, 2010). In 2008, approximately 34,000 individuals with cognitive impairments in the U.S. were victims of non-fatal violent crime, with approximately 1,500 incidents classified as rape or sexual assault (Harrell & Rand, 2010).

Sexuality education and safety training are tools suggested by researchers and practitioners to decrease vulnerability to victimization for individuals with ID (e.g., Champagne & Walker-Hirsh, 1993; Planned Parenthood, 2009; Sobsey, 1994). Peer-to-peer training is one method of safety and sexuality education for specific populations of children and adults with disabilities (Bullard & Wallace, 1978; Orzeck, 1984; Utley et al., 2001). However, there is a no published literature regarding this peer-to-peer safety and sexuality training for adults with ID.

This exploratory qualitative case study provided new information on peer-to-peer safety and sexuality training for individuals with ID. Naturalistic, qualitative inquiry is beneficial for examining novel concepts, therefore qualitative methods were employed for the current study. The study presented a bounded case analysis of the peer-to-peer safety and sexuality training provided by individuals with ID at The Thomas Adventures

in Lifelong Learning (TALL) Institute in Cincinnati, Ohio, using individual interviews, observations of peer-to-peer trainings, and analysis of the safety and sexuality curriculum. This case study is a rich, thick description of the peer-to-peer safety and sexuality training provided by individuals with ID at The TALL Institute.

The central research questions were: 1) What is the peer-to-peer safety and sexuality training program at The TALL Institute? 2) How do students at The TALL Institute describe their experiences as peer-to-peer health, safety, and sexuality trainers for individuals with ID? 3) How do students at The TALL Institute provide peer-to-peer safety and sexuality training to other individuals with ID? Analysis of interviews, observations, and documents revealed eight emerging themes, including their relationship to relevant literature and disability theory, specifically the four models of disability as described by Smart & Smart (2007). Lessons learned, including recommendations for future research and implications for policy and practice are also provided.

*I would like to dedicate this dissertation to my grandmother, Gloria Tatum Williams.  
Your life's work, both personally and professionally, has truly been an inspiration to me.*

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## **Chapter 1: Introduction**

The current case study provides a rich, thick description of the peer-to-peer safety and sexuality training program for individuals with intellectual disabilities (ID) at The Thomas Adventures in Lifelong Learning (TALL) Institute in Cincinnati, Ohio. The case study includes information collected using three methods of data collection, including observations of peer-to-peer safety and sexuality trainings delivered by students at The TALL Institute, individual interviews with the six students at The TALL Institute who serve as peer-to-peer safety and sexuality trainers and the director of the program, and document analysis of the curriculum used to deliver the peer-to-peer safety and sexuality training. Further analysis revealed emerging themes that will add to the body of knowledge on this topic. Implications for future research and practice, along with recommendations for Counselor Educators, Licensed Professional Counselors (LPCs), and Certified Rehabilitation Counselors (CRCs) are also provided. The current chapter will present the background of the study, the statement of the problem, the purpose of the study, along with significance and research questions, an overview of the methodology, limitations and delimitations, and a list of key terms used throughout the study, along with their operational definitions.

### **Background of the Study**

Approximately 6.5 million people in the United States have an ID (The Arc, 2009). According to the American Association on Intellectual and Developmental Disability ([AAIDD], 2012), ID is a term used to describe significant impairments in cognitive and intellectual functioning, resulting in limitations in adaptive behavior, such as conceptual, practical, and social skills, described below. ID is usually diagnosed in



childhood, prior to age 18, most often using an assessment of intellectual functioning such as an IQ (intellectual quotient) test (AAIDD, 2012). Four general categories are used to describe the severity of an ID diagnosis, including borderline, mild, moderate, and severe, based on the actual IQ score and the severity of limitations in adaptive behavior. An IQ of 70 and below is one criterion used in a comprehensive assessment resulting in a diagnosis of ID (AAIDD, 2012).

In addition to an IQ test, such as the WISC-IV (Wechsler Intelligence Scale for Children, 4th Edition), other aspects of functioning are also assessed (AAIDD, 2012). These include assessments of adaptive behavior within certain contexts, including three types of skills: conceptual skills, social skills, and practical skills (AAIDD, 2012). Conceptual skills include number concepts, mathematics skills, counting, and reasoning skills. Social skills include the ability to engage interpersonally with others, the ability to recognize and respond to danger, and engage in pro-social behavior (AAIDD, 2012). Practical skills include activities of daily living (ADLs), such as getting dressed, brushing one's teeth, and other examples of self-care, in addition to telling time, and the ability to count money (AAIDD, 2012). In addition to a comprehensive assessment of intellectual functioning and adaptive behavior, AAIDD recommends professionals, parents, and educators also consider the development of same-age typical peers, cultural differences in communication styles and other factors, with an emphasis on the strengths of the child (AAIDD, 2012). With appropriate levels of support and early intervention, a diagnosis of ID is not the lifelong stamp that it once was and many individuals are able to live successful, independent, and productive lives (AAIDD, 2012).

On October 5, 2010, President Obama signed Rosa’s Law (Public Law 111–256), which replaced the term mental retardation (MR) with the term ID in several pieces of federal legislation, including the Individuals with Disabilities Education Improvement Act of 2004, described later in this chapter. A common tool used to diagnose mental and emotional disorders, The *Diagnostic and Statistical Manual of Mental Disorders, Fourth Version, Text Revision (DSV-IV-TR)*, published in the year 2000 by the American Psychiatric Association, currently contains MR as a disorder diagnosed in childhood; however the fifth revision of this text, with a proposed publication date of May 2013, will likely replace MR with “intellectual developmental disorder” or similar language (AAIDD, 2012).

ID shares a relationship with developmental disability (DD). While a diagnosis of ID always describes impairments in cognitive functioning, DD may or may not describe a mental impairment (AAIDD, 2012). Similar to ID, a diagnosis of DD is usually given in childhood, prior to age 22, and describes impairments that may be pervasive throughout an individual’s life (AAIDD, 2012). Although DD and ID may co-occur (e.g., Down syndrome, Fetal Alcohol Spectrum Disorder), some DD results in impairments that are purely physical and may or may not coincide with an intellectual impairment (e.g., cerebral palsy, epilepsy, Autism Spectrum Disorder) (AAIDD, 2012). DD may be mental or physical in nature, and may or may not result in a cognitive impairment. Research has shown, with appropriate supports, individuals with ID may live successful, independent, productive lives (AAIDD, 2012).

Individuals with a documented ID diagnosis are eligible to receive services through a variety of local, state, and federal programs. Federal legislation such as the

Individuals with Disabilities Education Improvement Act (Public Law 108–446), amended in 2004, effective July 1, 2005, provides guidelines for determining eligibility for services for children with documented disabilities ([IDEIA], 2004). ID is a disability category that is covered under IDEIA and children families are able to access services from birth to age 21, under this law (IDEIA, 2004). Services for infants and toddlers, from birth to age two, are available through provisions listed in Part C of the law, while preschool and school age services are listed in Part B, covering children with disabilities ages three to 21, who primarily access services through public schools. According to the federal government, more than 6.5 million children are eligible to receive services under IDEIA (U.S. Department of Education, 2013).

Over \$436 million dollars have been provided to states in the U.S. to serve 350,000 infants and toddlers eligible for services under Part C (U.S. Department of Education, 2013). These services are multidisciplinary, multiagency early intervention in the areas of physical, cognitive, communication, socio-emotional, or adaptive development, depending on the needs of the child (U.S. Department of Education, 2013). Specific services may include home visits, family training, counseling, special instruction, speech-language pathology and audiology services, and sign language services, occupational therapy, physical therapy, psychological services, service coordination services, medical services for diagnosis or evaluation, early identification, screening, and assessment services, health services, social work, ophthalmology, assistive technology devices and assistive technology services, and transportation and related services (U.S. Department of Education, 2013). Services for school-age children often include development and implementation of an Individualized Education Program (IEP).

IEPs include measurable academic goals and accommodations that will assist with attainment of those goals. Depending on the nature of the disability and the individual needs of the child, services such as Speech and Language Therapy, Occupational Therapy, assistive technology, behavioral modifications, or specific academic supports in reading or mathematics, among other services, may be included as components of a child's IEP (U.S. Department of Education, 2013).

While IDEIA provides comprehensive information regarding services for infants, toddlers, and school age children with ID and other disabilities, the Developmental Disabilities Assistance and Bill of Rights Act of 2000 (Public Law 106–402), referred to in brief as the DD Act, provides information regarding lifelong support and assistance for children and adults with DD (DD Act, 2000). Individuals with ID are eligible for services under the DD Act if they meet criteria listed in the federal definition of DD. According to the DD Act, a diagnosis of DD means: 1) the limitation is the result of a mental or physical impairment, or combination of both, 2) the limitation was manifested prior to age 22, and 3) the limitations are likely to persist throughout an individual's lifetime (DD Act, 2000). The federal definition of DD also states the impairment must result in a minimum of three significant limitations from the following list of major life activities: self care, receptive and expressive language, learning, mobility, self-direction and capacity for independent living, economic self-sufficiency, and a demonstrated need for individual supports or assistance (DD Act, 2000).

A wide range of services are available for the more than 4.5 million children and adults in the U.S. who meet the criteria for eligibility under the DD Act, comprising about 1.5 percent of the U.S. population (DD Act, 2000). The 64-page DD Act defines a

broad range of services available for individuals with DD including supported employment, early intervention, transportation, education, direct care support, housing, health and recreation, and specific provisions for individuals with DD from underrepresented groups, such as rural and urban residents, individuals from multicultural backgrounds, and limited English proficiency (DD Act, 2000). Although the federal government passed this legislation, states are responsible for the delivery of services to individuals with DD within their respective jurisdictions, according to Section 106 of the DD Act.

One unique characteristic of the DD Act, when compared to other legislation relevant to individuals with disabilities, is the specific inclusion of language related to harm reduction, specifically to protect members of this population from abuse and neglect. The drafters of this legislation found it necessary to include a list of minimum standards regarding the provision of services for individuals with ID and the first of these standards mandates:

The Provision of care that is free of abuse, neglect, sexual and financial exploitation, and violations of legal and human rights and that subjects individuals with developmental disabilities to no greater risk of harm than others in the general population. (DD Act, 2000, Section 109)

Considering the lifelong supports many individuals with ID will require over their lifetime, due to the nature of mental and possible co-occurring physical impairments, the federal government lists specific guidelines for provision of care that does not increase vulnerability to abuse and victimization. The previous section provided a background of the current case study by providing information prevalence and etiology of ID, the

relationship between ID and DD, and relevant federal legislation that guides provision of services. The following section will provide a statement of the problem, followed by the purpose and significance of the study.

### **Statement of the Problem**

In the U.S. approximately 730,000 nonfatal violent crimes and 1.8 million property crimes were committed against individuals with disabilities in 2008 (Harrell & Rand, 2010). A report by the Bureau of Justice Statistics, using results from the National Crime Victims Survey (NCVS) estimates individuals with cognitive disabilities (i.e., mental impairments such as ID), were raped, sexually assaulted, robbed, or physically assaulted at an increased rate compared to individuals with other types of disabilities, including hearing, vision, ambulatory, self-care, or independent living limitations (see Table 1) (Harrell & Rand, 2010). In 2008, approximately 12.9 per 1000 individuals with cognitive disabilities were estimated to be victims of serious violent crimes compared to rates of 4.8 per 1000 for individuals with hearing impairments, 7.2 per 1000 for individuals with visual impairments, and 4.2 per 1000 for individuals with ambulatory impairments (Harrell & Rand, 2010).

Table 1

*Violent Victimization Rates of Persons with Disabilities, by Type of Crime and Type of Disability, 2008*

Violent victimization rate per 1,000 persons with disabilities, by type of disability

Type of Crime	Hearing	Vision	Ambulatory	Cognitive	Self care	Independent Living
<b>Total</b>	13.6	18.2	12.8	34.3	9.7	12.7
<b>Serious violent crime</b>	4.8	7.2	4.2	12.9	3.3 <sup>^</sup>	4.3
Rape/sexual assault	1.3 <sup>^</sup>	0.6 <sup>^</sup>	0.9 <sup>^</sup>	1.5 <sup>^</sup>	0.4 <sup>^</sup>	0.7 <sup>^</sup>
Robbery	1.0 <sup>^</sup>	2.1 <sup>^</sup>	0.7 <sup>^</sup>	6.8	0.5 <sup>^</sup>	1.2 <sup>^</sup>
Aggravated assault	2.4 <sup>^</sup>	4.5 <sup>^</sup>	2.7	4.6	2.3 <sup>^</sup>	2.4 <sup>^</sup>
<b>Simple assault</b>	8.9	11.0	8.6	21.4	6.4	8.5

<sup>^</sup>Estimate based on 10 or fewer sample cases. (Harrell & Rand, 2010, p. 6)

The statistics in Table 1 provide the best available estimates of violent crimes committed against people with disabilities, nationally. At the federal level, Section 5 of The Crime Victims with Disabilities Awareness Act (Public Law 105–301), signed into law in 1998 by President Clinton, mandates the Bureau of Justice Statistics draft reports estimating rates of crimes against people with disabilities, based on information collected from samples across the U.S. (Harrell & Rand, 2010). Although no federal system for reporting such crimes exists to date, statistical data collection of crimes against people with ID began in the 1980s, at the state level (Petersilia, 2001). The Ohio Department of Developmental Disabilities, at <http://odmrdd.state.oh.us>, has a system of reporting, similar to the sex offender registry, where people who are convicted of crimes against

persons with DD are listed by name and by the type of crime (e.g., sexual abuse, financial crimes, physical assault, etc.).

Even with the NCVS and other systems, abuse rates of people with ID are largely underreported and the offenders in these cases are less likely to be prosecuted, when compared to cases involving violent crime against individuals without disabilities (Petersilia, 2001). Underreporting of crimes, limited prosecution of offenders, and factors related to the individuals' impairments increase vulnerability to abuse for individuals with ID (Petersilia, 2001; Sobsey & Calder, 1999). Sobsey and Calder (1999) created a Multifactoral Model of Violence to illustrate the primary factors that increase vulnerability to abuse for people with ID. These include victim-related factors, offender-related factors, and relationship factors. Victim-related factors include risk factors that occur as a result of the impairment including limited sexual knowledge, communication difficulties, and possible physical limitations (Sobsey & Calder, 1999). Offender-related factors include caregiver corruption, the abuse of power and domination, and the lack of prosecution of offenders by the authorities (Sobsey & Calder, 1999). Relationship factors include limited social skills, lack of support from staff and caregivers, and limited opportunities for pro-social engagement with others (Sobsey & Calder, 1999). According to the authors of the model, the interaction between these three factors increases the vulnerability to abuse of individuals with ID (Sobsey & Calder, 1999).

Considering the problem of increased vulnerability to abuse and victimization for individuals with ID, as described above, sexuality education and safety training are offered by researchers and practitioners as potential solutions (e.g., Champagne & Walker-Hirsh, 1993; Planned Parenthood, 2009). Although limited research provides



information on peer-to-peer training programs for individuals with disabilities, specifically on topics of safety or sexuality, there is currently no published research on peer-to-peer safety and sexuality training specifically targeted for individuals with ID. An extensive search of research databases (e.g., ERIC, PsycInfo) yielded only three articles related to peer-to-peer safety or sexuality training for individuals with disabilities, discussed briefly, below.

Orzek (1984) advocates in favor of peer-to-peer support groups for college students with learning disabilities. Bullard and Wallace (1978) document a peer-to-peer sexuality training program for adults with physical disabilities. Utley, Reddy, Delquadri, Greenwood, Mortweet, and Bowman (2001) conducted an empirical study that found class-wide peer tutoring to be an effective method of instructional delivery of a health and safety educational curriculum for elementary school-age students with DD. These three articles are summarized below.

The National Institute of Mental Health provided grant funding to the Human Sexuality Program at the University of California in San Francisco (UCSF) in 1976, with the goal of training individuals with disabilities as peer sexuality educators and counselors (Bullard & Wallace, 1978, p. 147). The duration of the training was one calendar year, provided by the supervisor and staff of The Sex and Disability Training Project at UCSF (Bullard & Wallace, 1978). Nine individuals were chosen to participate in the program as trainees from a pool of 38 applicants; seven of the trainees had physical disabilities, including multiple sclerosis, cerebral palsy, post-polio, and spinal cord injury; six of the seven trainees used wheelchairs to assist with mobility (Bullard & Wallace, 1978).

This group of trainees received positive evaluations (i.e., “moderately-to-extremely satisfied”) from their field placement supervisors for the counseling and education they provided to clients (Bullard & Wallace, 1978, p. 149). While Bullard and Wallace (1978) describe a peer-to-peer education and counseling program for adults with physical disabilities, Orzek (1984) discusses the importance of peer support groups for college students with learning disabilities (LD), described below.

As a conceptual argument as opposed to a research article, Orzek (1984) describes peer support groups as potentially beneficial for college students with LD. The author provides a brief list of LD diagnoses recognized under federal law, including brain injury, dyslexia, and minimal brain dysfunction syndrome (Orzek, 1984). Orzek (1984) uses Chickering’s (1969) seven-vector model of young adult development as proposed components of a peer support group program for college students with LD. In his theoretical argument, Orzek (1984) uses the seven vectors to identify possible areas of concern for this population of young adults, including: 1) developing competence, 2) managing emotions, 3) developing autonomy, 4) establishing identity, 5) freeing interpersonal relationships, 6) clarifying one’s purpose in life, and 7) developing integrity (Chickering, 1969). Orzek (1984) suggests counseling or disability service agencies on college campuses could sponsor such peer support groups to aid in the successful development of students with LD on their respective campuses.

While Orzek (1984) argues in favor of peer support groups for college students with LD, Utley et al. (2001) describes a class-wide peer tutoring model (CWPT) to teach health education and safety facts to elementary students with DD. CWPT is an alternative teaching method with an interactive game format that uses a four-part model of

instruction, with behavioral components, to provide multiple opportunities for students to participate and respond in class.

The purpose of the study was to “determine the effectiveness of CWPT on the acquisition and comprehension of names of body parts, body functions, poisons, dangerous situations, and drugs and their effects”, using a health and safety curriculum provided by the school district (Utley et al., 2001, p. 4). The authors conducted a quasi-experimental study using a self-contained classroom of five second-grade students with DD (Utley et al., 2001). IQ scores ranged from 52 to 57 on the Wechsler Intelligence Scale for Children-Revised and the Stanford-Binet Intelligence Scale, indicating the presence of co-occurring ID (Utley et al., 2001).

To summarize the results of the study, baseline scores collected at the beginning of the study revealed percentages lower than five percent for four students, with one student scoring 20% on assessments of health and safety, using content from the curriculum (Utley et al., 2001). However, using CWPT methods, students scored 92% and above on weekly assessments (Utley et al., 2001). Students also scored higher on weekly assessments using CWPT when compared to traditional teacher-led instruction, with scores of 85% or above with CWPT compared to 20% or below with traditional methods (Utley et al., 2001). The researchers attributed these results to the underlying principles of CWPT as a model of instruction, including immediate feedback, team competition, and error correction (Utley et al., 2001).

These studies have several implications for the current case study on peer-to-peer safety and sexuality training for individuals with ID. Although different in their purpose and scope, the results from the limited available published literature reveal peer-to-peer

training as an effective educational tool for people with disabilities, specifically adults with physical disabilities and children with DD, for topics related to sexuality and safety, respectively (Bullard & Wallace, 1978; Utley et al., 2001). Second, the researcher used these studies to critique the methods of instruction used to deliver the peer-to-peer safety and sexuality training analyzed in the current case study. The authors of the articles summarized above advocate for the use of behavioral methods of instruction (Utley et al., 2001), inclusion of key topics (Orzek, 1984), and solicitation of feedback from program participants (Bullard & Wallace, 1978). The researcher critically analyzed the methods of instruction used in the current case study, in comparison to the strategies described in the literature.

Although each of the three articles cited above provides critical information on peer-to-peer support (Orzek, 1984), education and counseling (Bullard & Wallace, 1978), and tutoring (Utley et al., 2001) on topics related to safety or sexuality for individuals with disabilities, the studies also have two limitations that are important to consider. First, two of the three articles describe research that was conducted in the 1970s and 1980s, indicating a need for more current research on peer-to-peer support and education for individuals with disabilities. Second, none of the studies above documents the experiences of the individuals who serve as peer-to-peer educators, counselors, or tutors or provides in-depth information on the curricula used for the trainings. Two of the articles present research that was collected using quantitative methods which limited the breadth and depth of information the researchers were able to collect.

The current case study will address the limitations presented in the limited amount of relevant published literature, summarized above. As a qualitative case study, the

current research will provide a rich, thick description of safety and sexuality training for individuals with ID, a population group that has not been explored in the literature on safety and sexuality training for people with disabilities. In addition, the current study centers on participant voice, an element that was absent from relevant published literature. The current case study presents a detailed picture of a peer-to-peer safety and sexuality training program for individuals with ID. The findings provide novel insight on safety and sexuality peer-to-peer training for individuals with ID, from multiple perspectives, including individual interviews with trainers, observations of training presentations, and a document analysis of the curriculum. The following section will provide a description of the purpose of the study.

### **Purpose**

The aim of the current case study is to generate a rich, thick description of the peer-to-peer safety and sexuality program provided by students at The TALL Institute. In an attempt to provide new information on the topic of peer-to-peer safety and sexuality training for individuals with ID, the researcher proposed a qualitative study, collected information from multiple sources, used three methods of data collection (i.e., observations of trainings, interviews with peer-to-peer trainers and the director of the program, and document analysis of the curriculum used in trainings). Limited published literature supports peer-to-peer education and counseling (Bullard & Wallace, 1978), support (Orzek, 1984), and tutoring (Utley et al., 2001) as effective methods of safety or sexuality training for individuals with disabilities, however no literature currently exists on peer-to-peer safety and sexuality training for individuals with ID. According to Patton (2002), qualitative methodology is beneficial for examining novel concepts; therefore

qualitative methods were employed to answer three research questions, listed below following a description of the significance of the study.

### **Significance**

The purpose of this study was to generate a rich, thick description of the peer-to-peer safety and sexuality program provided by students at The TALL Institute. This research is important because there is currently no published literature on peer-to-peer safety and sexuality training for individuals with ID. This research offers an in-depth description of the peer-to-peer safety and sexuality training program at The TALL Institute, selected as an instrumental case, to provide new information on this topic. Limited published research has provided support for peer-to-peer education and counseling for adults with physical disabilities (Bullard & Wallace, 1978), peer-to-peer support for college students with LD (Orzek, 1984), and peer-to-peer tutoring for elementary school-age students with DD (Ultey et al., 2001) as methods of teaching about topics related to safety or sexuality. However, no research has been published, to date, on peer-to-peer safety and sexuality training for individuals with ID, using qualitative methodology. The following paragraphs will provide a summary of the significance of the research conducted in the current case study.

Individuals with ID are at a greater risk of abuse and victimization when compared to individuals with other types of disabilities and when compared to individuals without disabilities (Petersilia, 2001; Sobsey, 1994). In 2008, approximately 12.9 per 1000 individuals with cognitive disabilities were estimated to be victims of serious violent crimes compared to rates of 4.8 per 1000 for individuals with hearing impairments, 7.2 per 1000 for individuals with visual impairments, and 4.2 per 1000 for

individuals with ambulatory impairments (Harrell & Rand, 2010). Safety and sexuality training and education are strategies researchers and practitioners propose to reduce vulnerability to victimization for members of this population (Champagne & Walker-Hirsh, 1993; Planned Parenthood, 2009).

Society's views toward disability, in general, have had serious implications for the well-being of individuals with disabilities. Four models of disability have been proposed by researchers to summarize these views and their associated implications for individuals with disabilities. These include: the Biomedical Model, the Functional Model, the Environmental Model, and the Sociopolitical Model (Smart & Smart, 2007). The Biomedical Model of disability generally presents the view that disability is a medical concern that exists within the individual (Smart & Smart, 2007). This model has roots in medieval traditions where people with disabilities were regarded as mentally or physically defective, in need of treatments or cures to restore "biological wholeness" (Smart & Smart, 2007, p. 78). This view led to increased levels of stigma and discrimination against people with disabilities. Although some components of the Biomedical Model are now viewed as problematic (e.g., blaming the individual instead of society), certain aspects of the model (e.g., clinical diagnostic categories for classification of mental or physical ailments) persist within the medical profession, to this day (Smart & Smart, 2007).

While the Biomedical Model of disability emphasizes mental or physical limitations at the individual level of impact, the Functional and Environmental Models (Dembo, 1982; Tanenbaum, 1986; Thomason, Burton, & Hyatt, 1999) of disability consider the impact of environmental barriers (Smart & Smart, 2007). The Americans

with Disabilities Act ([ADA], 1990) is an example of legislation implemented with the goal of decreasing physical barriers and increasing access to public facilities and services. These models begin to acknowledge the role of external barriers in exacerbating the difficulties associated with mental or physical limitations (Smart & Smart, 2007).

The Sociopolitical Model, also referred to as the Minority Model of disability (Hahn, 1985; Kleinfield, 1979) marks a radical shift from the assumptions held by the previous three models (Smart & Smart, 2007). This model redefines disability as a social construct that has no roots in the actual physical or mental limitation, but rather redefines disability as a result of society's negative views toward the impairment and the individual experiencing it (Smart & Smart, 2007). According to this view, individuals with impairments serve as the experts and take active roles in coordination of services (Smart & Smart, 2007). According to ADA (1990), individuals with disabilities have protected status similar to other diverse groups in the United States who have pursued equal treatment under the law.

These four models of disability allow researchers and practitioners to conceptualize society's views towards individuals with disabilities through four broad categories, ranging from internal causes of disability to consideration of functional and environmental factors to pursuit of equal protection under the law. Over time, these views have served to justify actions that have directly impacted the lives of individuals with disabilities. For example, views associated with the Biomedical Model of Disability led to actions such as infanticide of babies born with disabilities in Ancient Rome and Greece and institutionalization of individuals with disabilities during the 1940s (Smart & Smart, 2007; Wade, 2002). When views shifted towards the Functional and



Environmental Models of disability, individuals with disabilities were returned to the community, and provided with support to increase opportunities for success, beginning around the 1960s, with increased momentum in the 1990s (Smart & Smart, 2007). Today, through the work of organizations such as the National Disability Rights Network, individuals with disabilities are able to experience increasing benefits as a protected population group under federal law.

As a subpopulation within the larger disability rights movement, individuals with ID have experienced progress in recent years, specifically in terms of sexual expression. Similar to the views toward disability, described above, society's attitudes toward ID and sexuality have also impacted the lives of individuals with disabilities. Around the 1940s, individuals with ID were thought to be hypersexual, which provided further justification for proponents of the institutionalization movement (Wade, 2002). Two decades later, when large numbers of individuals with ID were released from institutions and placed in less restrictive environments, such as independent housing or group homes, society's views shifted towards protection of individuals with ID from sexual exploitation by members of the community (Wade, 2002). During the 1970s and 1980s, advocates such as Winifred Kempton emerged, publishing research and designing curriculum specifically to address the sexuality needs of individuals with ID (e.g., Kempton, 1976; Kempton, 1978; Kempton, 1988). Today, agencies such as Planned Parenthood provide sexuality education for individuals with ID using teaching methods that would have been considered highly controversial just a few decades ago, such as anatomically correct dolls and pictures and explicit videos (Planned Parenthood, 2009).

Considering the progress that has been made in recent decades, related to sexuality and ID, several types of professionals are currently able to provide safety and sexuality education and counseling for individuals with ID, including general and special education teachers, Certified Sexuality Educators (CSEs), Licensed Professional Counselors (LPCs), DD service providers in day treatment or habilitation settings, and Certified Rehabilitation Counselors (CRCs). While many types of providers now serve individuals with disabilities, in the past, these services were provided primarily by CRCs (Smart & Smart, 2007). The Commission on Rehabilitation Counselor Certification (CRCC) defines rehabilitation counseling as a “systematic process which assists persons with physical, mental, developmental, cognitive, and emotional disabilities to achieve their personal, career, and independent living goals in the most integrated setting possible through the application of the counseling process” (2013, para. 3). Limited research suggests CRCs may be hesitant to broach issues related to sexuality with clients, although this is an important area of competence as described by the CRCC (Kazukauskas & Lam, 2009; Kazukauskas & Lam, 2010). The current study provides implications and recommendations for CRCs who may serve clients with ID.

In summary, the current case study provides new information on an important topic, peer-to-peer safety and sexuality training for individuals with ID. The previous section described the significance of the study, considering vulnerability to victimization of individuals with ID and society’s views toward sexuality and ID. The role of CRCs in addressing sexuality issues with clients with ID was also discussed. The following section discusses the research questions for the current case study, followed by an overview of the methodology used in the study.

## **Research Questions**

The current case study used qualitative methodology to answer three central research questions: 1) What is the peer-to-peer safety and sexuality training program at The TALL Institute? 2) How do students at The TALL Institute describe their experiences as peer-to-peer health, safety, and sexuality trainers for individuals with ID? 3) How do students at The TALL Institute provide peer-to-peer safety and sexuality training to other individuals with ID?

## **Overview of Methodology**

The methodology for this study is qualitative. Qualitative methodology is beneficial for scholarly inquiry, specifically for research questions that are novel additions to the literature and exploratory in nature (Patton, 2002). Qualitative exploration provides rich, thick descriptions of topics and provides information that cannot be obtained using quantitative data collection methods (Lincoln & Guba, 1985; Patton, 2002). Qualitative scholarly inquiry is a legitimate form of scientific research, with rigorous standards to ensure credibility, trustworthiness, and transferability of findings (Patton, 2002). In contrast to more standardized forms of data collection (e.g., controlled lab settings, standardized survey instruments), qualitative inquiry is often more process than product driven, with an emphasis on open-ended, naturalistic forms of data collection (e.g., interviews, observations), resulting in in-depth descriptions of experiences and phenomenon (Patton, 2002).

Qualitative research studies share several broad characteristics that will be employed in the current study. Rossman and Rallis (2003) provide five key elements of qualitative research, including data collection in naturalistic settings, reliance on multiple

methods that are humanistic in nature, a focus on the context, the emergent nature of the process, and the interpretative nature of studies. In qualitative research, the researcher is the instrument that ultimately collects, analyzes, and interprets data. Therefore, qualitative researchers should maintain holistic views towards participants and the phenomenon of study (Rossman & Rallis, 2003), while engaging in ongoing self-reflection (Marshall & Rossman, 2010). Qualitative scholars also suggest researchers in this genre employ complex reasoning that vacillates between inductive and deductive logic (Creswell, 2013; Rossman & Rallis, 2003), while remaining sensitive to the impact of their personal identities and experiences, also referred to as reflexivity (Marshall & Rossman, 2010; Rossman & Rallis, 2003).

Qualitative methodology was useful in answering the research questions posed in this study. Quantitative data collection methods would have been ineffective in generating in-depth descriptions of peer-to-peer safety and sexuality training for individuals with ID. Qualitative methods, including interviews, observations, and document analysis generated rich, thick descriptions of the peer-to-peer safety and sexuality training delivered by students at The TALL Institute to individuals with ID in Ohio. Research on peer-to-peer safety and sexuality training for individuals with ID is a topic that is virtually absent from published scholarly literature. Qualitative methodology was employed to collect new information on this topic, from multiple perspectives.

Case study research has been described as an “in-depth description of a single case” in a “real-life, contemporary setting” (Creswell, 2013, p. 97). Case study is a term that describes both the *process* of study and the *product* that is generated as a result of study (Merriam, 1998). In addition, the term can also serve to identify the unit of study

(e.g., the individual, organization, or program being studied) (Merriam, 1998).

Scholars agree the case being studied is bounded by parameters of time and space, meaning the unit of study is situated within real boundaries of time and the setting or context in which the phenomenon occurs (Denzin & Lincoln, 2005; Merriam, 1998; Yin, 2009). The bounded system (or group of bounded systems) is referred to as a case (or cases); the qualitative researcher uses multiple methods of data collection to generate rich, thick descriptions of the case under study (Creswell, 2013).

The current study identifies The TALL Institute's peer-to-peer safety and sexuality program as the case study. This bounded case is a program of The TALL Institute in Cincinnati, Ohio where peer-to-peer safety and sexuality training is delivered to individuals with ID around the state of Ohio. Multiple methods of data collection, including in-depth, individual interviews with peer-to-peer trainers, observations of peer-to-peer trainings, and document analysis of the peer-to-peer training curriculum, generated a rich, thick description of the program. This particular program was selected for the case study because it provided an opportunity to generate a detailed description of peer-to-peer safety and sexuality training for individuals with ID. Individuals with ID are at increased risk of abuse and victimization, compared to people without disabilities and with other types of disabilities (Petersilia, 2001; Sobsey, 1994). The peer-to-peer safety and sexuality program at The TALL Institute served as an instrumental case (Stake, 1995) to attempt to understand this phenomenon and add new information to the published literature on safety and sexuality training for individuals with ID.

According to Yin (1993), theoretical orientations in case studies can assist the researcher with delimitation of cases, while also providing support for the transferability

of findings to other relevant cases. In the current case study, disability theory, using the models of disability as theoretical frameworks (Smart & Smart, 2007) guided data analysis and interpretation of findings.

The TALL Institute was the ideal site for collecting information regarding peer-to-peer safety and sexuality training for individuals with ID for three primary reasons. First, the Director of TALL, Barb Thomas, is a Certified Sexuality Educator and comprehensive sexuality education one of the educational services offered at The TALL Institute. Second, a group of students are trained as peer-to-peer safety and sexuality trainers, through one of the courses offered at The TALL Institute. Third, the Director of The TALL Institute is willing to collaborate with the researcher in order to facilitate successful completion of this study. These three factors led the researcher to select The TALL Institute as the sole site for data collection for the current study. In addition, The TALL Institute is unique because there are no other ID or DD agencies in the state of Ohio that provide the Health, Safety, and Sexuality Training for You & Me, with grant funding from the Ohio DD Council. The TALL Institute hosts the only known safety and sexuality training program for individuals with ID in the state of Ohio.

Marshall and Rossman (2011) describe four primary methods of data collection in qualitative research, including “participating in the setting, observing directly, interviewing in-depth, and analyzing documents and material culture”; these methods are described as “the staples of the diet” in qualitative inquiry (Marshall & Rossman, 2011, p. 137). Data collection methods in the current study included observation, individual interviews, and document analysis. The researcher participated as a volunteer at The

TALL Institute prior to data collection, as a means of gaining entry into the site and building rapport with potential participants.

In the current study, a semi-structured interview protocol (see Appendix B) elicited content as participants responded to knowledge questions, demographic questions, opinion questions, and feelings questions (Patton, 2002). The interview protocol evolved slightly from one interview to the next, due to the emergent nature of qualitative research. In addition to individual interviews, observation was another form of data collection that was used in the current study. Handwritten field notes were used to capture “concrete descriptions of what was observed” (Marshall & Rossman, 2011, p. 139) during observations and interviews. The researcher conducted two observations of peer-to-peer safety and sexuality trainings in Ohio. In addition to observations and individual interviews, the current study also included an analysis of the curriculum, “Health, Safety, and Sexuality Training for You & Me”, written by Shelly Snyder, Allen County Board of Development Disabilities in Ohio and edited by Barb Thomas, Director of The TALL Institute. Yin (2009) describes documents as a critical component of all case study research. Data from multiple sources also increases the credibility of the study, with each data source supplementing the limitations of another (Patton, 2002).

### **Limitations and Delimitations**

The limitations associated with this study included time constraints for data collection and limited finances for travel. The researcher originally planned to observe a minimum of three training presentations; however, the final training the researcher planned to observe was rescheduled for late January, outside of the time frame for data collection. Also, some of the trainings took place on days when the researcher was unable

to be excused from her place of employment. In addition to time constraints, a small research budget limited the number of times the researcher was able to travel to Cincinnati to interview participants. Consequently, all of the interviews were conducted on the same day, one after the other. Ideally, the researcher would have preferred to create space between the interviews to allow for preliminary data analysis between each interview.

An additional limitation associated with the current study was the inability to gather in-depth feedback from individuals who attended and participated in the peer-to-peer trainings offered by the trainers at The TALL Institute. Although evaluation forms were completed and collected at the end of trainings, these surveys were unable to capture the breadth and depth of comments, thoughts, and reactions to the training program, from the perspective of program participants.

In terms of delimitations, the current study did not provide information on peer-to-peer safety and sexuality training for individuals with DD and no co-occurring ID. All study participants had a diagnosis of an ID, in order to meet the criteria for inclusion as a participant. Therefore, no data was collected regarding individuals who have a DD diagnosis, with no co-occurring cognitive impairments.

An additional delimitation of the current study was the use of one site for data collection. While other agencies in Cincinnati and across the United States provide a variety of services to adults with ID, the TALL Institute was purposefully selected as the sole site for data collection, limiting the breadth of information collected for this case study. The TALL Institute was the ideal site for data collection because the institute



serves as the host agency for the peer-to-peer Health, Safety, and Sexuality Training for You & Me program for individuals with ID in the state of Ohio.

There were no anticipated benefits to participants, as a result of participation in this study. However, the benefits to the scientific community include providing new research related to peer-to-peer safety and sexuality training for individuals with ID and recommendations for Licensed Professional Counselors, Certified Rehabilitation Counselors, and Counselor Educators.

The current study was an initial attempt to explore a phenomenon that has been used in practical settings, such as The TALL Institute, but has not yet been examined in the literature. The intent is to provide a foundation for future scholarly inquiry, both quantitative and qualitative research, on the topic of peer-to-peer safety and sexuality training for individuals with ID. As a critical description of the peer-to-peer training experience, from multiple perspectives, the current study will be the precursor for future research on this topic.

### **Definition of Terms**

Several key terms, used throughout the study, are operationalized here, to provide working definitions of their usefulness for the current study.

Certified Rehabilitation Counselor (CRC): Rehabilitation counselors are currently the only group of professional counselors with specific training related to serving individuals with disabilities, and CRCs are nationally credentialed rehabilitation counselors who are held to the standards of practice in the Code of Professional Ethics for Rehabilitation Counselors (CRCC, 2009). As rehabilitation counselors, CRCs serve individuals with physical, cognitive, mental, emotional, and developmental disabilities

using assessment, diagnosis and treatment planning, case management, counseling, advocacy, placement services, and rehabilitation technology to help individuals accomplish independent living, career, and personal goals (CRCC, 2009).

Counseling: According to “20/20: A Vision for the Future of Counseling” Commission, a task force established within the American Counseling Association in 2005, “Counseling is a professional relationship that empowers diverse individuals, families and groups to accomplish mental health, wellness, education, and career goals” (Locke, 2011).

Counselor Education: describes graduate level (master’s or doctoral) education to prepare professionals to enter the workforce as counselors (master’s level) or counselor education faculty members, consultants, advanced level clinicians and administrators, or private practice clinicians (doctoral level).

Developmental Disability (DD): A diagnosis of DD means: 1) the limitation is the result of a mental or physical impairment, or combination of both, 2) the limitation was manifested prior to age 22, and 3) the limitations are likely to persist throughout an individual’s lifetime (DD Act, 2000). The federal definition of DD also states the impairment must result in a minimum of three significant limitations from the following list of major life activities: self care, receptive and expressive language, learning, mobility, self-direction and capacity for independent living, economic self-sufficiency, and a demonstrated need for individual supports or assistance (DD Act, 2000).

Intellectual Disability (ID): (formerly referred to as mental retardation or MR) ID describes significant impairments in cognitive and intellectual functioning, resulting in limitations in adaptive behavior, such as conceptual, practical, and social skills. ID is

usually diagnosed in childhood, prior to age 18, most often using an assessment of intellectual functioning such as an IQ (intellectual quotient) test (AAIDD, 2012). Four general categories are used to describe the severity of an ID diagnosis, including borderline, mild, moderate, and severe, based on the actual IQ score and the severity of limitations in adaptive behavior. An IQ of 70 and below is one criterion used in a comprehensive assessment resulting in a diagnosis of ID (AAIDD, 2012).

Licensed Professional Counselor (LPC): Although specific licensure requirements vary from state to state, LPCs are generally master's level trained clinicians, who have successfully completed an exam such as the National Counselor Examination for Licensure and Certification (NCE), who have completed a supervised internship in counseling, obtained licensure from their respective state boards, and deemed qualified to diagnose and treat mental, emotional, and behavioral disorders. According to the American Counseling Association Code of Ethics (ACA, 2005, p. 3), "counselors encourage client growth and development in ways that foster the interest and welfare of clients and promote formation of healthy relationships." LPCs work in a variety of settings, included but not limited to community mental health agencies, schools, private practice, and hospitals and clinics.

Rehabilitation Counseling: A "systematic process which assists persons with physical, mental, developmental, cognitive, and emotional disabilities to achieve their personal, career, and independent living goals in the most integrated setting possible through the application of the counseling process" (CRCC, 2013, para. 3).

Sexuality: As a broad construct, sexuality includes multiple components, including but not limited solely to the actual sex act. Schroeder and Kuriansky (2009)

provide an overview of the Holistic Model of Sexuality, originally created by Dennis Dailey. The Sexuality Information and Education Council of the United States (SIECUS) and others use Dailey's five-factor model as a general framework for conceptualizing sexuality. The five factors include 1) sensuality, 2) sexualization, 3) sexual identity, 4) intimacy, and 5) sexual health and reproduction. Historically, sex education in the U.S. has primarily focused on sexual health and reproduction, with focus on pregnancy, puberty, body parts, disease prevention, and other biological factors related to sex. While this is one component of sexuality, other factors such as relationships (intimacy), power, control, and coercive sexual behavior (sexualization), sensations and stimulation experienced through the five senses (sensuality), and experiences related to gender and gender roles (sexual identity), are often neglected in traditional sex education programs (Schroeder & Kuriansky, 2009).

Sexuality Education: SIECUS (2013) defines comprehensive sexuality education as “a lifelong process of acquiring information and forming beliefs about identity, attitudes, and values about identity, relationships, and intimacy” (para. 1). According to this definition, a comprehensive sexuality education program will address topics such as sexual development, reproductive health, interpersonal relationships, affection, intimacy, body image, and gender roles. From this perspective, sexuality is addressed in terms of biological, sociocultural, psychological, and spiritual dimensions in the cognitive domain, affective domain, and behavioral domain. In an effective sexuality education program, participants are taught the skills to communicate effectively and make responsible choices. This definition, which stands as a reflection of current societal attitude toward

sexuality, is the result of over 100 years of legislation and advocacy related to issues surrounding human sexuality and development (SIECUS, 1996).

### **Summary**

Individuals with ID are at increased risk for abuse and victimization, due to factors related to the impairment (Petersilia, 2001; Sobsey, 1994). Peer-to-peer safety and sexuality training is one tool used by The TALL Institute in Cincinnati, Ohio to reduce vulnerability to victimization for individuals with ID. There is currently a gap in the literature related to this method of training with members of this particular disability population. This qualitative case study is an attempt to generate new insights on safety and sexuality training for individuals with ID, using the program at The TALL Institute as an instrumental case. The case study generated a rich, thick description of the safety and sexuality training offered by the director and peer-to-peer trainers at TALL and offered lessons learned, including recommendations for future research and for practitioners, family members, and caregivers of individuals with ID. Implications for policy and preparation of LPCs and CRCs are also provided.

This chapter provided an introduction to the current case study, including the background, statement of the problem, purpose, significance of the study, followed by an overview of the methodology for the study, limitations and delimitations and a list of definition of terms used throughout the study. The next chapter will provide a review of relevant literature for the case study. The remaining chapters in the study include methodology for the study (Chapter 3), The TALL Institute and the Health, Safety, & Sexuality Training for You & Me Program (Chapter 4), the peer-to-peer trainers' stories and experiences (Chapter 5), and lessons learned (Chapter 6).

## Chapter 2: Literature Review

This chapter presents a comprehensive review of published literature related to safety and sexuality education and counseling for individuals with ID. The purpose of the current case study is to describe the peer-to-peer safety and sexuality training program for individuals with ID at The TALL Institute. This chapter will present a review of relevant literature, in order to provide context for the current case study. This chapter is divided into five broad categories, beginning with a discussion of ID, followed by sexuality and disability, sexuality and ID, sexuality education, and peer-to-peer safety and sexuality training for individuals with ID.

### **Intellectual Disability**

The following section includes information on diagnosis of ID, etiology and prevalence of ID, a discussion of the relationship between ID and DD, and treatment planning for individuals with ID.

**Diagnosis of ID.** The term ID has recently replaced the term mental retardation (MR), to describe significant limitations in intellectual functioning that result in impairments in adaptive behavior. The following paragraphs will describe diagnosis of ID, using the former terminology of MR, followed by a discussion of the etiology of ID. *The Diagnostic and Statistical Manual of Mental Disorders, Fourth Edition, Text Revision* (DSM-IV-TR), published in 2000 by the American Psychiatric Association lists MR as a disorder “usually diagnosed in infancy, childhood, or adolescence” (4<sup>th</sup> ed., text rev.; *DSM-IV-TR*, American Psychiatric Association, 2000, p. 39). The *DSM-IV-TR* lists three criteria for a diagnosis of MR:

Criterion A) sub average intellectual functioning; Criterion B) significant limitations in adaptive functioning in at least two of the following skill areas: communication, self-care, home living, social/interpersonal skills, use of community resources, self-direction, functional academic skills, work, leisure, health, and safety; and Criterion C) the onset must occur before age 18 years. (4<sup>th</sup> ed., text rev.; *DSM-IV-TR*, American Psychiatric Association, 2000, p. 41)

The American Psychiatric Association defines “sub average intellectual functioning” as an intellectual quotient (IQ) of about 70 or below, as assessed by an intelligence test, administered individually, such as the Wechsler Intelligence Scales for Children , now in its fourth edition (4<sup>th</sup> ed., text rev.; *DSM-IV-TR*, American Psychiatric Association, 2000, p. 41). The *DSM-IV-TR* lists four levels impairment to indicate the diagnostic severity of MR, ranging from mild, moderate, severe, to profound (4<sup>th</sup> ed., text rev.; *DSM-IV-TR*, American Psychiatric Association, 2000).

A diagnosis of mild MR is usually given in association with an IQ of 50–55 to 70, encompassing approximately 85% of all individuals with MR (4<sup>th</sup> ed., text rev.; *DSM-IV-TR*, American Psychiatric Association, 2000). “Educable” was a term used in educational settings to describe the level of functioning associated with a diagnosis of mild MR, indicating a capacity to learn, minimal impairments in intellectual functioning and adaptive behavior, and the need for low levels of support and assistance across the lifespan (4<sup>th</sup> ed., text rev.; *DSM-IV-TR*, American Psychiatric Association, 2000). The *DSM-IV-TR* lists a positive prognosis for individuals with mild MR who receive appropriate, individualized services (4<sup>th</sup> ed., text rev.; *DSM-IV-TR*, American Psychiatric Association, 2000).

A diagnosis of moderate MR is often used to refer to individuals with an IQ ranging from 35–40 to 50–55 (4<sup>th</sup> ed., text rev.; *DSM-IV-TR*, American Psychiatric Association, 2000). Individuals with moderate MR were previously referred to as “trainable” in educational settings, although such language is no longer used because it gave the false impression that individuals with these IQ levels are unable to learn and thrive (4<sup>th</sup> ed., text rev.; *DSM-IV-TR*, American Psychiatric Association, 2000). Approximately 10% of all individuals with MR fall within this range and often require additional supports, such as employment in sheltered workshops or supervised housing arrangements in independent or group settings, compared to individuals with diagnoses of mild MR (4<sup>th</sup> ed., text rev.; *DSM-IV-TR*, American Psychiatric Association, 2000).

Severe MR indicates an IQ of 20–25 to 35–40, affecting approximately 3–4% of individuals diagnosed with MR (4<sup>th</sup> ed., text rev.; *DSM-IV-TR*, American Psychiatric Association, 2000). This level of MR may indicate moderate to severe limitations in verbal behavior, requiring increased levels of supports depending on the specific limitations in adaptive skills (4<sup>th</sup> ed., text rev.; *DSM-IV-TR*, American Psychiatric Association, 2000). The term profound MR is associated with approximately 1–2% of all MR diagnoses, with the most significant impairments in intellectual functioning and adaptive behavior, often requiring constant supervision and individualized support (4<sup>th</sup> ed., text rev.; *DSM-IV-TR*, American Psychiatric Association, 2000).

Although the term ID is beginning to replace the term MR, the diagnostic categories of mild, moderate, severe, and profound continue to be used to classify the severity of ID diagnoses. In May 2013, the American Psychiatric Association will publish the *DSM-5*, which will replace the term mental retardation with intellectual disability



(intellectual developmental disorder) (APA, 2013, p.1). Additional proposed revisions to the current version of the DSM include an emphasis on “adaptive functioning rather than IQ tests alone” (APA, 2013, p.1), therefore removing IQ test scores from the criteria used to make a diagnosis of ID, although a discussion of IQ scores will remain in the description of ID, provided in the text. The American Psychological Association notes the importance of IQ tests in determining levels of intellectual functioning, however practitioners are encouraged to consider conceptual, social, and practical skills to “develop a fuller, more accurate picture of patients” to assist in the provision of effective treatment and services (APA, 2013, p. 2). The following paragraphs describe the etiology and prevalence of ID.

**Etiology and prevalence of ID.** ID is usually caused by significant events before, during, or after birth (AAIDD, 2009; AAIDD, 2010; The Arc, 2001). Conditions before birth include genetic or chromosomal disorders, lack of prenatal care, alcohol, tobacco, or other drug use/abuse, and other factors that impact fetal development, including accident or injury (AAIDD, 2009; AAIDD, 2010; The Arc, 2001). The most prevalent types of ID include Down syndrome, Fragile X Syndrome, and Fetal Alcohol Spectrum Disorder. Although the numbers vary, the best estimates of the prevalence rates of ID are approximately 1-3% of the population (The Arc, 2001). Factors during birth that can lead to an ID diagnosis include lack of oxygen during birth, decreased heart rate, and other problems that occur during delivery (AAIDD, 2009; AAIDD, 2010; The Arc, 2001). Problems after birth include, but are not limited to accident or injury, exposure to toxins, extreme deprivation or lack of stimulation (failure to thrive), or physical, emotional, or psychological impairments resulting from abuse or neglect (AAIDD, 2010).

**Relationship between ID and DD.** ID shares a relationship with developmental disability (DD) – while a diagnosis of ID always describes impairments in cognitive functioning, DD may or may not describe a mental impairment (AAIDD, 2012). Similar to ID, a diagnosis of DD is usually given in childhood, prior to age 22, and describes impairments that may be pervasive throughout an individual’s life (AAIDD, 2012). Although DD and ID may co-occur (e.g., Down syndrome, Fetal Alcohol Spectrum Disorder), some DD results in limitations that may or may not coincide with an intellectual impairment (e.g., cerebral palsy, epilepsy, Autism Spectrum Disorder) (AAIDD, 2012). Some DD may be mental or physical in nature, and may or may not result in a cognitive impairment. Research has shown, with appropriate supports, individuals with ID may live successful, independent, productive lives (AAIDD, 2012). The subsequent paragraphs provide an overview of treatment services available for individuals with ID.

**Treatment planning.** According to The Arc, a national advocacy organization for people with ID and DD, ID has no known cure, although individuals with ID diagnoses may be eligible for a range of treatment services, including case management, day treatment, special education, early intervention, housing assistance, school-to-work transition services, and vocational and independent living support (The Arc, 2012). While a variety of service providers, with various levels of education and training, work with individuals with ID, Certified Rehabilitation Counselors (CRCs) are one of the primary groups of professionals trained at the graduate level, with nationally recognized credentials, to provide vocational, case management, counseling, and related services to individuals with ID and other disabilities.

The Smith Fess Act of 1920 established vocational rehabilitation at the state and federal level, and subsequent legislation, such as the Vocational Rehabilitation Act Amendments of 1954, provided funding to train master's level rehabilitation counseling professionals (Rubin & Roessler, 2001). The original goal of this early legislation was to provide counseling, training, and job placement services to veterans with disabilities to returning from World War I; however later legislation expanded services to civilians (Rubin & Roessler, 2001). The Rehabilitation Act of 1973 expanded the scope of rehabilitation counseling, beyond employment, to include quality of life, inclusion, and empowerment goals that extended to individuals with more severe impairments. These goals are outlined in Individualized Written Rehabilitation Programs (IWRP) or Individualized Plans for Employment (IPE), co-developed through collaboration between individuals with disabilities and rehabilitation counselors.

Adolescents with ID may be eligible for transition services from rehabilitation counselors, beginning at age 14 years, to identify post high-school opportunities for employment, education, or independent living. Adults with ID may be eligible for rehabilitation counseling services related to vocational assessment and evaluation, job training and placement, education, assistive technology, and independent living, among other services. Although sexuality is an integral component of the human experience, these discussions are often not included in IWRPs, counseling, and other forms of treatment planning for individuals with ID. The following section will discuss historical views toward sexuality and disability, in general, followed by a discussion of sexuality and ID. Views of individuals with ID, parents and caregivers, and CRCs toward sexuality and ID will also be considered.

## **Sexuality and Disability**

The relationship between sexuality and disability has been the subject of critical debate over the past several decades, through the work of scholars and practitioners such as Winifred Kempton, Tom Shakespeare, Harlan Hahn, and Russell Shuttleworth (Hahn, 1985; Kempton & Kahn, 1991; Shakespeare, Gillespie-Sells, & Davies, 1996; Shuttleworth, 2000). As an educational director for Planned Parenthood, Kempton developed some of the earliest sexuality education curricula for individuals with and without disabilities (e.g., Kempton, 1973; Kempton, 1975). Hahn challenged the medical model of disability and advocated in favor of sexuality as a component of the emerging disability rights movement, at that time (Hahn, 1985). Shakespeare, Gillespie-Sells, and Davies (1996) are widely regarded for their seminal work on this topic, from the perspective of individuals with disabilities. While these and many others have paved the way for groundbreaking research and policy change related to opportunities for sexual expression for individuals with disabilities, Shuttleworth (e.g., 1996, 1999, 2007) is becoming one of the most widely cited authors in the field of sexuality and disability.

While the advocates of the functional and environmental models of disability challenged the status quo by decreasing physical barriers to public services, education, and employment (Shakespeare, Gillespie-Sells, & Davies, 1996; Shuttleworth & Mona, 2002), society's current views on disability do not adequately address the sexuality needs of individuals with disabilities. Although many in society accept the Sociopolitical Model of disability, holding society as opposed to the individual responsible for change, issues related to disability are rarely included in larger discussions of sexuality, and the opposite is also true regarding sexuality topics infused in conversations related to disability. For

example, Shuttleworth (2007) discusses the limited inclusion of disability populations in empirical research related to the HIV/AIDS epidemic of recent decades. Also, limited research examines the experiences, such as double discrimination, of individuals with disabilities who identify as lesbian, gay, bisexual, or transgender (LGBT) (e.g., Guter & Killacky, 2004). Shuttleworth (2007) speaks in favor of sexuality education for youth with disabilities, in particular, encouraging the use of peer-support groups where older adults with disabilities could mentor younger adults and teens, based on their lived experiences. Shuttleworth (2007) dedicates a significant portion of the article specifically to issues related to sexual expression for individuals with intellectual impairments, including dignity of risks, capacity to consent to sexual activity, and vulnerability to abuse, topics that will be addressed thoroughly in subsequent sections of this chapter. Shuttleworth (2007) further challenges researchers to include participant voice in studies of sexuality and disability, in order to affect policy change in the near future.

There is a clear, established need for additional critical research pertaining to sexuality and disability. While some progress has been made in terms of disability rights and human sexuality, these two fields of study are recently beginning to merge in scholarly discourse that employs critical frameworks. The current case study includes two of the recommendations provided by Shuttleworth (2007), including the use of peer-group models to address topics related to sexuality, specifically for individuals with intellectual impairments, and the emphasis on participant voice in research on sexuality and disability. The following section summarizes the relationship between counselor education and disability, followed by CRCs attitudes toward sexuality and disability.

**Counselor education and disability.** Although CRCs are the primary practitioners with graduate-level training to assist individuals with disabilities with achievement of educational, employment, and independent living goals, mental health counselors, licensed in many states as LPCs, are increasingly providing mental health services to individuals with disabilities, particular in community mental health, residential, and medical settings. As an LPC in a community mental health clinic in rural southeast Ohio, the researcher has several clients on her caseload who have co-occurring mental or physical disabilities, as do the other counselors in the clinic. Because CRCs receive specialized training related to disability, such topics have often been omitted from other counselor education programs, including preparation of mental health counselors and school counselors (Smith, Foley, & Chaney, 2008). Smith, Foley, & Chaney (2008) encourage counselor education programs to challenge graduate students to “confront their own ablesim” in an effort to adequately meet the needs of all clients, including those with disabilities (p. 306). As individuals with disabilities continue to access services that are not disability-specific in schools and communities through legislation such as IDEIA (2004) and ADA (1990), counselor education programs would do well to prepare future counselors to meet the needs of this client population (Smith, Foley, & Chaney, 2008). Further research is needed to study the relationship between counselor education and disability, in general, and LPC and counselor educator attitudes toward sexuality and disability, in particular. However, there is limited literature examining CRCs views toward sexuality and disability, discussed below.

**CRCs views toward sexuality and disability.** Although CRCs have the “primary responsibility to promote the welfare and respect the dignity of clients,” (Commission on

Rehabilitation Counselor Certification [CRCC], 2009, p. 3), limited research suggests many CRCs are hesitant to address issues related to sexuality for their clients with disabilities, although many clients view these issues as central to their well-being. Regardless of the CRCs personal thoughts, feelings, and beliefs, topics such as pregnancy, STD prevention and treatment, homosexuality, masturbation, and relationships are just as important as employment, housing, and vocational training.

As mentioned previously, people with ID are at increased risks of sexual victimization when compared to the general population (Petersilia, 2001; Sobsey, 1994) and have complex needs related to healthy sexual expression. Sexuality is an important issue for clients and CRCs must exhibit some level of comfort in order to effectively address these issues (Kazukauskas & Lam, 2009). Kazukauskas and Lam (2009, 2010) are the first to conduct studies related to sexuality and disability, from the perspective of CRCs and their first study (Kazukauskas & Lam, 2009), discusses the importance of addressing sexuality in CRC practice. The researchers used an adapted version of the Family Life Sex Education Goal Questionnaire 2003-R by Godwin, Frank, and Jacobson, (1998), completed by 199 CRCs, to assess beliefs about sexuality and the general disability population.

A factor analysis revealed six factors: a) Contraception, Pregnancy, and STDs, b) Counseling and Education, c) Sexual Development and the Body, d) Traditional Values, e) Contemporary Values, and f) Family Inclusion (Kazukauskas & Lam, 2009). The first factor included 26 questions related to STDs, contraception, and pregnancy. The second factor contained 13 questions related to open communication, education about sexuality and disability, and referrals to outside agencies. The third factor had six items related to

sexual development, physical appearance, and fears about sexuality. The fourth factor, with five items, assessed attitudes related to abstinence, “traditional” American family values, and abortion alternatives. The fifth factor, with six items, included questions on topics such as diverse sexual orientations, negative impact of traditional gender roles, and collaboration with other agencies for sexuality rehabilitation. The sixth and final factor included four items on the involvement of the family in sexuality planning and workshops for family members (Kazukauskas & Lam, 2009).

Although all six factors were rated by CRCs as important, CRCs rated the Counseling and Education factor as most important; the remaining factors are listed here in descending order of importance – Contraception, Pregnancy, and STDs; Sexual Development and the Body; Family Inclusion; Traditional Values; and Contemporary Values (Kazukauskas & Lam, 2009). CRCs also responded to open-ended questions regarding the types of sexuality issues they are most likely to encounter with clients; the majority of responses centered on the impact of the disability or injury on sexuality (n = 49), sexual orientation and identity (n = 28), and relationship issues and marriage (n = 22).

Although this study had limitations, including the revision and subsequent use of an instrument that was originally designed to assess attitudes of family and community members toward sex education in public schools, the implications are far-reaching. One implication relates to CRCs attitudes towards diverse sexual orientations, classified in this study as Contemporary Values. Although still considered important, Contemporary Values were rated lowest among the six factors by CRCs in this study, but came in second in terms of issues clients address in rehabilitation; and fourteen percent of the



sample reported sexual orientation and identity as issues that arise with clients (Kazukauskas & Lam, 2009). Future research could address a gap in the literature related to LGBT issues and people with disabilities, in terms of CRC attitudes and preparedness to address issues related to sexual diversity.

An additional study, by the same research team (Kazukauskas & Lam, 2010) also addressed disability and sexuality from the perspective of CRCs. In addition to assessment of attitudes, the study also assessed CRCs level of comfort and knowledge related to sexuality and disability. In their previous study, 60% of respondents reported some level of formal training during graduate studies, specifically related to sexuality and disability, either as a complete course or a component within a course (Kazukauskas & Lam, 2009). However, previous literature has identified discrepancies between rehabilitation professionals' knowledge and behavior. A study by Haboubi and Lincoln (2003) reported 90% of rehabilitation professionals viewed sexuality as a component of holistic practice with clients, but only 32% had ever initiated discussed on sexuality issues with clients. Both CRCC and The Council on Rehabilitation Education (CORE) emphasize the importance of human sexuality and disability issues (Kazukauskas & Lam, 2010), and in an increasingly diverse society it is imperative that CRCs possess the knowledge, skills, and attitudes to promote healthy sexuality.

One-hundred ninety-nine CRCs completed the Knowledge, Comfort, Approach, and Attitudes toward Sexuality Scale (Kendal, Booth, Fronek, Miller, & Geraghty, 2003), a 45-item survey originally designed to assess professionals' knowledge, attitudes, and comfort addressing sexuality of individuals with spinal cord injury. The instrument was revised to be applicable to disabilities, in general, for the purposes of this study

(Kazukauskas & Lam, 2010). Using a multiple regression analysis, the researchers found as knowledge on sexuality issues increased, personal discomfort among CRCs decreased (Kazukauskas & Lam, 2010). Demographic factors (race/ethnicity, religion, gender, age, etc.) did not significantly impact CRCs comfort in addressing sexuality issues. A second part of the study assessed comfort level when CRCs are hypothetically approached by a client in a sexual manner; demographic variables did impact comfort levels. Age was a significant predictor of comfort levels with approach-related issues; younger CRCs reported higher levels of discomfort than older CRCs (Kazukauskas & Lam, 2010). The results of this study imply increased knowledge on issues related to human sexuality could positively impact CRCs level of comfort with sexuality-related issues, as they arise with clients.

Considering the multiple barriers, persistent stigma, and the attitudes, knowledge, and comfort level of rehabilitation professionals, individuals with ID may face significant challenges related to sexual development and expression. Graduate programs, under CORE standards, are obligated to provide training on the interaction between human sexuality and disability. Increased training in sexuality and disability, guided by current and future literature and research, could provide positive outcomes for diverse client populations who desire assistance in this area. Future research, specifically in rehabilitation counseling, could increase the limited amount of literature on ID and sexuality. By increasing the amount of attention given to these issues, professionals would have the opportunity to increase the quality of life for clients with ID.

## **Sexuality and ID**

The following section provides an overview of sexuality and disability, including a discussion of historical perspectives, attitudes of caregivers, attitudes of individuals, capacity to consent to sexual activity, demographic considerations, and a discussion of sexual abuse and victimization of individuals with ID.

**Historical perspectives.** As early as 1000 BCE, people who were born with any kind of mental or physical ailments were perceived as cursed, evil, and were excluded from society. In Ancient Rome and Greece, infanticide was a common practice where babies born with mental or physical handicaps were killed or exposed to the elements and left to die, as a way of breeding out those members of society who were considered unfit for reproduction. In the 1400s, during the Middle Ages, people with disabilities were hired as court jesters and used for entertainment for the wealthy (Petersilia, 2001). In 1619, the first diagnosis of mental retardation (MR) was given, and the etiology was listed as “overindulgence in sexual pleasure” (Wade, 2002). These negative views toward difference are clearly illustrated in the following quote by Alexander Pope in 1733, “Order is heaven’s first law and this is confessed, some are and must be better than the rest” (Gould, 1981). These views of the ideal versus the unfit continued to expand, and reached a peak during the Eugenics movement of the 1800s (Gould, 1981).

The term “eugenics”, coined by Galton, cousin of Darwin, was used widely in the 1800s to describe the process of encouraging certain members of society to reproduce based on certain criteria considered hereditarily favorable (Gould, 1981). The advent of statistics, measurement, and probability during the 1800s led to the publication of volumes of texts on brain measurement, cranial size, and comparisons between groups of

people. The Bell Curve was one such invention (Dudley-Marling & Gurn, 2005) that sparked the ongoing classification of groups of people into arbitrary, hierarchical categories, based on perceived intelligence, the size of their head, or the color of their skin. Race, gender, ability, geographic location, and social status were negatively impacted during this time when people of African descent, women, residents of rural areas, and the poor often failed such “tests” (Gould, 1981). These trends in testing failed to take into account individual differences and were self-serving in their goal of promoting and advancing a Eurocentric, patriarchal agenda.

Some of the negative outcomes of the early 1900s included Goddard’s “research” of the Kallikaks, a pseudonym Goddard created for a rural family in New Jersey using the Greek words “kallos” meaning beauty and “kakos” meaning bad (Gould, 1981). Goddard used his “research” to support the notion that people from rural, poorer communities also exhibited certain mental deficiencies and a sense of “evilness” that would be cured as a result of rigorous training from wealthy, more “civilized” members of society (Gould, 1981). It was later discovered that Goddard altered pictures to make his subjects appear deranged and psychotic, however, the implications regarding negative, stereotypic perceptions of rural Americans continues to this day (Gould, 1981).

Two decades later, society’s views on sexuality began to shift, with the establishment of Planned Parenthood by Margaret Sanger in the 1920s, and the rebellion against legislated morality during the 1930s (Wade, 2002). However, while women, in general, were gaining momentum in regards to sexual freedom, women with ID continued to struggle to achieve reproductive rights. In 1927, the Supreme Court upheld the constitutionality of a Virginia ruling on the involuntary sterilization of a woman with

ID (Buck vs. Bell, 1927). Also during this time, the rise of the Nazi party in Germany and the mass killing of over 275,000 people with disabilities, as a sort of “intellectual cleansing” caused the U.S. to reconsider certain policies regarding disability (Wade, 2002). In the 1940s, thousands of individuals with ID, particularly with more severe impairments, were institutionalized in sub humane conditions in the U.S. and abroad, with limited privacy and no access to sexuality education or safety training programs (Kempton & Kahn, 1991; Wade, 2002).

In the 1950s, parents began to demand more humane treatment of their children with ID who resided in facilities; in the 1960s, many individuals with ID were released to community or group home settings which led to increased opportunities for independence. One particular philosophy, referred to as “dignity of risks” (Kempton & Kahn, 1991), increased advocacy efforts in favor of the rights of individuals with ID to make mistakes and learn from their experiences as opposed to a sterile, heavily supervised existence. In addition, President John F. Kennedy’s sister, Rosemary, who was diagnosed with MR, brought increased attention and awareness to issues concerning members of this population. President Kennedy, probably more than any President before or since, was successful in passing legislation to improve the lives of people with cognitive limitations (Wade, 2002).

Views toward sexuality continued to progress during this time; the Food and Drug Administration approved the contraceptive pill in the 1960s, Congress provided federal funding for Planned Parenthood in 1970, and Roe vs. Wade in 1973, legalized elective abortions. In the 1980s, in response to a steady increase in the number of unwanted pregnancies, and the HIV/AIDS epidemic, the Regan administration signed the 1981

Adolescent Family Life Act which provided federal funding for abstinence only until marriage (AOUM) sex education programs in public schools. Current discussions related to sexuality and ID in the U.S. and globally include reports of abuse, sexual health and reproduction, and sexuality education, as discussed in the following pages. Then and now, progress has been made, however individuals with ID continue to face challenges related to sexuality.

**Attitudes of caregivers.** Staff, educators, parents, and caregivers play an important role in the lives of individuals with ID; their views, opinions, and attitudes have a direct bearing on the opportunities people with ID have, especially in terms of sexuality and sexual expression. Cuskelley and Bride (2004) found older caregivers in Australia have less positive attitudes toward the parenting abilities of people with ID, as opposed to younger caregivers. Chou and Lu (2011) found parents and husbands of women with ID in Taiwan are largely in favor of sterilization, whether voluntary or involuntary. Aunos and Feldman (2002) found special education teachers in Canada had more positive views toward sexuality and ID than the parents of their students. Evans, McGuire, Healy, & Carley (2009) also found interesting results when surveying parents of children with ID and staff members at agencies for people with ID: 55% of the parents wanted more training on issues related to sexuality, compared with 95% staff; 50% of the male staff members said parents should not be involved in decisions regarding sexuality, compared to 18% of female staff. The most shocking finding was in response to a question that asked if the individual should be the primary decision-maker regarding issues related to sexuality – 80% of the staff agreed with this statement, compared to only 20% of the parents surveyed (Evans et al., 2009). In an effort to protect their children

with ID, parents' views on sexuality are potentially putting the individuals at a disadvantage and increasing their vulnerability to victimization.

**Attitudes of individuals.** Researchers Healy, McGuire, Evans, & Carley (2009) interviewed individuals with ID in Ireland, using focus groups, to obtain their perspectives related to sexuality. One man expressed his frustration with barriers to sexuality saying, "I do really think that we don't matter because we don't have any much of a life anyway" (Healy et al., 2009, p. 910). Several of the individuals had inadequate levels of sexual knowledge, including misinformation about pregnancy and birth control, and many of the individuals expressed negative attitudes toward homosexuality (Healy et al., 2009).

Individuals with DD have also been interviewed regarding their views towards various aspects of human sexuality. Lesseliers and Van Hove (2002) of Belgium interviewed 46 women and men with DD, ranging from 20 to 65 years old. Participants discussed various aspects of sexuality including, dating and relationships, sexual intimacy, sexual abuse, marriage and children, the need for sexuality education, and lack of parental and caregiver support.

Data analysis revealed several major findings related to each of the topics listed above. In terms of dating and relationships, one man stated, "girlfriends cost too much" (Lesseliers & Van Hove, 2002, p. 73), while a woman described her relationship as a necessary component of her well-being, stating "without him I felt so weak" (Lesseliers & Van Hove, 2002, p. 73). Sexual intimacy was regarded as a positive experience by some participants, while others described the sex act as painful or undesirable. The researcher broached sensitive topics such as masturbation, regarded in the literature as an

important part of sexual expression for many individuals with disabilities; however, many of the participants, particularly the women, experienced difficulties when asked to share their views on the topic.

Parents, staff, and other stakeholders have a unique opportunity to enhance the quality of life for individuals with ID. Rather than building “prisons of protection” (Hingsburger, 1995), Koller (2000) suggests parents and caregivers create “rings of safety” and cultivate healthy sexual development for people with ID. All people are sexual beings, regardless of ability (Gomez, 2011) and to deny this opportunity to people with ID effectively prohibits them from a fundamental aspect of the human experience.

**Capacity to consent to sexual activity.** In addition to sexual knowledge and vulnerability to abuse, capacity to consent is another legal issue relevant to the discussion of sexuality and ID. According to AAIDD, legally adequate consent requires three components: capacity, information, and voluntariness. This means an individual must adhere to the minimum age requirements for consent in their particular state, must have a functional understanding of sexuality, and must understand that legal sexual behavior is voluntary and void of coercion. Capacity to consent is a term used repeatedly in the literature to describe the ability of individuals with ID to legally consent to sexual activity (Dukes & McGuire, 2009; Kennedy & Niederbuhl, 2001; Luckasson & Walker-Hirsch, 2007; Mayer & Poindexter, 1998; Murphy & O’Callaghan, 2004; O’Callaghan & Murphy, 2007; Wacker, Parish, & Macy, 2008).

Although there is no widely established criteria for capacity to consent, most states have laws that explicitly define three classes of nonconsensual sex to include sexual contact by force and without consent, sexual context with a child or minor, and



sexual contact with a person deemed mentally defective or unable to give consent (Sexual Assault Statutes, 2006). Most states also define sexual assault as an act committed against another person who is unwilling or unable to physically, mentally, or legally consent (Sexual Assault Legislation, 2004). Legislation in 45 states classifies all sexual activity among persons with ID and other mental disabilities as illegal; these states (not including Colorado, D.C., Nebraska, Nevada, Georgia, Massachusetts, and Missouri) have laws that state individuals with mental deficiencies are incapable of legally consenting to sexual acts (Sexual Assault Statutes, 2006). Such restrictive legislation, written with the intent to protect people with ID, has serious implications for expressions of healthy sexuality for members of this population.

The idea of capacity to consent is controversial because people with ID are held to a much higher standard for consent than their non-disabled counterparts (Stavis, 1991). Further, an individual's capacity to consent to sexual activity has even been questioned in situations involving violent rape and sexual assault of individuals with ID, something that has been deemed inappropriate for female victims without disabilities. History shows the courts have also failed to provide justice for women with ID, refusing to extend them the same rights and protections provided to women without disabilities. In 1927, the Supreme Court upheld a Virginia law that allowed involuntary sterilization of a woman with ID, and over 20 other states followed suit. In 1989, in Glen Ridge, New Jersey, and the same year in North Carolina, two women with ID were brutally victimized by men using objects such as broom handles and baseball bats (McCarthy, 1999). During both of these trials, the mental capacity of the women was the primary focus as opposed to the brutal acts they endured as victims of violent sexual abuse (McCarthy, 1999). Society has

failed to adequately address misconceptions related to sexuality and ID, and women with ID have continued to suffer, as a result. Additional details regarding the role of gender are provided in a later sub-section along with other demographic considerations. The following paragraphs summarize three models of capacity to consent to sexual activity for adults with ID.

Capacity to consent to sexual activity usually involves three components: 1) knowledge of the decision, including risks and benefits, 2) intelligence or understanding that is consistent with the individual's values/beliefs, and 3) voluntariness (Stavis, 1991). Although there are no widely established criteria to determine an individual's capacity to consent several groups have put forth models, grounded in research and practice (Kennedy & Niederbuhl, 2004; Mayer & Poindexter, 1998; Murphy & O'Callaghan, 2004).

One such model is the CLASP acronym, developed by Mayer and Poindexter (1998) to teach individuals about their rights and responsibilities related to sexual activity. The C stands for consensual; the L stands for legal; the A stands for adult; S is for safer; and P is for private (Mayer & Poindexter, 1998). Each of these letters serves to remind individuals that appropriate and legal sexual behavior involves two consenting adults who both have the right to withdraw at any time, in a manner that reduces potential risks and occurs in a private location (Mayer & Poindexter, 1998).

Kennedy & Niederbuhl (2001) put forth a five factor model based on input from 332 members of the American Psychological Association (APA). A factor-analysis revealed the following five-factors as important criteria for capacity to consent: Factor 1 – Consequences of Sexual Activity; Factor 2 – Basic and Essential Sexual Knowledge;

Factor 3 – Unessential Sexual Knowledge; Factor 4 – Safety for Self and Others; and Factor 5 – Basic Safety Skills (Kennedy & Niederbuhl, 2001). Participants considered Factor 5 as the most necessary criterion for capacity to consent (Kennedy & Niederbuhl, 2001).

An additional model, by Murphy & O’Callaghan (2004) lists six factors as crucial elements in determination of capacity to consent. These include a) basic sexual knowledge, b) knowledge of the consequences of sexual activity, c) understanding of appropriate sexual behavior, d) understanding the importance of choice, e) the ability to recognize potentially abusive situations, and f) ability to demonstrate assertiveness skills (Murphy & O’Callaghan, 2004). Models such as these have been critiqued as too restrictive, holding individuals with ID to a higher standard than the general population.

Considering the challenges associated with sexual knowledge, vulnerability to abuse, and capacity to consent to sexual activity, comprehensive sexuality education has been purported as one method to improve sexual knowledge and understanding of the law for individuals with ID and DD, as evidenced in a study by Dukes and McGuire (2009). Two male and two female participants with ID participated in the Living Your Life individualized sex education program (Bustard, 2003). The Sexual Consent and Education Assessment ([SCEA]; Kennedy, 1993) was administered at baseline, pre-treatment, and post-treatment, and at 6-month follow up. Data analysis revealed all four participants increased their sexual knowledge and three of the four maintained higher scores on the SCEA at follow-up (Dukes & McGuire, 2009). Although the size of the sample was small, the results of this study imply capacity to consent is fluid rather than

static and may improve over time with adequate support and training (Dukes & McGuire, 2009).

**Demographic considerations.** Individuals with ID are not a monolithic group. Individual members of this population experience similar classifications of “difference” as the non-disabled population, including demographic characteristics such as gender, socioeconomic status, race and ethnicity, sexual orientation, and rural-urban residence. These demographic considerations will be examined below, in relation to their impact on sexuality of individuals with ID.

***The role of gender.*** Recent court cases have served as illustrations of the role of gender in regards to sexuality and ID. In 1989 in Glen Ridge, New Jersey, a woman with DD was raped repeatedly with a baseball bat, a broom, and a stick (Block, 2000; Lefkowitz, 1997). The victim’s cognitive impairment, as opposed to the horrific sexual assault, became the primary focus of the trial. The defense argued the victim “craved the euphoria because her brain functioned that way” (Biklen & Schein, 2001, p. 438) and the victim’s own attorney stated “normal human beings wouldn’t tolerate such acts of cruelty, humiliation, and degradation” (Biklen & Schein, 2001, p. 438). In a similar case in North Carolina, five men raped a woman with cognitive disabilities using a broom handle, a pipe, and a candle, while recording the incident on video, promising her a date if she refused to report the incident (Ayers, 1993). Gender plays a role in these cases and others, dating back to *Buck vs. Bell* in 1927, when women with disabilities, particularly ID and other cognitive limitations, are not extended the same protection as women without ID. Advocates for women’s rights have been successful in passing legislation such as the Rape Shield Statutes (2003) which prevent a woman’s sexual history from

inclusion in cases involving rape and sexual assault, unless the history is materially relevant. Women with ID have been double-victims, first by the perpetrators of the assault, and again by a legal system that fails to serve their best interests.

***LGBT concerns.*** Similar to the challenges women with ID face, individuals with ID who identify as lesbian, gay, bisexual, or transgender (LGBT) also face additional barriers, as a minority within a minority. Approximately 1-3% percent of individuals in the U.S. have been diagnosed with mental retardation (The Arc, 2001), and no data exists on the number of individuals with ID who are LGBT; however, best estimates suggest less than one fraction of 1% (Allen, 2003). In one residential agency in the United Kingdom, when two men with ID were found having sex in a shed, the staff members took down the shed (Abbot & Howarth, 2007) instead of appropriately addressing the incident with the individuals. In a residential facility in New Zealand (Hamilton, 2002), agency staff supported a man with ID who was in the process of “coming out” as gay, despite his mother’s denial of his sexual orientation. These are two examples of the failure of caregivers to embrace issues related to LBGT concerns for people with ID.

One organization has simultaneously worked to dismantle stigma and empower individuals with ID who are LGBT. The Rainbow Support Group (RSG) in New Haven, Connecticut, was established in 1998 as a support group for LGBT individuals with ID (Allen, 2003). The group meets for 90 minutes, monthly, and has a core group that ranges from 10 to 20 members, with as many as 50 participants since the group’s inception (Allen, 2003). Members’ ages range from 30 to 50 years old and many report coming out experiences around ages 10 to 15, which is similar to the coming out process for people without disabilities (Allen, 2003).

The group is a testament to the fact that individuals with ID are able to articulate thoughts and feelings related to sexual orientation and gender identity. Members are able to gain support, connect with others, share literature, and engage in activities to support their own liberation. Members report difficulties with courtship and dating, overprotection, judgment, and misunderstanding from parents and caregivers; one member reported intimacy in general was discouraged in his living environment, and opportunities for LGBT individuals were further limited (Allen, 2003). Among the first of its kind in the nation, RSG has served as a model for other groups in Massachusetts, Minnesota, and Vermont (Allen, 2003). Sexuality is a part of every person's experience, regardless of ability and RSG is one outlet that assists individuals with discovery and exploration of sexuality in an environment that is safe, inclusive, and empowering (Allen, 2007). The following section provides information on the role of socioeconomic status as a demographic consideration for individuals with ID.

***Socioeconomic status.*** People with ID are more likely to experience financial difficulties compared to people without disabilities due to limited employment opportunities, lower levels of education, and limited vocational skills (Emerson, 2007). Poverty is also a factor that contributes to the prevalence of ID, including factors such as limited access to prenatal care, malnutrition, and lack of stimulation during early childhood (Emerson, 2007). According to Emerson (2007), families who have a child with ID may be at a greater risk for poverty than parents of children without disabilities, due to costs associated with medical care and ongoing support for their child. In addition to socioeconomic status, location is the final demographic consideration for individuals with ID, discussed in the following section.

***Rural and urban considerations.*** People with ID who live in institutions far from home are at increased risk of sexual victimization (McCormack et al. 2005, Beadle Brown et al. 2010). Access to services in rural areas is limited and individuals with ID are more likely to experience out-of-town placement as opposed to their peers in urban settings. This puts them at increased risk of abuse because family members are less likely to be involved, reducing the amount of support individuals are able to receive from caregivers.

***Sexual abuse and victimization.*** The following section will discuss sexual abuse and victimization of individuals with ID, including the rates of abuse, identification of likely perpetrators of abuse, locations of abuse, risk factors that increase the likelihood of abuse, along with discussion of the mental health implications of sexual abuse of individuals with ID.

***What are the rates of abuse?*** Although the actual prevalence rates vary, Khemka (1997) found among a sample of 94 individuals with ID, over 80% of the female participants and more than 30% of male participants reported past histories of sexual abuse. Khemka and Hickson (2000) found, among a sample of 35 people with ID, 83% of the women surveyed and 32% of the men reported past experiences of sexual abuse. Sobsey (1994) reports children with disabilities are twice as likely to experience sexual abuse, when compared to their non-disabled peers, and women with ID are twice as likely to be abused, regardless of their race, gender or socioeconomic status. Petersilia (2001) reports women with ID are at an even higher risk of abuse, four to ten times more likely to be abused than women without disabilities. Even with the NCVS and other systems, abuse rates of people with ID are largely underreported and the offenders are less likely

to be prosecuted, as opposed to cases involving non-disabled victims of violent crime (Petersilia, 2001).

***Who are the perpetrators?*** McCormack, Kavanagh, Caffrey, and Power (2005) conducted a 15 year study of sexual abuse cases of people with ID in Ireland. The study examined data in 250 reported cases of abuse. Researchers found 94% of perpetrators were male, when gender of the perpetrator was known (McCormack et al., 2005). In a similar study, Beadle Brown, Mansell, Cambridge, Milne, and Whelton (2010) examined 1,926 cases of abuse, with 17% involving sexual abuse from 1998–2005 in England. The researchers found 91% of the sexual abuse cases involved a single male perpetrator (Beadle-Brown et al., 2010). Forty-eight percent of the sexual abuse cases were recorded “as perpetrated by other service users”, meaning other individuals with ID, while 31% of sexual abuse cases listed a family member as the perpetrator (Beadle-Brown et al., 2010, p. 578). Although the exact numbers were not listed, the authors stated few cases of abuse resulted in criminal prosecution (Beadle-Brown et al., 2010).

***Where does the abuse occur?*** Abuse of individuals with ID may occur at home, in day treatment programs, or in residential settings, depending on the individual’s activities within the community. Sexual abuse of individuals with ID may occur during toileting, during transport, and in residential settings.

Beadle Brown et al. (2010) found sexual abuse of individuals with ID is significantly more likely to occur in residential facilities than at home. For individuals with ID who lived in out-of-town placements, rates of abuse nearly doubled at 86% compared to 49% for individuals with ID who resided in facilities closer to home (Beadle Brown et al., 2010). While this study examined almost 2,000 reported cases of abuse of



individuals with ID in England, additional research is needed to collect information regarding locations of abuse of individuals with ID in the United States.

*Why does the abuse occur?* Sobsey and Calder (1999) created a Multifactorial Model of Violence to illustrate the primary factors that increase vulnerability to abuse for individuals with ID. These include victim factors, offender factors, and relationship factors. Victim factors include risk factors that occur as a result of the impairment including limited sexual knowledge, communication difficulties, and possible physical limitations. Offender factors include caregiver corruption, the abuse of power and domination, and the lack of prosecution of offenders by the authorities (Sobsey & Calder, 1999). Relationship factors include limited social skills, lack of support from staff and caregivers, and limited opportunities for pro-social engagement with others. Each of these factors increases the vulnerability to abuse of individuals with ID.

Assessments of sexual knowledge have been used as tools to assess the relationship between ID and vulnerability to sexual abuse. Two studies by Murphy and O'Callaghan (Murphy & O'Callaghan, 2004; O'Callaghan & Murphy, 2007) found adults with ID have limited sexual knowledge compared to young people (ages 16-18 years) without disabilities. The Ireland-based research team (Murphy and O'Callaghan, 2004; O'Callaghan & Murphy, 2007) also found a relationship between sexual knowledge and vulnerability to abuse for adults with ID. In a 2007 study, O'Callaghan and Murphy found adults with ID had limited sexual knowledge compared to a comparison group of young people (ages 16-17 years) without disabilities. The adults with ID did not know there were laws specifically created to protect people with ID from sexual abuse; and they also did not know the laws on rape and sexual assault also extended protection to

people with ID (O’Callaghan & Murphy, 2007). Also, the adults with ID were unaware of the fact that sexual activity with someone under age 16 years is considered illegal (O’Callaghan & Murphy, 2007).

In a previous study conducted in 2004, adults with ID scored lower on assessments of sexual knowledge (the SEX-KEN-ID by McCabe, 1994) and also performed worse on assessments of vulnerability, using vignettes created for the study and quantitative assessments of vulnerability (Murphy & O’Callaghan, 2004). The researchers also found relationships between sexual knowledge and vulnerability to abuse; adults with ID who scored lower on assessments of sexual knowledge also performed worse on assessments of vulnerability to sexual abuse (Murphy & O’Callaghan, 2004; O’Callaghan & Murphy, 2007). These studies are two examples of the importance of sexual knowledge and vulnerability to abuse for individuals with ID. The following section will discuss the mental health implications of sexual abuse for individuals with ID.

***What are the mental health implications?*** The role of clinical assessment cannot be underestimated in the context of ID and sexuality. Individuals with ID are among the most vulnerable victims of sexual abuse (Sobsey, 1994) and the mental health implications of sexual abuse are significant for this population (Matich-Maroney, 2003). Matich-Maroney (2003) used the Prout Strohmer Assessment System (Strohmer & Prout, 1989) and the Psychopathology Inventory for Mentally Retarded Adults (Matson, 1988) to assess several factors related to the mental health of 18 adults with ID who reported past experiences of sexual abuse. Twenty-five adults with ID with no reported history of sexual abuse also participated in the study and completed the same instruments, as a

comparison group. Matich-Maroney (2003) found the adults with past histories of sexual abuse reported significantly higher levels of depression, anxiety, dissociation, sexual maladjustment, and dual diagnosis (MR and a co-occurring psychiatric disorder). Individuals with reported sexual abuse histories were also more likely to have been prescribed psychotropic medication than the comparison group with no reported sexual abuse history.

Although the authors of this study report several limitations including non-random sampling procedures, decreased sample size, and potential confounding variables (some individuals in the comparison group may have experienced sexual abuse but declined to report), the implications for research and practice are far reaching (Matich-Maroney, 2003). The vulnerability of this population to sexual victimization cannot be underestimated (Petersilia, 2001; Sobsey, 1994) and the mental health implications of sexual abuse against individuals with ID are not dissimilar to the effects on people without disabilities (Matich-Maroney, 2003). Additional research is needed to identify effective mental health treatments for sexual abuse survivors, in addition to continual development of effective prevention strategies, such as comprehensive sexuality education and social skills training. Thorough clinical mental health assessment, followed by evidence-based interventions is crucial for individuals with ID who are survivors of sexual abuse and victimization.

Peckham, Howlett, and Corbett (2006) evaluated the effectiveness of a survivor's group for women with ID who survived episodes of sexual abuse. The researchers used five instruments to assess participants' level of trauma, self-esteem, anger, depression, and challenging behavior. Seven individuals (White females with ID) participated in the

survivor's group and their caregivers (also White females) participated in an educational support group. Data was collected at baseline, after the 10<sup>th</sup> session, after the final (20<sup>th</sup>) session, and 12-15 weeks later at follow-up. For the individuals in the support group, levels of knowledge increased significantly. Five individuals experienced reductions in trauma at follow up; however there was no significant difference in self-esteem, levels remained low. Levels of anger were high at the beginning of the group, increased at the end and decreased at follow-up. Levels of depression decreased significantly between baseline and follow up for five individuals. Challenging behaviors also decreased significantly between the 10<sup>th</sup> and 10<sup>th</sup> sessions, and between the 10<sup>th</sup> session and follow-up (Peckham, Howlett, & Corbett, 2006).

One limitation of this study was the small sample size, which reduced the level of power and effect size for the results (Peckham, Howlett, & Corbett, 2006). However, the results of this pilot study add to the limited amount of literature on recovery from sexual trauma for women with ID. Additional research is needed to examine the efficacy of survivors' groups; the practical implications of such studies are significant in the treatment of men and women with ID who have experienced histories of abuse.

While Peckham, Howlett, & Corbett (2005) examined the impact of a survivors group on depression, anger, and self-esteem, Champagne (2007) discussed a model for individuals with ID who suffer from PTSD as a result of sexual abuse. According to Champagne (2007), this type of treatment can only be provided by a skilled clinician who is experienced in treatment of PTSD and who understand the complexities of sexuality and ID. Thorough assessment is needed to identify any co-occurring disorders such as depression, anxiety; referrals for pharmacological treatment may be required for more

severe diagnoses (Champagne, 2007). The importance of trust and rapport cannot be underestimated in the therapeutic relationship; behavioral interventions, clear terminology, and the use of charts and images can increase the likelihood of successful outcomes (Champagne, 2007). One useful suggestion was to divide the traditional 45-50 minute therapy session into three distinct sections where the first 15-minute block is used to review past progress, the second 15-minute segment includes new skills for the session, and the final 15-minute segment includes developing a written or pictorial chart to encourage generalization of skills outside the session.

The previous section described several topics related to sexuality and ID, including historical perspectives, attitudes of caregivers, attitudes of individuals, capacity to consent, demographic considerations, and sexual abuse and victimization. The following section will present a discussion of sexuality education, followed by a more specific examination of sexuality education and ID.

### **Sexuality Education**

The following pages present an overview of sexuality education in the U.S., including an examination of sexuality education for people with ID. This section will conclude with an exploration of commonly used curricula and best practices, including a discussion of past, current, and future trends in sexuality education for individuals with ID.

**History of sexuality education.** In addition to an overview of society's views toward sexuality and ID, the historical progression of sexuality education in the U.S. is also worth noting. Schroeder and Kuriansky (2009) provide an overview of the history of sexuality education in the U.S. that dates back to the 1900s. During this time, sex

education was largely behavioral and the primary emphasis of was to change reduce the spread of venereal disease (VD) and the number of unwanted pregnancies. Note the use of language; “sex” as opposed to “sexuality” illustrates the emphasis on biological aspects of sexuality, including harm reduction and disease prevention. In 1905, a physician, Dr. Prince Morrow founded the American Society of Moral Sanity and Prophylaxis to increase awareness on the harmful outcomes associated with premarital sexual activity. During this time, sex was only acceptable in the context of marriage, and only for purposes of procreation. There was no discussion of activities such as masturbation or sex of pleasure. Dr. Morrow’s society was influential in shaping society’s beliefs toward sex and sexuality (Schroeder & Kuriansky, 2009).

As early as 1913, attitudes toward sex began to shift (Schroeder & Kuriansky, 2009). During 1913, the first school-based sex education program began in Chicago and Thomas Galloway, an early advocate of comprehensive sexuality education, began to challenge society’s repressive attitudes towards human sexuality. In 1916, Maurice Bigelow published the first article on sex education and in the same year, the first birth control clinic in the U.S. was opened, Planned Parenthood founded by Margaret Sanger, which allowed women to access legal methods of contraception. In 1918, the Chamberlain Kahn Act was passed, which provided federal funding for school-based sex education methods, using primarily biological components teaching about VD, pregnancy, and other aspects of sexual health and reproduction (Schroeder & Kuriansky, 2009).

The 1920s and 30s, around the time of the Great Depression and the beginning of World War II, society’s attitudes toward sexuality experienced another shift. This time

period was marked by increased rates of juvenile delinquency, a rise in prostitution, a decline in the number of marriages, and a general rebellion against legislated morality (Schroeder & Kuriansky, 2009). In the 1920s, 40-45% of all public schools offered some form of sex education, beginning in 8th grade (Schroeder & Kuriansky, 2009). The 1940s and 1950s were somewhat less active in terms of sex and sexuality, although the first issue of Playboy magazine was published in 1953 as a slightly less formal method of sex education for the general public. During the 1960s, the Federal Drug Administration approved the birth control pill as a method of contraception, and SIECUS was founded in 1964 by Mary Calderone, with the original name of Sex Information and Education Council of the U.S.; the name was later changed to “Sexuality” to reflect a more holistic view towards human sexuality (Schroeder & Kuriansky, 2009).

The 1970s was marked with further progress, including the passage of Roe vs. Wade, which legalized elective abortions and increased reproductive rights for women. In the 1980s, there was a rise in conservatism, which marked another shift in society’s attitudes, including important legislation signed by the Reagan administration. In 1981, the Adolescent Family Life Act provided federal funding for abstinence-only until marriage (AOUM) in public schools. The trend of AOUM continues, although in 2010, Congress passed the Personal Responsibility and Education Planning (PREP) Act, which also funded AOUM initiatives, but included an emphasis on healthy relationships and the other socio-emotional components of sexuality, including intimacy, dating, and marriage.

After critical examination of the history of sexuality education in the U.S., for all children, there is still much work to be done. A report published by SIECUS in 1996, using data collected by the National Guidelines Task Force on Sexual Health, provides

the following statistics: 90% of parents surveyed were in favor of sexuality education for their children; 23 states mandate sexuality education in public schools; 13 other states encourage sexuality education in public schools; over 90 organizations were in favor of comprehensive sexuality education for all children; however, only five percent of all children in the U.S. received any form of sex education in a school setting (SIECUS, 1996). Although the U.S. is moving towards more comprehensive methods of human sexuality education, much work remains to be done, especially in regards to children with disabilities.

**Sexuality education and ID.** How has society favored in terms of sexuality education for children with disabilities, specifically ID? As early as the 1960s, there were efforts to reduce the number of individuals with ID who lived in institutions and other segregated facilities (Schroeder & Kuriansky, 2009; Wade, 2002). During this time, parents, educators, and other stakeholders advocated for protection for individuals as they returned to the community. In 1975, Warren Johnson, one of the earliest advocates in favor of sexual health and rights of people with ID, published work on three distinct views toward sexuality and ID: eliminate, tolerate, cultivate.

Historically, people with disabilities were discouraged or prohibited from expressing themselves sexually; parents and others worked diligently to prevent or eliminate any forms of sexual expression (Johnson, 1975). The second wave, which occurred largely during Johnson's time, involved parents and others who tolerated the sexual expression of people with ID (Johnson, 1975); the ultimate goal of Johnson's efforts included cultivation of healthy sexuality for people with ID. The passage of legislation such as the Rehabilitation Act of 1973, the Education for All Handicapped



Children Act of 1975 (now referred to as IDEIA – Individuals with Disabilities Education Improvement Act of 2004), and the Americans with Disabilities Act of 1990 has done little, if anything, to address the holistic sexuality needs of children and adults with disabilities. Although IDEIA has done much to improve special education in the U.S., the document is void of any content related to sex or sexuality education for children with disabilities.

Individuals with ID engage in sexuality education for a variety of reasons; however limited literature suggests the primary goals are to decrease vulnerability to victimization or to correct inappropriate sexual acting out behavior (McCarthy, 1996). McCarthy (1996) found of 185 individuals with ID referred for sexuality education in England, the 65 women in the sample were mostly referred due to concerns of vulnerability to abuse, while the 120 men in the sample were referred for sexually inappropriate behavior. The majority of referrals were made by staff, with few self-referrals, although the exact number is not listed in the study (McCarthy, 1996). Approximately half of the women in the sample of the women reported engaging in sexual activity, although they lacked interest (McCarthy, 1996). The men in the sample were significantly more likely to engage in same sex intercourse than the women in the sample (McCarthy, 1996). Twenty-nine percent of the men in the sample participated in “cottaging” behavior, described as sex in public toilets with other men (McCarthy, 1996). Considering these primary reasons for referrals to sexuality education, the following paragraphs will discuss curricula and best practices, psychoeducational prevention strategies, the use of visual tools, and past, present, and current trends in sexuality education for individuals with ID.

*Curricula and best practices.* The current status of sexuality education in the U.S., for all children, has been critiqued as “too little, too late” (SIECUS, 1996). Weaver, Smith, and Kippax (2005) found teenagers in the U.S. have higher rates of shame, higher rates of unwanted pregnancies, and increased rates of sexually transmitted diseases (STDs), when compared with their same-age peers in the Netherlands, France, and Australia. Further, the current methods of sex education leave children with disabilities at increased risk of victimization, compared with their peers (Gill, 2007). Children with disabilities, specifically ID, are at a disadvantage because of lower sexual knowledge (Murphy & O’Callaghan, 2004), limited opportunities for healthy sexual expression (Gill, 2007), and limitations that co-occur as a result of the disability (e.g., limited communication abilities, inability to recognize danger, inability to resist and accurately report abuse) (Petersilia, 2001). Comprehensive sexuality education is one method that has been proposed as a means of protecting children with ID from abuse, while also teaching skills related to healthy expressions of sexuality.

Researchers and practitioners have designed curricula to help fill in gaps in knowledge and skills to increase healthy sexual expression and decrease vulnerability to abuse for children with ID. Examples include the CIRCLES Curriculum (Champagne & Walker-Hirsch, 1993), No-Go-Tell (Schwier, 2000), and Go-Slow-Stop, developed by Planned Parenthood. Ideally, parents serve as a child’s first educators, and children with ID and DD are no exception. Although there are specific toolkits available, the major themes in the literature on sexuality education for children with ID and DD center on the appropriate content, including what to teach and when to teach it, and effective teaching and evaluation methods. Gill (2007) offers the following prompts as suggestions for

selecting appropriate curricula to teach children with ID and DD about issues related to sexuality: Is the content value-laden? Is there a discussion of the emotional aspects of sexuality? What are the methods of evaluating learning? Can accommodations be made for children with different abilities? Is the content holistic in scope? Is there a discussion of abuse prevention? These questions, among others, can be useful in assisting parents, educators, and counselors with selection of appropriate tools to teach children with ID about human sexuality.

Schwier (2000) offer the following four stages of parenting as a model of teaching children with ID: Hold Me Tight, Put Me Down, Leave Me Alone, and Let Me Go. The first stage of parenting, Hold Me Tight, describes those infant years where healthy attachment begins to develop between the child and primary caregivers (Schwier, 2000). While this stage may be difficult due to the nature of the child's disability, it is important for parents to encourage healthy interaction in environments that are safe, engaging, and stimulatory to encourage healthy development. The second stage of parenting, Put Me Down, describes the toddler and early childhood years, where children typically begin to interact more independently with their environment (Schwier, 2000). At this age most children enter school settings, such as Head Start, Pre-Kindergarten, or daycare settings; Schwier (2000) suggests parents begin to teach children to name body parts, explain where babies come from, teach the difference between good touch and bad touch, the meaning of privacy, and discuss the differences between boys and girls. During the Leave Me Alone stage, which includes older children and pre-teen/teenage years, Schwier (2000) encourages parents to discuss reproduction, puberty, the difference between love and sex, masturbation, wet dreams, and how babies are made. The final stage of

parenting, *Let Me Go*, takes place during late adolescence where the focus is on healthy relationships, safe sex practices, child birth and childrearing, and other aspects of preparation for adulthood (Schwier, 2000).

Koller (2000) reminds caregivers, staff, and parents to be realistic about the skills they teach; for example, youth and adults with more severe disabilities who reside in permanent residential settings may need increased focus on safe and appropriate masturbation techniques, with limited discussion of relationships. On the contrary, youth in community settings may need increased training related to boundaries with peers, family members, and others in the community. The CIRCLES curriculum (Champagne & Walker-Hirsch, 1993) is one widely-used method that has been used to teach children and adults with disabilities about social boundaries. The five circles, from smallest to largest, include the close hug circle, big hug circle, handshake circle, wave circle, and danger circle. Individuals can use actual photos and other visual tools to demonstrate who is allowed to enter each circle. Examples include family members and intimate partners in the “close hug” circle; teachers, staff and other caregivers in the “big hug” circle; members of the community in the “handshake” circle, if you know their name; and so on. Although the circles will vary for each individual, one principle guides the curriculum: the individual is at the center of her or his own circle and has the power to decide who has permission to enter. Also, fewer people are allowed in the circles, as you move towards the center; this helps children with disabilities understand many more individuals are strangers, and fewer people are considered close and intimate friends (Champagne & Walker-Hirsch, 1993).

In addition to CIRCLES, two other methods of sexuality education are widely used for children with ID; these include “Go-Slow-Stop” by Planned Parenthood and No-Go-Tell by Schwier (2000). Both of these methods focus on building assertiveness skills and increasing an individual’s ability to recognize and flee potentially dangerous situations. Both of these can be offered in group or individual settings. The “Go-Slow-Stop” method, by Planned Parenthood, uses scenarios, which may be generated by the participants or by the instructor. Also, a stoplight (real or re-created using construction paper or other visual methods) is used to identify situations that are safe (green light – Go), situations to proceed with caution (yellow light – Slow), or situations that could be dangerous (red light – Stop). The conversation during the activity includes discussion of appropriate and inappropriate behavior, and helps individuals process reactions to situations they may have faced in the past or could potentially encounter in the future. No-Go-Tell (Schwier, 2000) is a similar type of activity that teaches individuals to refuse to comply with an inappropriate request (say “No”), to leave a situation that is unsafe (“Go”), and to break a promise not to report abuse (“Tell”). Although these steps may appear simple, they could present challenges for individuals who have been taught to always comply with orders as instructed.

These three curricula are but a sample of methods used to increase the sexual knowledge and decision-making skills of children with ID. Each of these has strengths, including focus on boundaries, increasing assertiveness skills, and prevention of abuse; however one method can never be all-inclusive. One model, created by Annon (1976) helps professionals and parents identify the level of need once an individual with ID faces a specific situation related to sexuality, such as masturbating in public or after

experiencing an episode of abuse. Six steps are involved: 1) preparation, 2) identify the most basic need, 3) set a goal, 4) teach new skills, 5) measure and evaluate progress, and 6) repeat and reinforce (Annon, 1976). The PLISSIT (Permission, Limited Information, Specific Suggestions, Intensive Treatment) model uses an inverse triangle to guide professionals and parents with selection of appropriate interventions. The wide base of the triangle, at the top, includes Permission, which all people with ID need. This involves understanding about consent, appropriate behavior, and legal and related sexual activity. The next step, which less people need is Limited Information; this includes information specifically related to the situation at hand and may not require professional intervention. Specific Suggestions, are more detailed and relate to learning new skills to reduce likelihood of further victimization or to reduce further acting out behavior. Intensive Treatment is the last step, which the least amount of people need, depending on the nature of the situation. This model is useful in conceptualizing appropriate interventions and identifying level of need for people with ID who have experienced a situation related to sexuality.

As discussed previously, effective sexuality education is comprehensive and lifelong, beginning at birth (SIECUS, 1996) and requires an entire community of educators including parents, P-12 teachers, counselors, medical doctors, and so on. As a parent of a child with a disability and one of the most often cited sources on sexuality and ID, Sobsey (1994, 1999) offers several recommendations for effective sexuality education for children with ID. These and other recommendations for parents, educators, and parents, are listed below.

Pownall, Hastings, Jahoda, and Kerr (2011) conducted a qualitative study with a small group of mothers of children with various types of ID (e.g., cerebral palsy, Down syndrome) who also had children without disabilities. The mothers were much more comfortable addressing issues related to sexuality with their non-disabled children as opposed to their children with ID. The mothers wanted to prolong sexual activity as long as possible, were generally in favor of sterilization and expressed less favorable attitudes towards the possibility of their children with ID getting married or having their own children. One mother thought her son with ID would learn about sexuality by listening to conversations she would have with his brothers, as opposed to speaking to him directly (Pownall et al., 2011). This study is one example of the difficulties faced by children with disabilities, in terms of sexual information and opportunities for sexual expression. To counter these biases and beliefs, Sobsey (1994) encourages parents to seek support, and focus on opportunities to have fun with their children with ID. Sobsey also encourages parents to begin discussions related to sexuality at an early age, as opposed to waiting until puberty. When parents are able to set aside their own biases and judgments, they are able to create a safe environment in order to cultivate healthy sexual expression (Johnson, 1975).

Gill (2007) encourages educators to set aside their biases as well, and offers suggestions such as “Fuck You Bingo”, a game that uses street language to decrease stigma associated with talking about sex and related issues. Gill notes the harmful effects of stigma and notes much of the curricula for children in general, and children with ID in particular, are heterosexist and fail to discuss variations in ability, sexual and gender identity, and sexual orientation. Counselors, educators, and parents are

encouraged to bracket their own biases and introduce material that is relevant and diverse in terms of its presentation and the topics covered. More research is needed to assist in the development of materials that depict people with varying skin tones, diverse family and relationship constructions, and more accurate depictions of sex organs. For example, Gill notes in most materials, the clitoris is absent from pictures of women's bodies. These depictions are rooted in historical influences that de-emphasized the role of pleasure in sexual experiences, a conversation that remains limited even today. Many educators, parents and other professionals would argue in favor of supporting children with ID so they can live healthy, productive lives. How can we say we are working toward this goal when we deny opportunities for healthy sexual expression? All individuals are sexual beings and to deny this opportunity for children with ID not only increases their vulnerability to victimization, it also denies them of one of the most integral components of the human experience.

In order to adequately manage risks while also supporting healthy sexuality of individuals with ID, Rose & Rennie (2007) offer recommendations for agencies, the public, family members, and clients (individuals with ID). Failure to adequately address issues related to sexuality actually increases the risks and potential for negative outcomes, whether the individual is in an agency or community setting (Rose & Rennie). Individuals with ID have the same feelings and desires of people without disabilities, however family, agency, and caregiver perceptions regarding relationships, marriage, parenting, and sexual activity send messages that such life roles are out of reach (Ailey, Marks, Crisp, & Halm, 2003). For example, while most people with or without ID enjoy physical contact with a consenting partner, in residential facilities in New York, physical



contact between individuals with ID is limited to hand-holding and friendly hugs (Rose & Rennie, 2007). False perceptions regarding sexuality and ID result in social isolation and limited opportunities for healthy sexual expression. In extreme cases, individuals may internalize the false messages and believe they do not have a right to healthy, consensual sexual expression.

To combat these misconceptions and break the cycle of social withdrawal, Rose and Rennie (2007) offer the following suggestions for agencies, professionals and staff, family members, and clients. Agencies are encouraged to fulfill their missions to promote client well-being by increasing staff competency in sexuality issues and developing policy that effectively addresses all aspects of sexuality, including education, prevention of abuse, and establishment of ethics and client rights boards to handle violations of agency policy (Rose & Rennie). Direct Support Professionals (DSPs) are encouraged to follow their code of ethics, as outlined by the National Alliance for Direct Support Professionals, and maintain high standards of practice that incorporate basic training in sexuality education, as appropriate depending on the age and development of the client (Rose & Rennie, 2007). Family members are encouraged to take an “eyes wide open” approach and acknowledge their children’s sexuality. Parents should serve as their child’s first teacher, especially in terms of topics related to human sexuality. Lastly, but most importantly, clients are encouraged to confront any fears and serve as their own advocates by taking an active role in their sexual emancipation (Rose & Rennie, 2007).

***Psychoeducational prevention strategies.*** While the studies listed above discuss curricula and best practices in sexuality education for individuals with ID, there is also literature focused on skills training and prevention of abuse. Khemka (2000) has

conducted several studies examining the decision-making capacities of individual with ID, in terms of identifying and choosing effective responses in simulated situations of abuse (Khemka & Hickson, 2000; Khemka, Hickson, & Reynolds, 2005). The Khemka studies use the Socio-Interpersonal Decision-Making Video Scale (Khemka, 1997) to assess the decision-making skills of men and women with ID. One study (Khemka & Hickson, 2000) found individuals with ID are able to accurately identify and define the problem in situations involving physical, sexual, and psychological/verbal abuse; the percent correct ranged from 86% to 97% for the various scenarios.

In a different study, Khemka (2000) found women with MR are able to exhibit more effective decision-making skills after participating in a self-directed training group that included both cognitive and motivational components when compared to women who participated in a decision-making training that included only cognitive components. The women in the self-directed training group also scored significantly higher than women who received no decision-making training, and participated only in traditional sex education. The women in the self-directed training group also had a significantly more internal locus of control than the women in the other two groups, as measured by scores on the Nowicki-Strickland Internal-External Scale (Nowicki & Duke, 1974).

Yet another study by Khemka and her research team evaluated the effectiveness of the ESCAPE curriculum on abuse prevention and empowerment of women with mild and moderate MR (Khemka, Hickson, & Reynolds, 2005). ESCAPE, developed by the researchers, is comprised of 12 interactive lessons and 6 support groups, each 40-50 minutes in duration, with small groups of about three participants. Using the same Decision-Making Video Scale, along with several other instruments the ESCAPE

curriculum was found to be effective in three of four outcome measures, including knowledge of abuse, empowerment, and decision-making (Khemka, Hickson, & Reynolds, 2005). In addition to prevention strategies, clinical mental health assessment, and treatment interventions, the use of visual tools in reporting abuse is another aspect of this issue that has been examined in the literature related to sexuality and ID.

**Visual tools.** Sexuality and disability for individuals with ID is a complex issue comprised of multi-faced components such as assessment of sexual knowledge, mental health implications of sexual abuse, mental health treatment of sexual abuse, and the forensic aspects of reporting abuse. Limited ability or inability to report abuse is one factor that increases the vulnerability to victimization for this population (Petersilia, 2001; Sobsey, 1994). Researchers have advocated for the use of visual tools (i.e. live models, anatomical dolls and pictures) in cases involving sexual abuse of adults with ID in order to increase the accuracy of such reports (Lunsky & Benson, 2000; Valenti-Hein, 2002). The use of visual tools is common in cases involving young children without disabilities; however, the efficacy of these tools has been cautioned for use with children less than five years of age (Smith & DeLoache, 1995) due to an inability to adequately recognize the relationship between symbols and the object the symbol is intended to represent. This cognitive process, referred to as dual representation is a skill often acquired in children without disabilities around 36 months of age and is a skill that many adults with more severe ID lack (Lunsky & Benson, 2000; Smith & DeLoache, 1995).

Limited research on the efficacy of visual tools with the ID population was the impetus for experimental studies by Lunsky and Benson (2000) and Valenti-Hein (2002). In their hypothesis, Lunsky & Benson (2000) doubted the effectiveness of visual tools

with individuals with more severe ID. In a Columbus, Ohio study, the researchers replicated a study by Smith & DeLoache (1995) with minor modifications. The researchers used anatomically detailed Hyland dolls and anatomically-detailed Groth drawings. The study contained five conditions: 1) doll-to-doll, 2) self-to-self, 3) pic-to-pic, 4) self-doll, and 5) self-to-pic. In each of the five conditions, the researcher placed a sticker on the participant, the doll, or the picture (e.g. on the leg, elbow, foot) and the participant was instructed to place a sticker on the same body part on him/herself, on the doll, or on the picture, depending on the condition. The first three conditions were copying tasks while the final two conditions involved dual representation (Lunsky & Benson, 2000).

Using a repeated-measures 3 X 5 ANOVA (3 cognitive levels: borderline/mild, moderate, and severe; and 5 conditions), the researchers found no significant main effect for the doll-to-doll condition (Lunsky & Benson, 2000). However, individuals with severe ID performed significantly worse in all four of the other conditions, while individuals with borderline/mild ID were able to complete tasks using dolls and drawings with 90% accuracy (Lunsky & Benson, 2000). The results from this study indicate visual tools may not be appropriate reporting methods for adults with more severe ID; however dolls appear to be better options than pictures or drawings. Future research could examine the effectiveness of visual tools for individuals with ID who report past histories of sexual abuse; this question was not included in the scope of this study. The authors also offer training as an option to increase the dual representation skills of individuals with severe ID (Lunsky & Benson, 2000).

A similar study using visual tools was conducted by Valenti-Hein (2002). This study used a smaller sample than Lunsky & Benson (2000) with 30 adults as compared to 68; the study also used Groth pictures and anatomically detailed dolls. The study used a 2 X 3 X 2 ANOVA with two levels of ID (mild and moderate), three types of visual tools (live models, dolls, and pictures), and two response types (verbal and performance). Similar to the method used in the Lunsky and Benson (2000) study, the researcher placed a sticker on the live model, doll, or picture. In contrast to Lunsky & Benson (2000), the Valenti-Hein (2002) study included two types of responses; participants were asked to tell the researcher where the sticker was located (verbal) and were then asked to place a sticker on the corresponding body part on themselves, the doll, or the picture (performance).

In analysis of the data, researchers found no significant differences between response type for individuals with mild MR; verbal and performance responses proved equally effective (Valenti-Hein, 2002). For individuals with moderate MR, performance responses were more accurate than verbal responses and accuracy increased significantly with live models as opposed to dolls or drawings. For both groups, accuracy in reporting improved with the use of live models. However, there seemed to be some difficulties with generalization and body part identification for all participants; the researchers suggested sex education programs return to the basics to increase these skills for adults with ID (Valenti-Hein, 2002). Limitations of this study include small sample size and the exclusion of individuals with more severe ID. The Lunsky & Benson (2000) and Valenti-Hein (2002) studies provide several implications for forensic investigation and sex education for individuals with ID.

***Past, current, and future trends.*** Among practitioners and scholars familiar with sexuality education for individuals with ID, three names are likely to emerge from discussions: Kempton, Carmody, and Hingsburger. Over the past several decades these individuals have created innovative tools including videos, curricula, and even the establishment of non-profit organizations to promote healthy sexual development of individuals with ID. The following paragraphs will summarize the groundbreaking, yet sometimes controversial, accomplishments of these individuals in terms of past, current, and future trends related to sexuality education for individuals with ID.

In the 1970s, scholar and practitioner Winifred Kempton, Educational Director of Planned Parenthood in Southeastern Pennsylvania from 1969 to 1980, developed sexuality education curricula for individuals with disabilities, including those she referred to as “mentally handicapped” (e.g., Kempton, 1973; Kempton & Stigall-Muccigrosso, 1980). Prior to her death in August of 2010, at age 92, Kempton was the author of such texts as *Love, Sex, and the Mentally Retarded*, published in 1979 by Planned Parenthood. Kempton also advocated for inclusion of individuals with severe cognitive limitations in sexuality education programs. Kempton was critical of many programs at the time, classifying them as “skimpy, fragmentary efforts” that failed to address issues other than unwanted pregnancies, AIDS, and abuse (Kempton & Stigall-Muccigrosso, 1980, p. 209).

In 1988, Mary Ann Carmody founded Choices, Inc., a non-profit organization that produces sexuality education films for individuals with ID and other developmental disabilities. In the 1990s, Carmody produced three well-known sexuality education films cast with individuals with ID as actors, including *Person-to-Person* (1991), *Roots and*

*Wings* (1995), and *Making Connections* (1995), which are available for purchase at [www.choicesinceducationalvideos.org](http://www.choicesinceducationalvideos.org).

In the following decade, Dave Hingsburger produced three book and video sets on sexuality and ID and DD, including *Under Cover Dick* (2000), *Finger Tips* (2000), and *Hand Made Love* (2000). Hingsburger's productions were more controversial than his predecessors because he focused on topics such as male and female masturbation as forms of self-pleasure. The kits, published by Diverse City Press in Ontario, Canada, include step-by-step guides for condom use and masturbation. These videos are listed on virtually every reputable resource list for sexuality education and ID.

While several of the materials listed above are currently used by agencies such as Planned Parenthood who provide sexuality education training for individuals with ID, there remains a need for more relevant materials that address holistic aspects of sexuality for individuals with ID. Future trends in sexuality education and ID could include discussion of LGBT and related concerns (Abbott & Burns, 2007), legal and ethical implications associated with consensual and nonconsensual sexual activity, alternative sexual practices and behaviors (Reynolds, 2007), and inclusion of individuals with ID from diverse racial and ethnic backgrounds in educational videos and curricula. The previous section provided a discussion of sexuality education and ID, and the following pages will discuss peer-to-peer safety and sexuality training as one method of teaching individuals with ID to protect themselves from abuse and victimization.

### **Peer-to-Peer Safety and Sexuality Training for Individuals with ID**

Although limited research provides information on peer-to-peer training programs for individuals with disabilities, specifically on topics of safety or sexuality, there is

currently no published research on peer-to-peer safety and sexuality training specifically targeted for individuals with ID. An extensive search of research databases (e.g., ERIC, PsycInfo) yielded only three articles related to peer-to-peer safety or sexuality training for individuals with disabilities, described below.

Orzek (1984) advocates in favor of peer-to-peer support groups for college students with learning disabilities. Bullard and Wallace (1978) document a peer-to-peer sexuality training program for adults with physical disabilities. Utley, Reddy, Delquadri, Greenwood, Mortweet, and Bowman (2001) conducted an empirical study that found class-wide peer tutoring to be an effective method of instructional delivery of a health and safety educational curriculum for elementary school-age students with DD. A description of each of these studies is provided below.

The National Institute of Mental Health provided grant funding to the Human Sexuality Program at the University of California in San Francisco (UCSF) in 1976, with the goal of training “disabled and non-disabled persons as socio-sexual educator-counselors for disabled persons, their spouses, intimates, and families; and health care providers and agencies” (Bullard & Wallace, 1978, p. 147). The duration of the training was one calendar year, provided by the supervisor and staff of The Sex and Disability Training Project at UCSF (Bullard & Wallace, 1978). Nine individuals were chosen to participate in the program as trainees from a pool of 38 applicants; the group of nine included four men and five women ages 22 to 44 (Bullard & Wallace, 1978). Seven of the trainees had physical disabilities, including multiple sclerosis, cerebral palsy, post-polio, and spinal cord injury; six of the seven trainees used wheelchairs to assist with



mobility (Bullard & Wallace, 1978). The staff that provided the training also included individuals with and without disabilities.

The nine trainees had varying levels of previous counseling experience, ranging from “minimal to master’s degree level” and the staff who provided the training “included a clinical psychologist, a marriage, family, and child counselor, a social worker, a consulting physician, and a consulting psychologist for evaluation” (Bullard & Wallace, 1978, p. 150). The training included a didactic phase and a practicum phase. The didactic phase included 16 hour per week session during the first five months of the program covering topics in “basic counseling, sex education and counseling, and disability and medical information” (Bullard & Wallace, 1978, p. 150). The didactic phase of the training was delivered using nine methods of instruction:

1. Didactic presentation
2. Small group experience for personal growth
3. Role playing of counseling issues
4. Co-counseling of actual clients and staff
5. Individual research papers on topics of interest
6. Personal journals
7. Speaking in panels at various workshops
8. Participation in intensive weekend workshops (totaling over 75 hours)
9. Outside reading of four hours per week. (Bullard & Wallace, 1978, p. 150)

The practicum phase of the training was seven months in duration, although trainees and staff continued to meet weekly for ongoing didactic training components, listed above (Bullard & Wallace, 1978). Staff also supervised trainees’ work at field

placements, which included “four rehabilitation hospitals, three independent living centers, a disabled students’ program, and a cooperative residential center for disabled persons” (Bullard & Wallace, 1978, p. 150).

The services provided by the trainees included consultation, in-service presentations to clients and staff, and short-term psycho-educational counseling with clients (Bullard & Wallace, 1978). This group of trainees received positive evaluations (i.e., “moderately-to-extremely satisfied”) for the counseling and education they provided to clients, according to feedback provided by the staff who trained them (Bullard & Wallace, 1978, p. 149). In addition to being evaluated by staff on the grant, trainees also completed self-assessments, rated other trainees’ performance, and received formal evaluations from agency staff and clients at their respective field placement sites (Bullard & Wallace, 1978). Although Bullard and Wallace (1978) included only two comments from agency staff evaluations in their article, the feedback was positive, indicating agency staff “became more comfortable in discussing sexual issues” and “It is the first time in the history of our institution that human sexuality has been openly recognized as part of the totality of rehabilitation” (Bullard & Wallace, 1978, p. 152).

While Bullard and Wallace (1978) describe a peer-to-peer education and counseling program for adults with physical disabilities, Orzek (1984) discusses the importance of peer support groups for college students with learning disabilities (LD), described below. As a conceptual argument as opposed to a research article, Orzek (1984) describes peer support groups as potentially beneficial for college students with LD. Citing legislation such as the Education for All Handicapped Children Act (later renamed IDEIA) and Section 504 of the Rehabilitation Act of 1973, the author provides a

brief list of LD diagnoses recognized under federal law, including brain injury, dyslexia, and minimal brain dysfunction syndrome (Orzek, 1984). The definition of disability under Section 504 of the Rehabilitation Act of 1973 is more broad than the definition listed in IDEIA and students who may not qualify for an IEP under IDEIA may be eligible to receive services through creation of an individualized document referred to as a 504 plan (NICHY, 2012). Under Section 504, an individual with a disability is defined as defined as a person “with a physical or mental impairment which substantially limits one or more major life activities” (U.S. Department of Health and Human Services, 2006). Because this legislation entitles children with disabilities, ages three to 21, to a free and appropriate education, many students with LD diagnoses are eligible to receive accommodations from state universities receiving federal funds (Orzek, 1984).

Orzek (1984) uses Chickering’s (1969) seven-vector model of young adult development as proposed components of a peer support group program for college students with LD. Each of Chickering’s (1969) seven vectors of development contains a specific direction and magnitude, meaning development could progress or regress, in varying degrees. In his theoretical argument, Orzek (1984) uses the seven vectors to identify possible areas of concern for this population of young adults, including developing competence, managing emotions, developing autonomy, establishing identity, freeing interpersonal relationships, clarifying one’s purpose in life, and developing integrity (Chickering, 1969). Orzek (1984) suggests counseling or disability service agencies on college campuses could sponsor such peer support groups to aid in the successful development of students with LD on their respective campuses.

While Orzek (1984) argues in favor of peer support groups for college students with LD, Utley et al. (2001) describes a class-wide peer tutoring model (CWPT) to teach health education and safety facts to elementary students with DD. CWPT is an alternative teaching method with an interactive game format that uses a four-part model of instruction, with behavioral components, to provide multiple opportunities for students to participate and respond in class (Delquardi, Greenwood, Stretton, & Hall, 1983). The four parts of the model include the following: first, the teacher facilitates instruction, with verbal and written components; second, students are divided into pairs and complete tasks with one student serving as the tutor and one serving as the tutee; third, the student tutor provides corrective feedback to the tutee; and fourth, individual reinforcement is provided by the tutor to the tutee and team reinforcement is provided by the teacher to all student pairs (Utley et al., 2001).

The purpose of the study was to “determine the effectiveness of CWPT on the acquisition and comprehension of names of body parts, body functions, poisons, dangerous situations, and drugs and their effects”, using a health and safety curriculum provided by the school district (Utley et al., 2001, p. 4). The authors conducted a quasi-experimental study using a self-contained classroom of five second-grade students with DD (Utley et al., 2001). Three students were Black and two were Caucasian; students’ ages ranged from seven to nine years old; IQ scores ranged from 52 to 57 on the Wechsler Intelligence Scale for Children-Revised and the Stanford-Binet Intelligence Scale, indicating the presence of co-occurring ID (Utley et al., 2001).

To summarize the results of the study, baseline scores collected at the beginning of the study revealed percentages lower than five percent for four students, with one

student scoring 20% on assessments of health and safety, using content from the curriculum (Utley et al., 2001). However, using CWPT methods, students scored 92% and above on weekly assessments (Utley et al., 2001). Students also scored higher on weekly assessments using CWPT when compared to traditional teacher-led instruction, with scores of 85% or above with CWPT compared to 20% or below with traditional methods (Utley et al., 2001). The researchers attributed these results to the underlying principles of CWPT as a model of instruction, including immediate feedback, team competition, and error correction (Utley et al., 2001).

These studies have several implications for the current case study on peer-to-peer safety and sexuality training for individuals with ID. Although different in their purpose and scope, the results from the limited available published literature reveal peer-to-peer training as an effective educational tool for people with disabilities, specifically adults with physical disabilities and children with DD, for topics related to sexuality and safety, respectively (Bullard & Wallace, 1978; Utley et al., 2001). In addition, the researcher used these studies to critically analyze the methods of instruction used to deliver the peer-to-peer safety and sexuality training observed in the current case study. The authors of the articles summarized above advocate for the use of behavioral methods of instruction (Utley et al., 2001), inclusion of key topics (Orzek, 1984), and solicitation of feedback from program participants (Bullard & Wallace, 1978). The researcher examined the methods of instruction used in the current case study, in comparison to the strategies described in the literature. The researcher also examined the preparation of the peer-to-peer safety and sexuality trainers at the TALL Institute, compared to the trainee preparation described in Bullard and Wallace (1978). The trainees in Bullard and Wallace

(1978) engaged in one year of intensive preparation, including five months of didactic training and seven months of supervised practicum experiences, prior to providing peer counseling and sexuality education for individuals with physical disabilities. The researcher compared and contrasted the training preparation of the peer-to-peer safety and sexuality trainers, in light of similar training discussed in limited available published literature (Bullard & Wallace, 1978).

Although each of the three articles cited above provides critical information on peer-to-peer support (Orzek, 1984), education and counseling (Bullard & Wallace, 1978), and tutoring (Utley et al., 2001) on topics related to safety or sexuality for individuals with disabilities, the studies also have two limitations that are important to consider. First, two of the three articles describe research that was conducted in the 1970s and 1980s, indicating a need for more current research on peer-to-peer support and education for individuals with disabilities. Second, none of the studies above documents the experiences of the individuals who serve as peer-to-peer educators, counselors, or tutors or provides in-depth information on the curricula used for the trainings. Two of the articles present research that was collected using quantitative methods which limited the breadth and depth of information the researchers were able to collect.

The current case study presents a detailed picture of a peer-to-peer safety and sexuality training program for individuals with ID. The findings provide novel insights on safety and sexuality peer-to-peer training for individuals with ID, from multiple perspectives, including individual interviews with trainers, observations of training presentations, and a document analysis of the curriculum. The case study centers on the voices and experiences of peer-to-peer trainings and the researcher makes connections

between the data and relevant literature and theory. The research conducted in this case study is an initial attempt to describe and analyze a peer-to-peer safety and sexuality training program for individuals with ID, with the intent of decreasing vulnerability to victimization for members of this population. Implications for research, policy, and practice are also provided as lessons learned.

### **Summary**

This chapter provided a broad overview of literature relevant to the research that was conducted in the current study. Divided into five broad categories, the chapter began with a discussion of ID; followed by a discussion of sexuality and disability, in general; sexuality and ID, in particular; sexuality education; and concluded with literature related to peer-to-peer safety and sexuality training for individuals with ID. The next chapter will describe the methodology for the current case study.

### **Chapter 3: Methodology**

This chapter describes the methodology that was used in the current study. This chapter provides an overview of the rationale for selecting the methodology, the research design, the setting for data collection, including site selection, the sampling strategy and recruitment of participants, data collection methods, and data analysis techniques. The chapter concludes with consideration of ethical issues raised in the study and a discussion of the researcher as the instrument of data collection, analysis, and interpretation. The current study used qualitative methodology to answer three central research questions: 1) What is the peer-to-peer safety and sexuality training program at The TALL Institute? 2) How do students at The TALL Institute describe their experiences as peer-to-peer health, safety, and sexuality trainers for individuals with ID? 3) How do students at The TALL Institute provide peer-to-peer safety and sexuality training to other individuals with ID?

#### **Rationale for Methodology**

The methodology for this study is qualitative. Qualitative methodology is beneficial for scholarly inquiry, specifically for research questions that are novel additions to the literature and exploratory in nature (Patton, 2002). Qualitative exploration provides rich, thick descriptions of topics and provides information that cannot be obtained using quantitative data collection methods (Lincoln & Guba, 1985; Patton, 2002). Qualitative scholarly inquiry is a legitimate form of scientific research, with rigorous standards to ensure credibility, trustworthiness, and transferability of findings (Patton, 2002). In contrast to more standardized forms of data collection (e.g., controlled lab settings, standardized survey instruments), qualitative inquiry is often more process than product driven, with an emphasis on open-ended, naturalistic forms of data



collection (e.g., interviews, observations), resulting in in-depth descriptions of experiences and phenomenon (Patton, 2002).

According to Creswell (2013), four philosophical assumptions guide qualitative research and these assumptions will guide the current study. These four assumptions are thoroughly described in published texts on qualitative research (Denzin & Lincoln, 2011; Guba & Lincoln, 1988) and will be discussed here, briefly. In short, qualitative research is ontological, epistemological, axiological, and methodological (Creswell, 2013). The ontological assumption of qualitative inquiry allows researchers to draw meaning from multiple perspectives while the epistemological assumption allows researchers to become engrossed, as intimately as possible, with the participants or phenomenon of study (Creswell, 2013). The axiological assumption refers to the influence of values in research, and the methodological assumption refers to the process and procedures that guide qualitative inquiry (Creswell, 2013).

In alignment with these four assumptions, qualitative research studies share several broad characteristics that will also be employed in the current study. Rossman and Rallis (2003) provide five key elements of qualitative research, including data collection in naturalistic settings, reliance on multiple methods that are humanistic in nature, a focus on the context, the emergent nature of the process, and the interpretative nature of studies. In qualitative research, the researcher is the instrument that ultimately collects, analyzes, and interprets data. Therefore, qualitative researchers should maintain holistic views towards participants and the phenomenon of study (Rossman & Rallis, 2003), while engaging in ongoing self-reflection (Marshall & Rossman, 2010). Qualitative scholars also suggest researchers in this genre employ complex reasoning that vacillates

between inductive and deductive logic (Creswell, 2013; Rossman & Rallis, 2003), while remaining sensitive to the impact of their personal identities and experiences, also referred to as reflexivity (Marshall & Rossman, 2010; Rossman & Rallis, 2003).

In the current study, the researcher delineated her experiences with the topic and population of study and also explicated her interests that led to selection of this research topic, prior to entering the field and engaging in the data collection and analysis process. During data collection and analysis, the researcher remained as close to the data as possible, providing quotes and descriptions of observations to illustrate and support interpretations and analysis of emerging themes and findings. These are examples of tools the researcher used to remain reflexive during the research process.

Qualitative methodology was useful in answering the research questions posed in this study. Quantitative data collection methods would have been ineffective in generating in-depth descriptions of peer-to-peer safety and sexuality training for individuals with ID. Qualitative methods, including interviews, observations, and document analysis, described later in this chapter, generated rich, thick descriptions of the peer-to-peer safety and sexuality training delivered by students at The TALL Institute to individuals with ID. Research on peer-to-peer safety and sexuality training for individuals with ID is a topic that is virtually absent from published scholarly literature. Qualitative methodology was employed to collect new information on this topic, from multiple perspectives.

### **Research Design**

The research design or “plan for conducting the study” is described in the following paragraphs (Creswell, 2013, p. 49). While the rationale for the selection of

qualitative methodology has been provided above, the following sections include descriptions of the conceptual framework and the context for the study, the rationale behind selection of the site, the process of gaining entry, the sampling strategy, recruitment of participants, data collection methods, and the plan for data analysis and interpretation. The following pages will also include ethical considerations, methods of increasing the trustworthiness and credibility of the study, and discussion of the role of the researcher as the instrument of data collection, analysis, and interpretation.

The current study uses a case study approach (Merriam, 1988; Stake, 1995; Yin, 2009) to describe The TALL Institute's safety and sexuality peer-to-peer training program for adults with ID. Disability theory, as summarized by Smart & Smart (2007), served as the interpretative lens for the study. Both of these frameworks are described below.

**Case Study.** Case study research has been described as an “in-depth description of a single case” in a “real-life, contemporary setting” (Creswell, 2013, p. 97). Case study is a term that describes both the *process* of study and the *product* that is generated as a result of study (Merriam, 1998). In addition, the term can also serve to identify the unit of study (e.g., the individual, organization, or program being studied) (Merriam, 1998). Scholars agree the case being studied is bounded by parameters of time and space, meaning the unit of study is situated within real boundaries of time and the setting or context in which the phenomenon occurs (Denzin & Lincoln, 2005; Merriam, 1998; Yin, 2009). The bounded system (or group of bounded systems) is referred to as a case (or cases); the qualitative researcher uses multiple methods of data collection to generate rich, thick descriptions of the case under study (Creswell, 2013).

The primary strength associated with case study research is the breadth and depth of information that can be collected about a single case (Yin, 2009). Selection of one site for data collection could also serve as a potential limitation, in comparison to the selection of multiple cases to highlight a particular phenomenon. The researcher in this study was intentional when considering the number of sites to serve as cases for the study. The rationale behind the selection of the peer-to-peer safety and sexuality training program at The TALL Institute as a single instrumental case is delineated below.

The current study identifies The TALL Institute's peer-to-peer safety and sexuality training program as the case study. This bounded case is a program of The TALL Institute in Cincinnati, Ohio where peer-to-peer safety and sexuality training is delivered to individuals with ID around the state of Ohio. Multiple methods of data collection, including in-depth, individual interviews with peer-to-peer trainers, observations of peer-to-peer trainings, and document analysis of the peer-to-peer training curriculum, generated a rich, thick description of the program. These methods of data collection center on the voice of individuals with ID who serve as peer-to-peer trainers. Qualitative case study methods also allowed the researcher to capture individuals' experiences using their own words and external observation, with analysis of documents to add contextual information to the case.

Case study was the most appropriate method of qualitative data collection and analysis for the current research. As a case study, the current research generated a rich, thick description of the peer-to-peer safety and sexuality training program for individuals with ID at The TALL Institute in a manner that would not have been possible using other approaches. This particular program was selected for the case study because it provided

an opportunity to generate a detailed description of peer-to-peer safety and sexuality training for individuals with ID.

The peer-to-peer safety and sexuality program at The TALL Institute served as an instrumental case (Stake, 1995) to attempt to understand this phenomenon and add new information to the published literature on safety and sexuality training for individuals with ID. As opposed to an exploratory intrinsic case study, which would look within the case for answers or explanations, the analysis and interpretation in this study was guided by sources outside of the case itself, namely disability theory and previously published literature to answer the research questions posed in the study (Stake, 1995). As with other instrumental case study research (Stake, 1995), the researcher in this study selected theory and methods prior to collecting data, using indicative analysis to collect information to answer the research questions. Using disability theory, described below, and previously published literature, described in Chapter 2, the researcher answered the three research questions posed in the study and offered lessons learned for safety and sexuality training for individuals with ID, using the program at TALL Institute as an instrumental case, or a unique case selected for a specific purpose, to support the implications and recommendations.

**Disability Theory.** According to Yin (1993), theoretical orientations in case studies can assist the researcher with delimitation of cases, while also providing support for the transferability of findings to other relevant cases. In the current case study, the critical lens of disability theory will guide data analysis and interpretation of findings. Using critical theory, in general, and models of disability, in particular, interpretation of data in this study will assume certain power structures in society disadvantage individuals

who are perceived to have a disability, namely an ID. An in-depth discussion of the models of disability, in the context of society's historical views toward sexuality and disability is provided in Chapter 2, in the review of literature for the study. An overview of the major models of disability is provided here, situated in the context of their relevance to the current case study.

The four major models of disability include: the Biomedical Model, the Functional Model, the Environmental Model, and the Sociopolitical Model (Smart & Smart, 2007). Although many types of mental and behavioral health professionals (e.g., Licensed Professional Counselors, career counselors, etc.) currently provide services to individuals with disabilities, in the past, this role was fulfilled primarily by Certified Rehabilitation Counselors (CRCs) (Smart & Smart, 2007). The Commission on Rehabilitation Certification (CRCC) defines rehabilitation counseling as a "systematic process which assists persons with physical, mental, developmental, cognitive, and emotional disabilities to achieve their personal, career, and independent living goals in the most integrated setting possible through the application of the counseling process" (CRCC, 2013, para. 3). These four models of disability are described in the rehabilitation counseling literature to provide CRCs with an overview of society's historical views towards individuals with disabilities, in order to better understand and advocate for the rights and welfare of this growing segment of the population (Smart & Smart, 2007).

The Biomedical Model of disability generally presents the view that disability is a medical concern that exists within the individual (Smart & Smart, 2007). This model has roots in medieval traditions where people with disabilities were regarded as mentally or physically defective, in need of treatments or cures to restore "biological wholeness"

(Smart & Smart, 2007, p. 78). During this time, children born with disabilities were thought to be victims of spells or curses, or regarded as a punishment for the sins of their parents (Wade, 2002). This view of disability places the burden on the individual as opposed to society. Environmental factors were not considered and individuals were not afforded the opportunity to be active agents in their own treatment planning (Smart & Smart, 2007). This view led to increased levels of stigma and discrimination against people with disabilities. Although some components of the Biomedical Model are now viewed as problematic (e.g., blaming the individual instead of society), certain aspects of the model (e.g., clinical diagnostic categories for classification of mental or physical ailments) persist within the medical profession, to this day (Smart & Smart, 2007).

While the Biomedical Model of disability emphasizes mental or physical limitations at the individual level of impact, the Functional and Environmental Models (Dembo, 1982; Tanenbaum, 1986; Thomason, Burton, & Hyatt, 1998) of disability consider the impact of environmental barriers (Smart & Smart, 2007). The Americans with Disabilities Act ([ADA], 1990) is an example of legislation implemented with the goal of decreasing physical barriers and increasing access to public facilities and services. These models begin to acknowledge the role of external barriers in exacerbating the difficulties associated with mental or physical limitations (Smart & Smart, 2007). Smart and Smart (2007) note the Functional and Environmental Models of disability decrease stigma associated with mental or physical impairment by moving the burden from the individual to society.

The Sociopolitical Model, also referred to as the Minority Model of disability (Hahn, 1985; Kleinfield, 1979) marks a radical shift from the assumptions held by the

previous three models (Smart & Smart, 2007). This model redefines disability as a social construct that has no roots in the actual physical or mental limitation, but rather redefines disability as a result of society's negative views toward the impairment and the individual experiencing it (Smart & Smart, 2007). According to this view, individuals with impairments serve as the experts and take active roles in coordination of services (Smart & Smart, 2007). According to ADA (1990), individuals with disabilities have protected status similar to other diverse groups in the United States who have pursued equal treatment under the law.

In addition to generating a rich, thick description of the case, the researcher was also interested in critically examining power structures that impact the safety and sexuality of individuals with ID. The researcher anticipated such structures would emerge as salient themes during data analysis and interpretation. In the context of the current case study, these four models of disability served as the interpretative framework, guiding data analysis and interpretation. Data collected in the current study was viewed in the context of the above models of disability, in search of information that supports or contradicts the historical models. The context of the current study, including rationale for site selection and the process of gaining entry, is described below.

### **The Context of the Study**

The context is a crucial element in case study research (Merriam, 1998). The context for the current study is an educational/day treatment program for adults with ID in urban Cincinnati, Ohio. The case included data collection at the individual, program, and institutional levels. At the individual level, the researcher conducted individual interviews with peer-to-peer safety and sexuality trainers, who are students at The TALL



Institute. At the program level, the researcher conducted observations of peer-to-peer safety and sexuality training for individuals with ID, and analyzed the curriculum used for the training. At the institutional level, the researcher described The TALL Institute, to provide additional information regarding the setting and participants.

**Site selection.** The TALL (Thomas Adventures in Lifelong Learning) Institute is a program of TECS (Thomas Educational Consulting Services) Education Center, located at 3950 Edwards Road in Cincinnati, Ohio. The mission of TALL is “to provide unprecedented lifelong learning opportunities that empower adults with intellectual and developmental challenges to be happy, healthy, and safe” (Thomas, 2013, para. 4). The TALL Institute has two full-time staff, Barb Thomas, M.Ed., C.S.E (Certified Sexuality Educator), JSOC (Juvenile Sex Offender Counselor) and Christopher Thomas, M.B.A. As the founder of TALL, Barb serves as the agency’s Executive Director and Director of Education, and her husband, Chris, serves as the Director of Operations.

The TALL Institute was the ideal site for collecting information regarding peer-to-peer safety and sexuality training for individuals with ID for three primary reasons. First, the Director of TALL is a Certified Sexuality Educator and comprehensive sexuality education one of the educational services offered at The TALL Institute. Second, a group of six students are trained as peer-to-peer safety and sexuality trainers, through one of the courses offered at The TALL Institute. Third, the Director of The TALL Institute was willing to collaborate with the researcher in order to facilitate successful completion of this study. These three factors led the researcher to select The TALL Institute as the sole site for data collection for the current study.

**Gaining entry.** To gain entry to the site, prior to data collection, the researcher observed all four sessions of the peer-to-peer safety and sexuality training at The TALL Institute, both as a volunteer and as a participant observer. These observations were not included in data analysis or interpretation, because they occurred prior to approval of the study by the researcher's faculty committee and Institutional Review Board (IRB) of Ohio University, and the observations occurred without a formal consent process. However, the time spent was helpful in allowing the researcher to gain entry and build rapport with participants prior to collecting data. The researcher was able to learn the curriculum along with the students at TALL. The researcher was also able to build a working relationship with the Barb Thomas who provided feedback regarding the feasibility of the study. These observations were beneficial in framing interview questions that were appropriate and relevant, based on the knowledge gained about the program and its participants.

### **Sampling Strategy**

The sampling strategy for this study was purposive, a characteristic that is common in qualitative research, specifically in single case studies (Creswell, 2013). The current site and participants represent an instrumental case that generated a thick, rich description of peer-to-peer safety and sexuality training for individuals with ID. Criterion sampling was used for selection of the case, and was employed when selecting individuals for interviews. Although specific criteria for participant recruitment are listed below, the general criteria for inclusion is a diagnosis of an ID and experience as a peer-to-peer safety and sexuality trainer at The TALL Institute. For the interview portion of

the case study, the researcher interviewed all six individuals who serve as peer-to-peer trainers in the safety and sexuality training program offered by The TALL Institute.

**Recruitment of participants.** Individuals were recruited, voluntarily, as prospective participants for the study, through a face-to-face conversation with the researcher. All six peer-to-peer trainers were invited by the researcher to participate in the study and all six agreed. Voluntary consent was obtained from five peer-to-peer trainers, in writing, using the consent form included in Appendix A. Due to guardianship regulations, one peer-to-peer trainer provided voluntary written assent, after obtaining written parental consent to participate in the research study. The researcher read the appropriate consent or assent form to each peer-to-peer trainer and obtained a signature at the commencement of each interview. Each peer-to-peer trainer was provided with \$10 cash by the researcher as compensation for their time.

The criteria for inclusion as a participant in this study included:

- 1) Chronological age of 18 or older,
- 2) A diagnosis of ID, and
- 3) Ability to engage in verbal communication, with or without the assistance of a communication device, sign language interpreter, or other reasonable accommodations.

All six of the peer-to-peer trainers at The TALL Institute met the criteria for inclusion listed above. According to Barb Thomas, all six peer-to-peer trainers were diagnosed with ID (B. Thomas, personal communication, August 2, 2012) although the researcher was unable to verify this information due to HIPPA regulations. Participants were allowed to withdraw during any part of the study, with no negative repercussions.

Participation was voluntary and in no way impacted eligibility for services or participation in programs at the affiliated agency.

### **Data Collection Methods**

This section describes the data collection methods that were used in the current case study. Marshall and Rossman (2011) describe four primary methods of data collection in qualitative research, including “participating in the setting, observing directly, interviewing in-depth, and analyzing documents and material culture”; these methods are described as “the staples of the diet” in qualitative inquiry (Marshall & Rossman, 2011, p. 137). Data collection methods in the current study included observation, individual interviews, and document analysis. The researcher participated as a volunteer at The TALL Institute prior to data collection, as a means of gaining entry into the site and building rapport with potential participants.

The unit of analysis for this study was the peer-to-peer safety and sexuality training program at The TALL Institute, however, the hallmark of the case study was individual interviews with the six students at TALL who serve as peer-to-peer trainers. The researcher conducted individual interviews with students who have participated in the program as peer-to-peer safety and sexuality trainers. In addition, the researcher observed two full-length peer-to-peer safety and sexuality trainings provided by the students at TALL to other individuals with ID across the state of Ohio. The researcher also critically analyzed the safety and sexuality curriculum used in the peer-to-peer safety and sexuality training. Data collection began November 1, 2012 and ended on December 11, 2012, with pre-field observations in August, September, and October. Each method of data collection in the current case study is described, individually, below.

**Interviewing.** Open-ended interviews are often the hallmark of qualitative studies (Marshall & Rossman, 2011). Patton (2002) describes the purpose of interviewing as a tool to explore a participant's inner world and perspective, in a manner that cannot be obtained using any alternative approach. Advantages of interviews in case study research include generating insight from program participants and the ability to solicit targeted information (Yin, 2009). Limitations associated with interviews include potential response bias from participants, poor recall of past events and experiences, and limited information due to poorly constructed interview questions (Yin, 2009).

In the current study, a semi-structured interview protocol (Appendix B) elicited content as participants responded to knowledge questions, demographic questions, opinion questions, and feelings questions (Patton, 2002). The interview protocol evolved slightly from one interview to the next, due to the emergent nature of qualitative research. Also, insight obtained from the observations generated new interview questions. The researcher conducted individual interviews after observing two trainings; however, each of the peer-to-peer trainers had conducted four or five trainings at the time of interview.

All six individual interviews were conducted at TECS Education Center in Cincinnati, Ohio, located directly adjacent to The TALL Institute, on December 11, 2012. TECS and TALL are located in two storefronts on a main street in Cincinnati, in a neighborhood named Oakley, a few feet from Interstate 71. TECS and TALL are on the same block as a hair salon and a florist and across the street from a Speedway gas station where many of the students from TALL walk to purchase Mountain Dew® and other snack products. The interviews were conducted in a classroom, approximately 12 feet by 14 feet in size. The researcher and participants sat at a round table across from each other.

Each of the interviews lasted approximately 30-minutes in duration, following a semi-structured interview protocol included in Appendix B. The interviews followed a relaxed, conversation-style format and were digitally recorded using an iPod Nano ®. The researcher also took field notes to capture information obtained from the interviews. Interviews were transcribed by the researcher at a later date and analyzed for salient, recurring themes and unique characteristics. Twenty-six pages of transcripts from individual interviews were analyzed for consistency and variation across participant samples (Patton, 2002). In addition to individual interviews, observation is another form of data collection that was used in the current study.

**Observation.** Marshall and Rossman (2011) define observation as the “systematic noting and recording of events, behaviors, and artifacts in the social setting” (p. 139). “Field notes” is a term used to describe the records generated during observations (Marshall & Rossman, 2011, p. 139). While some qualitative studies employ observations or interviews as sole methods of data collection, observation has also been used to supplement data collected through individual interviews (Patton, 2002). According to some researchers, observations are critical components of all qualitative research (Marshall & Rossman, 2011). In case studies, observation can add to the richness of the descriptions of the phenomenon of study by providing additional details about the context in which the phenomenon occurs (Yin, 2009). Rich descriptions, including sights, sounds, smells, and other perceptions are not as easily accessible from interview data (Patton, 2002).

Additional advantages of observation as a data collection method include reduced reliance on second-hand sources, and the ability to obtain information participants would

otherwise be hesitant to reveal during an interview (Patton, 2002). Considering these advantages, observation of peer-to-peer safety and sexuality trainings was a critical component of the data collection for this study. In order to protect the confidentiality of participants, the researcher did not use audio or video recording during observations of peer-to-peer safety and sexuality trainings. Handwritten field notes were used to capture “concrete descriptions of what is observed” (Marshall & Rossman, 2011, p. 139)

The researcher observed two peer-to-peer Health, Safety, and Sexuality trainings for the purposes of this study. The first observed training was on November 2, 2012 from 9:00 a.m. until 12:00 p.m. at Hearts of Hope Institute in The Plains, Ohio. Six individuals attended as participants and four peer-to-peer trainers traveled from Cincinnati with Barb as the facilitator. The second observed training was on November 16, 2012 from 9:30 a.m. to 12:30 p.m. at Bridges Rehabilitation Service in Cleveland, Ohio. A total of 25 participants attended this training, along with all six of the peer-to-peer trainers, including Barb and Chris Thomas of The TALL institute.

Using 20 pages of field notes from these two observations, the researcher looked for patterns and the observations became more systematic once patterns or themes began to emerge. In addition to the concrete, factual descriptions, observer’s comments were documented, separately from raw data, as a preliminary form of analysis and interpretation (Marshall & Rossman, 2011). Field notes from two observations of peer-to-peer safety and sexuality trainings were analyzed along with other forms of data, including interview transcripts, described above, and documents, described below.

**Document analysis.** In addition to observations and individual interviews, the current study also includes an analysis of the 44-page curriculum, “Health, Safety, and

Sexuality Training for You & Me”, written by Shelly Snyder, Allen County Board of Development Disabilities in Ohio and edited by Barb Thomas, Director of The TALL Institute. Additional documents analyzed in the case study included the 2012 Schedule, a 16-page color booklet published by the TECS Education Center. This document was not included as an appendix because it includes confidential information, such as names and photos of students at TALL. The researcher used this document to obtain additional information about the staff, students, and programs at TALL. Yin (2009) describes documents as a critical component of all case study research. According to Yin (2009), strengths of document analysis in case study research include breadth of information contained in documents, inclusion of exact details, an unobtrusive method of data collection, and the stable, unchanging nature of documents.

Although there are limitations associated with document analysis, including potential bias of the author, this additional form of data collection adds to the breadth of the current study. Readers may find information about the curriculum helpful when conceptualizing the context of the study. In addition, content from the curriculum was also helpful when conceptualizing recommendations for future research and practice. Readers can refer to the content described when determining applicability of the study’s findings to their client populations. Data from multiple sources also increases the credibility of the study, with each data source supplementing the limitations of another (Patton, 2002).

In addition to collecting data using observations, interviews, and document analysis, the researcher analyzed an interview recorded by Cincinnati Education Television (CET) with Barb Thomas on February 2, 2012 on an edition of *FOCUS*, a



television news program facilitated by Kathy Lehr. The video is 26 minutes in duration and is posted on the home page at TALL's website at <http://www.tallinstitute.org>. The information used from this interview was helpful in describing the context for the case study.

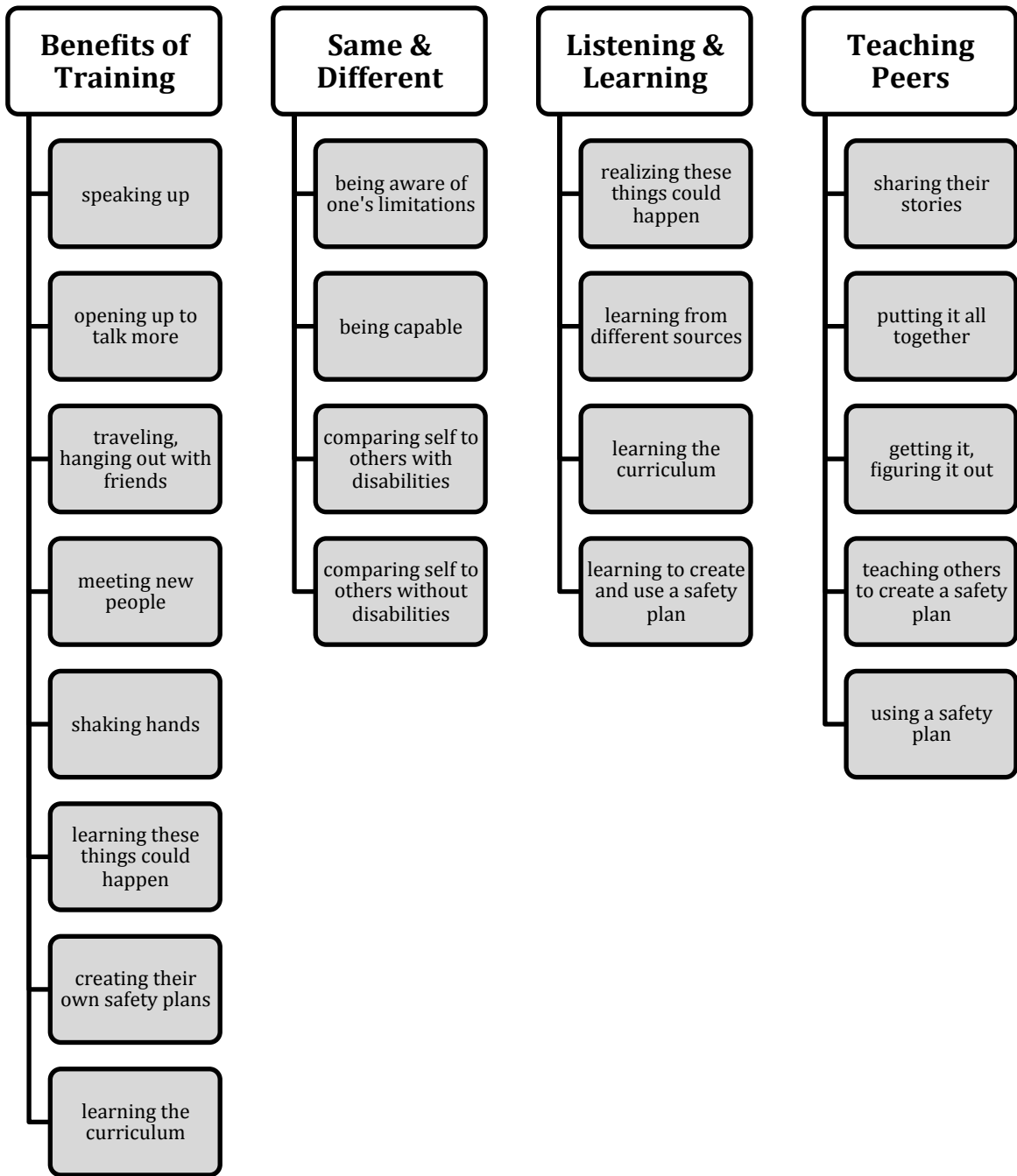
### **Data Analysis**

The goal of analysis for this case study is to generate a “detailed description of the case and its setting” (Creswell, 2013, p. 199). There is an endless number of data analysis strategies used in qualitative research and several methods created specifically to analyze data collected through case study research (see Creswell, 2013, p. 199, for examples). The qualitative data analysis strategy for the current case study followed the seven-step procedure described by Marshall and Rossman (2011). These included: organize the data, immerse oneself in the data, code the data, generate categories and themes, offer interpretations, search for alternative understandings, and write the report (Marshall & Rossman, 2011; p. 209).

First, data collected from field observations, interviews, and analysis of documents was organized electronically, using word processing software to sort all data chronologically, as it was collected in the field. Second, the researcher became immersed in the data, reading and rereading each transcript, note, and document individually. Third, line-by-line coding started the process of generating salient themes. During the coding process, the researcher combed through text, line-by-line, posing questions such as “What is the process here?” or “What is this about?” (Charmaz, 2006). The answers to these questions were phrased using “gerunds” or action-driven words such as *exploring* or *driving* (Charmaz, 2006; Glaser, 1978). At this point, codes were gathered into

subclusters, or groups of related codes (Marshall & Rossman, 2011). Fourth, general themes or categories were generated using the codes from the previous step. In addition, data was analyzed for unique characteristics that did not span across participants, yet provided salient information that added to the richness of the description. Fifth, interpretations of themes were offered. Sixth, alternative explanations or of the interpretations were explored. Seventh, the researcher wrote a final report based on the broad thematic categories generated from the data (Marshall & Rossman, 2011).

Line-by-line coding generated a list of gerund phrased codes (Charmaz, 2006) that were grouped into larger categories, based on an overarching theme (Marshall & Rossman, 2011). The following chart (Figure 1) lists the eight major themes and relevant codes for each theme. The themes are divided into two sections purely for page formatting purposes. These themes include: 1) Benefits of Training, 2) Same & Different, 3) Listening & Learning, 4) Teaching Peers, 5) Teaching the Youth, 6) Being Approached, 7) Relating & Reacting to Skits, 8) Spiritual Abuse.



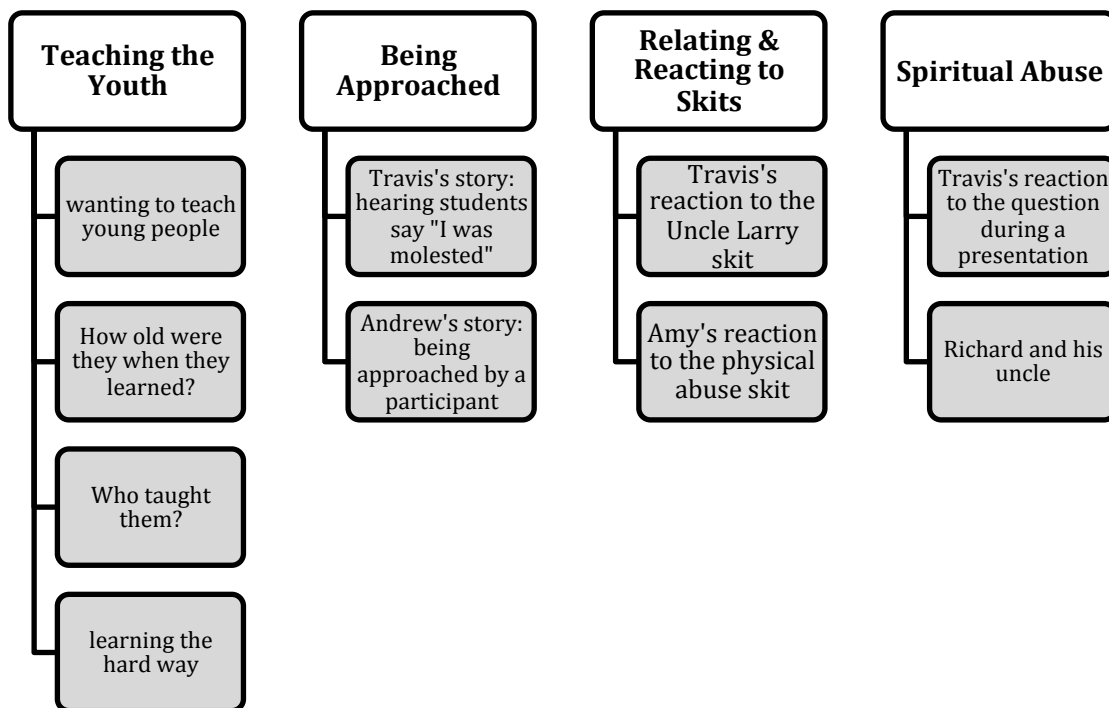


Figure 1. List of themes and relevant line-by-line codes.

An axial coding strategy, as described by Charmaz (2006) and originally developed by Strauss and Corbin (1990, 1998) (Figure 2) is included below to illustrate connections between the eight major themes that emerged from observation and interview data. In this figure, each major theme is listed in a different shape, with a corresponding list of relevant sub-themes (if applicable). The selection of shapes for each theme is of little importance; however, their relationship between each theme is indicated using a straight line to connect one shape to another. In this mind map, lines are used to connect themes, with darker lines indicating a stronger relationship. Among the eight themes, there are four apparent connections, between the following themes:

A. Benefits of Learning – Teaching Peers

B. Teaching Peers – Teaching the Youth

C. Benefits of Training – Listening & Learning

D. Listening & Learning – Being Approached.

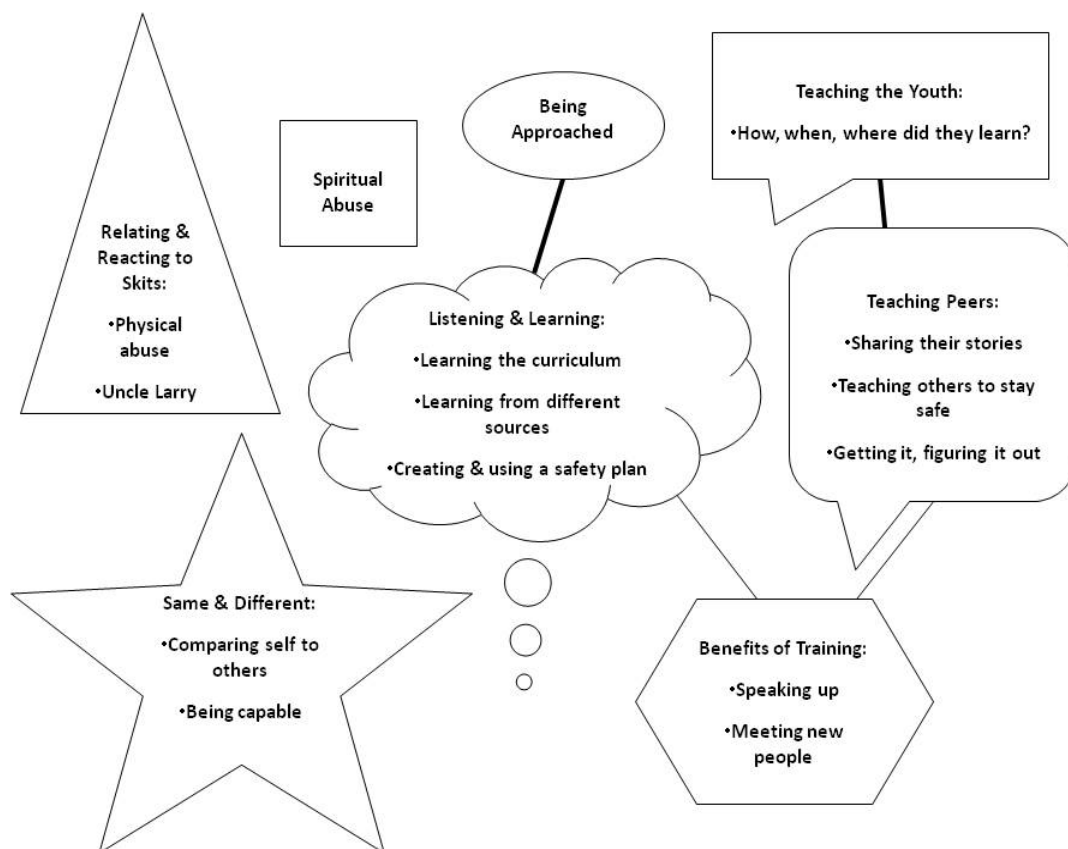


Figure 2. Axial coding strategy indicating relationship between themes.

### Trustworthiness and Credibility

Patton (2002) describes credibility as a construct comprised of three interrelated elements: “rigorous methods, credibility of the researcher, and philosophical belief in the value of qualitative inquiry” (p. 552). The current study involved extended time in the field with in-depth forms of data collection, referred to as rigorous methods. The current

study also builds on the knowledge and experience of the researcher, including a critical framework that guided data analysis, which adds to the credibility of the researcher. Further, this study operates with a genuine respect for the process and products produced by qualitative inquiry, described by Patton (2002) as philosophical belief in the value of qualitative inquiry.

Guion, Diehl, and McDonald (2011) build on Patton's (2002) conceptualization of credibility in qualitative research by proposing five types of triangulation: "1) data triangulation, 2) investigator triangulation, 3) theory triangulation, 4) methodological triangulation, and 5) environmental triangulation" (p.1). Data triangulation or triangulation of sources (Patton, 2002), "involves using different sources of information in order to increase the validity of a study" (Guion, Diehl, & McDonald, 2011, p. 1). In the current case study, the researcher used three data sources (observations, interviews, documents) to increase the credibility of the study. The second form of triangulation involves the use of multiple investigators to assist with data collection and analysis (Guion, Diehl, & McDonald, 2011). Investigator triangulation increases the strength of findings by adding multiple perspectives and experiences to the study. The researcher in the current case study was unable to employ investigator triangulation due to scheduling conflicts and limited availability of peer-reviewers. The third form of triangulation, theory triangulation, is described as using professionals from diverse disciplines as external reviewers to provide feedback on analysis and interpretation in a qualitative study (Guion, Diehl, & McDonald, 2011). This form of triangulation was not practical for the current study, due to time constraints and deadlines for study completion, as set forth by Ohio University.

The fourth and fifth forms of triangulation offered by Guion, Diehl, and McDonald (2011) are methodological and environmental triangulation. The current case study employed methodological triangulation through the use of three methods of data collection (interviews, observations, and document analysis). Environmental triangulation, or the use of “different locations, settings, and other key factors related to the environment in which the study took place, such as the time, day, or season” (Guion, Diehl, & McDonald, 2011, p. 2), was employed during observations of two peer-to-peer safety and sexuality trainings. The researcher conducted one observation in a rural location, The Plains, in southeast Ohio, and one observation of a training presentation in Cleveland, an urban area in Ohio. The researcher in the current case study used triangulation of data, methods, and environment to strengthen “diversity and quantity of data that can be used for analysis” (Guion, Diehl, & McDonald, 2011, p. 3), as described above. The next section will discuss the ethical considerations included in the current case study.

### **Ethical Considerations**

Many professional organizations publish codes of conduct that define ethical practice for practitioners in their particular field. The American Counseling Association (ACA) Code of Ethics and the Commission on Rehabilitation Counselor Certification (CRCC) Code of Ethics both state the primary obligation of mental health counselors and rehabilitation counselors, respectively, is to their clients (ACA, 2005; CRCC, 2009). CRCs are ethically responsible to uphold the six standards listed in the Codes, including autonomy, beneficence, nonmaleficence, justice, fidelity, and veracity. This means CRCs

are obligated to promote the independence of clients, do good to others, do no harm, act in a fair and just manner, act in an honest manner and be truthful (CRCC, 2009).

These codes will guide the ethical considerations of the researcher for this study, in addition to the guidelines put forth by the Institutional Review Board (IRB) of Ohio University. Individuals with disabilities in general, and ID in particular, are considered a protected population in terms of research and certain procedures are in place to ensure the welfare, dignity, and rights of potential study participants are protected. These processes are described below, as they relate to potential participants for the current study. The following sections include potential risks and benefits of participation in the study and safeguards to protect against risks.

The potential risks or discomforts associated with participation in this study may include negative feelings associated with recollections of past experiences related to human sexuality, including sexual trauma, assault, abuse, or victimization. If an individual chose to disclose such information during an interview, feelings of sadness, shame, or anger could have emerged as a result. This aspect of participants' experiences is beyond the scope of the current study and questions related to experiences of abuse and victimization was not included in the interview protocol.

In accordance with the guidelines of the IRB at Ohio University, the researcher was required to inform participants (or their parent/guardian, if applicable) that they may not benefit from participation in the current study. Although \$10 per interview was provided to each participant, this is considered compensation and not a benefit of participation. As listed on the consent documents, "This study is important because people with ID are not usually asked to talk to researchers about topics related to safety,



and sexuality.” Although the study could potentially benefit the scientific community by providing new information on this topic, individuals who participate in the study did not experience any direct benefits as a result of participation.

The researcher was prepared to minimize the potential risks associated with participation in the current case study. The researcher for this case study is a Professional Counselor, licensed to practice in the state of Ohio, and has developed counseling skills through educational and employment experiences (e.g., unconditional positive regard, empathy, redirecting, etc.). These skills will be beneficial in minimizing potential risks associated with study participation. The researcher has also completed a Master of Science degree in Rehabilitation Counseling and has experience counseling adults and children, with and without ID. As an Early Childhood Mental Health Specialist at Tri-County Mental Health and Counseling Services in Hocking County, Ohio, the researcher’s current responsibilities include assessment, diagnosis, and treatment of mental health and behavioral disorders in children ages 0 to 6. The researcher also conducts developmental assessments in young children, to identify children who qualify for DD services.

To minimize discomfort related to participation in this study, the following disclosure statement was read prior to each interview: “Today, we will talk about your experiences as a peer-to-peer trainer in the “Health, Safety, and Sexuality, Training for You & Me” program. If you want to end our talk, at any time, that is your choice and it is okay to make that choice. You can decide what things you want to talk about or not talk about. You can say ‘I want to stop talking now’ at any time and we will end our talk.”

If any disclosures would have been made related to sexual abuse or victimization, the researcher is legally mandated to report this information to the appropriate authorities. The researcher discussed this information with participants at the beginning of each interview and no such disclosures were made during interviews. If participants would have disclosed incidents related to recent or past experiences of abuse, either as a victim or an offender, the researcher would have made a report to Hamilton County Developmental Disability Services, Major and Unusual Incident Prevention, 24-hour Emergency Hotline 513-794-3308. If any individuals would have been interested in more information about sexual abuse and assault prevention services, the researcher would have directed them to the Sexual Assault Program at YWCA, 24-hour Crisis Intervention Assistance Hotline at 800-644-4460. Also, if participants would have expressed interest in mental health treatment as a result of sexual trauma, they would have been encouraged to call the hotline above and ask for a referral. No one requested such information during an interview. The above two paragraphs were also included in the consent documents and each participant was given a copy of the consent form to keep.

In addition to ethical considerations during individual interviews, safeguards were also in place during observations of trainings. During both trainings observed during this study, participants who attended trainings were provided with a handout, attached to the last page of their safety plans, that included a list of local resources in their respective counties, including phone numbers for emergency housing, police and sheriff departments, and local mental health facilities. Individuals who wanted to report or discuss past or current incidents of abuse and victimization were also encouraged to talk

to Barb or one of the peer-to-peer trainers to get additional information regarding appropriate resources.

The above paragraphs discuss ethical considerations for the current study, in terms of data collection. During and following data analysis, original files and transcripts will remain locked in 107 McCracken Hall, Ohio University, Athens, Ohio, for a maximum of one year. Beginning May 2013, all files will remain in the possession of the researcher and will be destroyed after two years (July 2014). Guidelines put forth by the 2010 American Psychological Association's (APA) Publication Manual was used to avoid bias in language when discussing participants' gender, sexual orientation, racial or ethnic group, disability, or age. Also, pseudonyms were assigned during data analysis to protect the identities of study participants, prior to writing and disseminating findings. The final section of this chapter will discuss the role of the researcher as the instrument for data collection, analysis, and interpretation.

### **Researcher as Instrument**

The role of the researcher is a crucial element in qualitative research. Qualitative scholars use terms such as *positionality* and *reflexivity* to describe the many ways in which qualitative researchers situate themselves and their experiences within phenomenon of study (Charmaz, 2006; Creswell, 2009; Marshall & Rossman, 2011). Positionality refers to the manner in which qualitative researchers describe their previous experiences or interests in a topic while also approaching participants and phenomena with an open mind (Marshall & Rossman, 2011). Reflexivity is defined by Charmaz (2006) as “the researcher’s scrutiny of her experience, decisions, and interpretations” in a manner that allows the researcher to reflect on the role past experiences may play in her

interpretations of the current inquiry (p. 188). A reflexive researcher will examine the role of personal characteristics and identities (e.g., gender, race, sexual orientation, socioeconomic status, etc.) on the analysis and interpretations of findings (Creswell, 2009).

As a qualitative researcher, the primary instrument of data collection, analysis, and interpretation is self (Creswell, 2013). Although information in this study was collected using methods such as observation, interviews, and documents, the protocol for collecting and organizing that information was created by the researcher. The following paragraphs will describe the researcher's interests in the current topic, along with a description of relevant personal identities that may potentially shape interpretations of findings in the current study.

The researcher is a single, Black, heterosexual female, in her late twenties from a large extended family, headed by a strong, religious matriarch. The researcher spent most of her childhood in an inner-city neighborhood in a mid-size city in the Central Plains region of the United States, although the majority of her extended family is from the rural South. The researcher was reared in a Protestant household with a mother and stepfather where values and faith were regarded in high esteem, and behaviors such as pre-marital sex, smoking, and cursing were unacceptable for "young ladies". The researcher has a sibling who is openly homosexual, and this sibling has received less than desirable treatment from some members of her nuclear and extended family. These early experiences, among many others, related to faith, values, and sexuality shaped the researchers' views toward sexuality. Although she described herself as a fundamental religious conservative during her teenage years, the researcher now describes herself as

open-minded. Experiences such as traveling abroad, moving from the Central Plains to the Midwest and developing close friendships with individuals from a broad range of sexual orientations, religious affiliations, and abilities has shaped the researcher's current views toward many socially-constructed classifications of "difference".

In terms of experiences with ID and sexuality, the researcher became involved with this particular topic as a result of a family member who wrote a book entitled, *Thirty Thieves of Innocence*. The researcher's relative, Ruthie Garrison-Christian, whose mother has been diagnosed with an ID since early childhood, was born as a result of a rape that left her mother pregnant. The researcher was always familiar with this incident but became more aware of the details after reading the book four years ago. *Thirty Thieves of Innocence* chronicles the history related to Mrs. Garrison-Christian and her mother's lives and sparked the researcher's interest in sexual abuse of people with ID.

The researcher has a Master of Science degree in Rehabilitation Counseling and has previous employment experience with children and adults with ID and DD. These work experiences have shaped her interest in ID and sexuality, specifically in terms of sexuality education for children and adults with ID and DD. The researcher has conducted trainings and conference presentations on sexuality education for children and adults with ID and DD for parents, teachers, and rehabilitation counselors. The researcher has been interviewed by local media in Athens, Ohio related to her interests with this topic. The researcher is a Licensed Professional Counselor in the state of Ohio, and is currently employed as an Early Childhood Mental Health Specialist at a local community mental health clinic where she diagnoses and treats mental and behavioral disorders in children from birth to six years. Approximately one-third of the clients on her caseload

have confirmed or alleged histories of sexual abuse and victimization. Although her previous experiences may impact the manner in which she views the current case study, the ultimate goal, for this researcher, was to generate a thorough description of the case in order to make a contribution to the literature on ID and sexuality.

### **Summary**

This chapter described the methodology that was be used in the current study. The chapter provided an overview of the rationale for selecting the methodology, the research design, the setting for data collecting, including sampling strategies and recruitment of participants, data collection methods, and data analysis and interpretation techniques. Methods for increasing the transferability and credibility of findings were also presented. The chapter concluded with consideration of ethical issues raised in the study, in addition to discussion of the role of the researcher as the instrument of data collection, analysis and interpretation. Chapter 4 will begin with a description of The TALL Institute and the Peer-to-Peer Health, Safety, and Sexuality Training Program.

## **Chapter 4: The TALL Institute and the Peer-to-Peer Health, Safety and Sexuality Training Program**

The purpose of this case study is to elucidate a rich, thick description of the peer-to-peer Health, Safety, and Sexuality training provided by students at The TALL Institute, using data collected from multiple sources. Students at the TALL Institute have various ID and DD diagnoses and provide peer-to-peer training to other individuals with ID and DD at agencies across the state of Ohio. This research is a critical first step to generating information on safety and sexuality education for individuals with ID. Individuals with ID are at a greater risk for abuse and victimization when compared to individuals without disabilities (Petersilia, 2001; Sobsey, 1994) and adults with other types of disabilities (Harrel & Rand, 2008). In 2008, The Bureau of Justice Statistics estimated approximately 34,000 people with cognitive impairments in the U.S. were victims of non-fatal violent crime, with approximately 1,500 of those crimes classified as rape or sexual assault (Harrell & Rand, 2010).

Sexuality education and safety training are tools suggested by researchers and practitioners to decrease vulnerability to victimization for individuals with ID (e.g., Champagne & Walker-Hirsh, 1993; Planned Parenthood, 2009; Sobsey, 1994). The current study used data gathered from individual interviews with peer-to-peer trainers, analysis of documents, and observations of peer-to-peer trainings to answer three central research questions: 1) What is the peer-to-peer safety and sexuality training program at The TALL Institute? 2) How do students at The TALL Institute describe their experiences as peer-to-peer health, safety, and sexuality trainers for individuals with ID?

3) How do students at The TALL Institute provide peer-to-peer safety and sexuality training to other individuals with ID?

This chapter delivers a rich, thick description of The TALL Institute and the Health, Safety, and Sexuality training program provided to individuals with ID and DD around the state of Ohio by students at The TALL Institute. This chapter includes a description of TALL, a description of the peer-to-peer training program, a description of a complete peer-to-peer Health, Safety, and Sexuality training presentation, and an analysis of the curriculum and dramatic skits used to deliver the trainings. This description was generated using data collected from time in the field, including two observations of complete trainings, analysis of documents, including scripts and curricula, used to deliver the peer-to-peer trainings, and repeated interactions with the director, staff, and students of The TALL Institute over a six-month period, from August 2012 until January 2013. The researcher used disability theory, specifically the models of disability described by Smart and Smart (2007) and relevant published literature (Bullard & Wallace, 1978; Orzek, 1984; Utley et al., 2001) to analyze the components of the peer-to-peer safety and sexuality training program offered by students at The TALL Institute.

While this chapter provides a description of the agency and the peer-to-peer training program, the following chapters will provide in-depth analysis of interviews with the six peer-to-peer trainers who traveled around the state of Ohio as part of the Health, Safety, & Sexuality Training for You & Me program. Observation, interview, and document data was analyzed using the seven-step method outlined by Marshall and Rossman (2011). As described in Chapter 3, these seven steps include: 1) sort the data, 2) become immersed in the data, 3) code line by line, 4) generate themes, 5) offer



interpretations, 6) search for alternate explanations, 7) draft final report (Marshall & Rossman, 2011). Disability theory served as the interpretative framework and the researcher searched for information that supported or contradicted the four models of disability, the Biomedical Model, the Functional Model, The Environmental Model and the Sociopolitical Model, as described by Smart and Smart (2007). The researcher also examined the data in the context of relevant published literature, specifically research related to peer-to-peer safety or sexuality training for individuals with disabilities (Bullard & Wallace, 1978; Orzek, 1984; Utley et al., 2001). The first section of this chapter provides a description of The TALL Institute in Cincinnati, Ohio, described below.

### **The TALL Institute**

Established in 2007, The TALL Institute, or Thomas Adventures in Lifelong Learning, is a program of Thomas Educational Consulting Services (TECS) Education Center, located at 3950 Edwards Road in Cincinnati, Ohio in a township referred to as Oakley. The mission of TALL is “to provide unprecedented lifelong learning opportunities that empower adults with intellectual and developmental challenges to be happy, healthy, and safe” (Thomas, 2013, para. 4). Cincinnati Education Television (CET) recorded a video interview with Barb on February 2, 2012 on an edition of *FOCUS*, a news program facilitated by Kathy Lehr (Wiener, 2012). In this interview posted on TALL’s website, Barb Thomas, founder, Executive Director, and Director of Education, states her reasons for starting the institute.

Well it began because I have a private practice as a Human Sexuality Educator and Offender Counselor working with folks with intellectual challenges and it

became very clear that many of the folks that I was working with on their social skills and personal development were really lacking in the ability to have friendships, make friends, keep friends, have a place to go where they can socialize. (Wiener, 2012)

Barb's reasons for opening The TALL Institute stemmed from her private practice where she built relationships with individuals, over time, and saw an unmet need related to engagement in ongoing relationships and socialization. In the interview, Barb discussed some of the original classes offered at TALL,

Some of the first classes were uh we did a class in um talking about movies and the arts and what are your favorite movies and books and things like that so that the folks had opportunities to really just talk about what they liked and what they didn't like so that they were really getting to know each other but in a way that was actually extending on to 'Hey, you know what I really like those kind of movies. Let's go to a movie this weekend.' So it really was a great way for them to interact with each other. (Wiener, 2012)

For Barb, it was important for the individuals in her program, referred to as students, to actively engage in social activities, rather than simply talking about their hopes or plans. Discussions between students eventually developed into meaningful relationships, both within and outside of TALL. Although there are other agencies in Cincinnati and Hamilton County, Ohio that provide educational or social programming for individuals with ID and DD, The TALL Institute is unique because Barb has designed educational and social programming, with classes taught by professionals in various fields. For example, the researcher participated in a self-defense class at TALL taught by a local

martial arts instructor. Also, TALL collaborates with local directors and film producers for the Tuesday class, Film, Photography, and the Arts. When the researcher asked Barb how many other organizations provide similar programs and activities as The TALL Institute, Barb described the TALL Institute as one-of-a-kind. According to Barb, Everyone has a component that they say is a class or whatever but most of the time, it's like a one shot deal, like, 'Okay today we're gonna do this activity and next week we're gonna do that activity,' and um I'm pretty certain no one has it where from start to finish you're taking this class [*sic*]. (B. Thomas, personal communication, February 5, 2013)

A handful of the students at TALL are also participants in other post-secondary vocational, social, or educational programs including Starfire Council, an organization that provides community integration for adults with DD and Easter Seals, an agency that provides day habilitation and employment opportunities and support for individuals with disabilities. The TALL Institute is unique, when compared to other DD agencies in Ohio, because of the background of the agency director and the quality of educational and social programming provided at TALL, described below.

The TALL Institute has two full-time staff, Barb Thomas, M.Ed., C.S.E (Certified Sexuality Educator), JSOC (Juvenile Sex Offender Counselor) and Christopher Thomas, M.B.A. As the founder of TALL, Barb serves as the agency's Executive Director and Director of Education, and her husband, Chris, serves as the Director of Operations. Barb has a Master's degree in Special Education and 38 years of experience as an educator. Barb designs the curriculum and programming at TALL, in addition to recruiting volunteers from the community and interns from local colleges and universities. Chris,

Barb's husband of 33 years, assists with transporting clients between their homes or places of employment to TALL, and transporting them home after programs, in addition to teaching classes he designs. This information regarding Barb and Chris' backgrounds was obtained from The TALL Institute's 2012 Schedule, a 16-page booklet that Barb distributes to program participants and their families. To protect the confidentiality of program participants, this booklet was not included as an appendix, as it contains photos and other identifiable information such as names and contact information.

Kelly Bresler, a special education major in her junior year at Xavier University in Cincinnati, is employed part-time at TALL and provides administrative support, assists with teaching classes and also transports students to and from TALL. Kelly has been working at TALL for approximately one year and describes Barb as a friend of her mother, which is how they met. All of the students at TALL are transported to and from the facility either by parents and caregivers, public transportation and taxi services, or receive rides from Barb, Kelly, or Chris. On January 2, 2013, a new TECS office was opened at 135 N. Broadway Street in Lebanon, Ohio, a suburb approximately 15 minutes northwest of Cincinnati. Barb and Chris hired additional staff to assist with the expansion, including their son Matt and Ashley Salerno, a young woman from the Cincinnati area.

When the researcher asked Barb how she became interested in this type of work, Barb discussed an experience she had in college with a young, red-headed man who she thought had Asperger's syndrome.

Um I went to college at a place called Marymount College in Virginia. It's in Arlington, VA, and my second semester of it was just a junior college, I hooked

up somehow, with one of my classes, one of my education classes or whatever, and I hooked up with a young boy that had red hair and I think he must have had Asperger's or something and I just I loved it, I absolutely loved it. I was probably 19 years old. (B. Thomas, personal communication, February 5, 2013)

Barb later met a family friend who was a doctor who suggested she apply for a summer job at Our Lady of the Wayside, a nonprofit agency providing residential services for adults and children with DD in Barb's hometown of Cleveland, Ohio. Initially hired as overnight staff, primarily assigned to laundry duty, Barb was later switched to day shift and her interactions with the residents at the center changed the course of her life, permanently. Rather than returning to school immediately, Barb decided to stay at Wayside because she "fell in love" with the children there. In an interview with the researcher, Barb recalled those days at Wayside with a smile,

That would have been the fall of 1971, I started working first shift 7 a.m. to 3 p.m. and I absolutely fell in love with it. It was a home for 'retarded' kids [*sic*]. I worked in the nursery and I worked with the older kids. And I definitely preferred working with the more capable kids. (B. Thomas, personal communication, February 5, 2013)

One of the female staff at Wayside encouraged Barb to return to school to pursue Special Education as a career. Barb had friends at The University of Cincinnati and they encouraged her to apply to UC's Special Education program. Barb recalled her career change "and that's how it happened. And it's really kind of, I happened to do this, I happened to get this job, it happened and it was absolutely what was meant to happen". According to Barb's descriptions, a chain of life events led her to choose special

education as a career choice – an encounter with a fellow student with a disability, obtaining a job at a residential facility, and encouragement from friends at UC. As a young college student, Barb grew increasingly interested in ID and DD work and she continued to pursue employment experiences relevant to these growing interests.

Barb later worked at Hamilton County MRDD Services, first as a student teacher while at UC, and later as an employee for 18 years. Within her first year at Hamilton County MRDD, Barb was asked to assist Shirley Everett Clark, a former employee of Planned Parenthood who is now deceased, and the two worked as part of a committee that designed a sexuality curriculum. Barb described the program during an interview with the researcher,

It was a workshop for this committee that was working to do a sexuality curriculum for Hamilton County DDS and so once I stopped doing that I started teaching that in the classroom and then I just kept teaching. The last three years that I was teaching I had been asked by the nurse at my school, ‘Hey do you wanna do a training for the Down Syndrome Association? They want us to talk about sexuality stuff.’ And I was like, ‘Sure I’ll do that.’ And I was being asked to go in the workshops for Hamilton County DDS and I was already doing it and so I quit my job. (B. Thomas, personal communication, February 5, 2013)

Planned Parenthood has a long history of sexuality training for individuals with ID, most notably with the work of Winifred Kempton in the 1970s and 1980s. While the topic of sexuality was increasingly popular during this time in the U.S., sexuality education for people with disabilities, specifically ID, remained taboo. Barb had an opportunity to engage with sexuality and ID at a time when such discussions were novel,

and at times, controversial. While societies views, at the time, were in line with the Biomedical Model of Disability with limited acknowledgement of sexuality concerns for individuals with ID (Smart & Smart, 2007), Barb and her colleagues were part of the progressive movement associated with the Sociopolitical Model of Disability (Smart & Smart, 2007), encouraging caregivers, family members and service providers of individuals with ID and DD to address topics related to human sexuality.

After leaving her position at Hamilton County, Barb immediately started teaching sexuality education for 6<sup>th</sup>, 7<sup>th</sup>, and 8<sup>th</sup> grade students at Saint Cecilia School, her parish school that her children also attended. At that time, Barb also connected with other schools to conduct sexuality education trainings and presentations while pursuing certification as a sexuality educator. By then, Barb had completed her master's degree and had already started her private practice as a Juvenile Sex Offender Counselor.

Drawing from her extensive background and experience in special education, and human sexuality, Barb designs programs, activities, and courses at TALL and offers her students a variety of opportunities to be “happy, healthy, and safe” according to the mission of the institute. For the 2012 programming year, TALL's programming schedule was divided into three semesters: winter, summer, and fall. Each semester, classes and activities are offered during the week to individuals with ID and DD, referred to as students. Adults ages 21 years and older who have received their high school diploma are eligible to participate as a student at TALL. TALL is an Individual Options (I/O) and Level One waiver and Hamilton County Developmental Disability Services (HCDDS) provider, meaning individuals who qualify for services through Medicaid or HCDDS may use their allotted funds to cover the costs of programs and activities at TALL.

Private pay clients are also welcome to participate. Waivers can cover the costs associated with most classes however many of the social activities have additional fees to cover costs associated with food, admission to events, and related expenses. The students at The TALL Institute range in age from 21 to 52 years, according to Barb. Barb also reports approximately 50 students total participate in the programs offered at TALL.

Regarding funding for the programs at The TALL Institute, Barb reports in the *FOCUS* Interview posted on her website,

It's funded through, um, the county, Hamilton County Developmental Disabilities Services. I have a contract with them for some individuals. There's a lot of individuals that have challenges that have what's called either an Individual Options waiver or a Level One Waiver which is funding through Medicaid dollars that comes from the state and then some people pay privately. (Wiener, 2012)

Funding for educational and social programming for individuals with ID and DD is provided through federal and state funds, as delineated in legislation such as IDEIA (2004), and the DD Act of 2000. These acts are examples of efforts to dismantle barriers to inclusion for individuals with disabilities in the U.S., often associated with the Functional and Environmental models of disability (Smart & Smart, 2007). Rather than blaming the individual for challenges associated with the disability, funding for services, in the form of waivers, service contracts, or Medicaid dollars, as described by Barb, have been provided as a method of dismantling environmental barriers and obstacles that preclude the success of individuals with ID (Smart & Smart, 2007).

Barb described the rationale behind the small class sizes and small number of students at The TALL institute in the *FOCUS* interview,



Well, we have about 50 members right now and that's like, Monday has nine people, Tuesday has 14 people, Wednesday has 12, so it's a little bit different for each day that people come in. And many of the people come once, twice, or three times a week. Uh, I see some people five days a week when they are coming for one of our WALL Weekends, so it just depends. And we're keeping our program small because we really want these folks to have the ability to continue making friends, even among those people they're maybe not so friendly with, yet, still to get to know. So we don't see ourselves growing any bigger in this particular environment, perhaps in another environment, but just kind of keeping [*sic*]. And there are some people that change up. They get a job, which is lovely, when that happens, because that means for many people that they've really learned how to better interact with people and um are more capable of keeping a job because they've learned that they need to be on time, they need to be there weekly, they need to be appropriate, and so we have lost people to jobs, but that's 'Yoohoo!' [*sic*]. That's a good thing for us. (Wiener, 2012)

Barb described the intent of smaller class sizes as a method of increasing the ability of students at TALL to form real, meaningful relationships. Students can select classes based on their interests and availability, considering scheduling concerns such as employment and participation in other educational and social activities in the community. The classes offered at TALL include, Garage Band Class/The TALL Stars offered on Mondays; Film, Photography, and the Arts on Tuesdays; Lifelong Learning A to Z on Wednesdays; and Girls Just Want to Have Fun...and Be Healthy on Thursdays. Fridays, Saturdays, and Sundays, twice per month, are WALL (Weekend Adventures in Lifelong

Learning) Weekends, and include a variety of social events such as baseball games, cookouts, concerts, festivals, and the like. According to Barb, WALL Weekends are:

Weekend Adventures in Lifelong Learning, and one time a month, and I didn't mention before that the classes during the week are from 2 p.m. to 7 p.m. which is different than other programs and I did that originally so that people, especially those people that live by themselves could at least one day a week have dinner with friends as opposed to sitting by themselves at home. Um but the WALL Weekends, when we have them is Friday evenings from 4:30 to 9:30 p.m., Saturday evenings from 4:30 to 9:30 p.m. and Sunday noon to 7 p.m.

It's just another way to get with friends on a weekend, and to be honest, it's rarely over at 9:30, you know by the time we finish up and take people home, and part of our program, some people say, 'Take me home last!' because everyone is having a good time. And part of the transportation is part of the program, where people are chatting and talking and maybe sitting next to someone that they like or whatever but we offer opportunities for people to go out in the community and do things that you and I might do, whether it's going to Hopfield House and raising a beer and singing a song or going over to someone's house to be in their man cave for the evening. We've done all sorts of different kinds of things.

(Wiener, 2012)

The researcher attended one WALL Weekend as a volunteer, during an overnight Christmas shopping trip in Cincinnati the first weekend in December 2012. This was an exciting opportunity to engage with about 25 students at TALL and about 5 TALL staff and volunteers. Students and staff spent the night at the Embassy Suites Hotel in

Cincinnati, paid for with activity fees and an additional cost to cover food and accommodations. Students decided which stores they wanted to go to and Barb and the staff and volunteers assisted with creating shopping lists, making selections in stores, and wrapping the gifts. This weekend was one example of the kinds of social events offered to students at TALL. In the *FOCUS* interview, when asked how she plans the classes and activities at TALL, Barb responded,

Well, I guess probably, I'd like to say it was me being really creative, and on some level I guess I have to be really creative with how we're going to be getting things done but anymore since we've been around since 2007, we really build on the classes from the class before. So whatever the students really want to do is what we do, so you know for our Tuesday class, which is our Film Outside the Line class where we collaborate with Media Bridges and Visionaries and Voices, um while we are not in session with Film Outside the Line the folks are still really interested in the arts so right now we're collaborating with the Playhouse in the Park to do acting lessons. And then once Film Outside the Line is back up again, they will have had these acting classes to go along with our filming classes. Um we also have a collaboration with the Cincinnati Art Museum where we're making a video with them to help other people that are gonna go to the art museum and actually be able to walk into the museum and know what's going on and where they should go as opposed to what I would normally do and turn in circles and say 'Oh, which way am I gonna go'. It's a way to, um, this video is gonna help people with challenges be able to watch it ahead of time, either with

their staff or their classroom teacher or their family so that they could go with a friend independently and actually get around the art museum. (Wiener, 2012)

Barb went on to describe The TALL Institute's collaboration with outside agencies,

We're really doing a lot of that, which is great. We did it with the Cincinnati Zoo. We made a video for the Cincinnati Zoo, um certainly with Media Bridges. We are also collaborating with an organization called Melodic Connections for our Garage Band. The gal that teaches there is a music therapist and has her master's in special ed and the other thing that I'd like to mention, most if not all of the classes are taught either by special ed teachers or by professionals in their field. And that's another thing that makes us really unique is that people that are teaching the classes are all professionals. (Wiener, 2012)

In the *FOCUS* interview, Barb was asked to describe how the classes at The TALL institute differ from mainstream educational settings. Barb responded,

I guess the only way that you could compare it would be to a college class because that would be the age range that you're talking about and um I guess the ability to really kind of design your own class, and really which in a college environment you're not gonna be able to do too much. The class is set up and you're gonna come in and you're gonna be taught, whereas in our class there's really a lot of interaction and discussion about what's going to happen next and what do we want to learn as opposed to what you have to learn so there's a lot of freedom there to be able to say, 'I wanna just learn. I just wanna have some

learning come my way.’ And it happens for them in many, many different areas. (Wiener, 2012)

Barb described the importance of allowing students to decide what they wanted to do and learn by providing direct input into the design of classes and social activities at TALL. During pre-field observations and participation as a volunteer at TALL, the researcher witnessed repeated discussions with students and Barb where individuals gave their feedback into major and minor details of events at the institute. This collective decision-making is a unique characteristic of TALL and evidence of the director’s adherence to the Sociopolitical Model of disability (Smart & Smart, 2007), empowering individuals to make choices and provide feedback on activities and events that impact their daily lives. Barb went on to describe what makes her agency unique, during the *FOCUS* Interview,

I think, like I said, it came from my private practice. I was really looking at those people that were coming to me that really were very, very capable and very needy as far as wanting friendships and that was really my original goal was to gather people together so that they could have relationships that were happy, and healthy, and safe, and it would get a little boring if all you ever did was offer classes on relationships. So the next best step is to offer classes that would encourage that and have the bottom line be that’s what you’re working at but to do it in a way that was gonna be fun. (Wiener, 2012)

When asked how she defines success in her program, during the *FOCUS* interview, Barb responded,

Seeing my students wanting to come and being there and being happy and taking some of their stuff to their homes or picking up the phone and calling a friend and actually going out and hearing that they did something that I didn't plan. That's a wonderful thing! So I think really the happy, health, and safe relationships that come from this are really the success. That's the goal, that's what we're looking for. (Wiener, 2012)

The *FOCUS* interviewer asked Barb about plans to expand the work of The TALL Institute outside of the Cincinnati area. Barb responded,

I was really hoping to be able to do that. We would like to open up another place. It probably would be somewhere in the Cincinnati area. We're not exactly sure whether we're gonna go a little bit north, or over to the west side, or whatever, but we would like to be able to start another program that we think we would probably start a weekend program, another WALL weekend program. Um we're not 100% sure about that. Our goal, I didn't mention that my husband is the Director of Operations for our program and our goal is to eventually be up in the Cleveland area since we're Browns and Tribe fans (laughing), but we've got a lot of family up there and we would really like to be able to replicate what we have in that area so that we could retire up there and still be able to have it. And we've got four children that are in Cincinnati, so we're not really going anywhere soon, but we really would like to. And as I said before, it would make so much more sense for the kind of program we're offering, where we really do encourage people with challenges to have friends, other friends with challenges. I think it's a really wonderful thing. It's nice also because I really do think the students and I

are friends but I do know that if they're going to pick up the phone and call someone, it's gonna be one of their classmates, someone that is more like them, closer to their age. And for us to be able to replicate and have another program, around the same size, would be great. (Wiener, 2012)

On January 2, 2013, Barb and Chris opened a second site for The TALL Institute in Lebanon, Ohio. This site will allow the TALL students who live in Lebanon to attend classes and programs closer to home, while also expanding the number of individuals the agency is able to serve. Barb's vision for creating opportunities for individuals to engage in meaningful relationships, while being "happy, healthy, and safe", as listed in TALL's mission, is evidenced in everything she does. The TALL Institute is the ideal site for the peer-to-peer safety and sexuality training program for individuals with ID, described in the following section. Barb's training, background, and experiences makes her the ideal facilitator for such a program. Also, the students who participate in the Tuesday class, Film, Photography, and The Arts collaborate with local agencies in Cincinnati to learn acting and public speaking skills which were useful in delivering the training presentations. The goal of the peer-to-peer training is to reduce vulnerability to abuse and victimization for individuals with ID in Ohio, a disability population that is increasingly vulnerable compared to people with other types of disabilities (Harrell & Rand, 2010). The next section of this chapter will provide a description of the peer-to-peer Health, Safety, and Sexuality Training for You & Me program offered by students at The TALL Institute.

### **The Health, Safety, & Sexuality Training for You & Me Program**

The six participants who were recruited for this study are involved in a peer-to-peer abuse prevention training program at TALL. A total of 14 students at TALL participated in the Tuesday class, Film, Photography, and the Arts, however, attendance varied from week to week, depending on students' availability. Eight women and six men participated in the class. Twelve of the students in the Tuesday class are White and one woman is multiracial. Do to HIPPA regulations, the researcher did not obtain detailed information regarding the students' ID and DD diagnoses, however, several of the students shared this information voluntarily, or the information was collected through observation of peer-to-peer trainings. Pseudonyms were used to protect the identities of peer-to-peer trainers and training participants.

In terms of physical and mental disabilities for the students in the Tuesday class, one male student used hearing aids, which were visible. Three women openly described their disabilities as Down syndrome, and one man also shared similar characteristics, although he did not report this as his disability. Six participants described their disability as learning disabilities. Although learning disability is a legal term used to describe discrepancies between intellectual ability and academic achievement (IDEIA, 2004) and does not include impairments as a result of ID, several of the students at TALL use the term learning disability to describe their cognitive limitations as a result of ID. This self-labeling and rejection of the term ID could be a result of limited knowledge regarding the difference between learning disability and ID, or could be a result of the stigma associated with intellectual impairments.



The remaining three students did not openly describe their disability or challenge. One woman who reported learning difficulties also reported she has cerebral palsy and she uses a cane and orthopedic shoes to assist with mobility. Ten of the 12 students wear glasses and none of the students use wheelchairs. One male student who reported learning challenges also reported problems with authority while another male student also reported problems with anger, in addition to a learning disability. One male student in the Tuesday class who has Down syndrome repeatedly engaged in inappropriate behavior, and often required additional prompting and redirection by students and staff in order to stay on task and engaged during class and on outings, as observed by the researcher. As of date, this individual is no longer a student at TALL.

Although medical diagnoses of disability have been misused, throughout history, to categorize individuals with disabilities as different from people without disabilities (Biomedical Model of Disability; Smart & Smart, 2007), the researcher noted the mental and physical limitations of the students in the class to add to the description of the peer-to-peer safety and sexuality training program at The TALL Institute. Agency staff or caregivers who are interested in creating such programs in their area can use this information to determine the applicability of the program to their client populations. This information regarding observed and self-described mental and physical limitations is shared with the intention of increasing the applicability of this program to other contexts.

The Film, Photography, & The Arts class was held on Tuesday evenings from 2 p.m. until 7 p.m. During four sessions, August 21, August 28, September 4, and September 11, 2012, students reviewed a copy of the curriculum (see Appendix C), entitled, Health, Safety, & Sexuality Training for You & Me © July 2008, written by

Shelly Snyder, Allen County Board of Development Disabilities and edited by Barb Thomas. Allen County is located in northwest Ohio, with the city of Lima as the county seat. The curriculum is a project of Partners in Justice, Disability Resource Network, funded by Ohio Developmental Disabilities Council. According to their website at [www.ohiopartnersinjustice.org](http://www.ohiopartnersinjustice.org), Ohio Partners in Justice (PIJ) is a advocacy organization, funded by the Ohio DD Council, comprised of criminal justice professionals, DD service providers, mental health clinicians and individuals who work together to increase the quality of training for professionals and enhance resources in the community for individuals with DD (Ohio Partners in Justice, 2005).

The peer-to-peer Health, Safety, and Sexuality training program is currently in its second year. When asked how this year's program differs from the previous year, Barb shared this year was "definitely an improvement" with the inclusion of professionally created skits. Although skits were included as part of the peer-to-peer training last year, Barb described those skits as:

They were really the most pitiful, measly, misely, [*sic*] little skits that I had kinda written up and had them do it. It was just not my... my goal is to get the information across to the individuals and I do it as a teacher, I do it lecture format and interaction and things like that. But I'm not necessarily someone who's gonna think to do skits. And I did but they were nothing compared to what Dramakinetics was able to do. I mean I wrote them with them but they were the ones that were able to kinda get the steps moving for them to have them see how they can be good learning tool. (B. Thomas, personal communication, February 5, 2013).

Prior to traveling around the state conducting peer-to-peer safety and sexuality trainings, the Tuesday class at TALL engaged in two educational sessions, where Barb presented students with the curriculum, in a lecture format. Barb used a paper copy of the curriculum to facilitate in-depth, interactive discussions on the topics covered in the curriculum, including vulnerability to abuse, types of abuse, and safety planning, discussed in detail in the following section of this chapter. During these educational sessions, the students also shared their personal experiences related to abuse and victimization and several of these stories were incorporated as part of the training presentations. Approximately one-half of the class was devoted to discussion of the curriculum content, with a break for dinner, followed by rehearsal of the skits that would be included as a component of the peer-to-peer safety and sexuality training presentations. The purpose of these educational sessions was for students to become familiar with the topics included in the curriculum and to rehearse the skits, described in a later section.

The peer-to-peer trainers at The TALL Institute engaged in four didactic training sessions and a number of evening and weekend rehearsals over the course of three months (August, September, and October) prior to conducting the first training presentation on November 2, 2012. The peer-to-peer trainers in Bullard and Wallace (1978) completed one year of training prior to conducting peer counseling and sexuality education at agencies that serve individuals with physical disabilities. Although the training the peer-to-peer trainers at The TALL Institute completed was smaller in scope, when compared to the sample described in Bullard and Wallace (1978), the roles and responsibilities of the peer-to-peer trainers differed between the two groups. The peer-to-

peer trainers at The TALL Institute conducted trainings that were facilitated by Barb, while the peer-to-peer trainers in the Bullard and Wallace (1978) study worked independently at their respective field experiences, although their work was supervised by trained staff, including counselors, psychologists, and social workers.

Also, the two groups of peer-to-peer trainers had distinctly different disabilities. In Bullard and Wallace (1978), the peer-to-peer trainers had physical disabilities with no co-occurring cognitive limitations. In contrast, the peer-to-peer trainers at The TALL Institute have various ID diagnoses. Due to the nature of their cognitive impairments, it would be difficult, if not impossible for this particular group of peer-to-peer trainers to travel around the state and conduct training presentations independently.

Similarities between the methods of preparation of the two groups of peer-to-peer trainers included didactic presentations to provide trainers with an opportunity to learn specific topics prior to teaching others. Also, while the peer-to-peer trainers in Bullard and Wallace (1978) completed research papers and engaged in personal journaling, the peer-to-peer trainer at The TALL Institute completed individual safety plans, as a part of /their training. Safety planning is an important component of the Health, Safety, & Sexuality Training for You & Me presentations, and Chris encouraged each student in the Tuesday class at TALL to complete a safety plan, during one of the didactic training sessions. Additional research is needed to examine the impact of trainer preparation on the effectiveness of peer-to-peer safety and sexuality training for individuals with ID. While the trainers in Bullard and Wallace (1978) used role plays and public speaking as part of their training process, the students at TALL rehearsed skits to illustrate the topics covered in the peer-to-peer safety and sexuality training. The following section provides

information regarding the skits that were used as a critical component of the safety and sexuality training provided by students at The TALL Institute.

The students in the Tuesday class rehearsed skits (see Appendix D for scripts) depicting the forms of abuse covered in the curriculum (physical abuse, verbal abuse, neglect, theft, taking advantage, and sexual abuse). The skits also depict the creation of a safety plan, which is also discussed in the curriculum, reviewed in the next section of this chapter. This peer-to-peer Health, Safety, & Sexuality Training for You & Me program is sponsored by a grant from Ohio Developmental Disabilities Council, with support from The Partners in Justice Disability Resource Network, where Barb Thomas serves as the Chairperson of the Victims Subcommittee.

Dramakinetics assisted the students with recording and film production of the skits. According to their website,

Dramakinetics (DK) of Cincinnati is the benchmark of excellence in integrated arts and education programs in Great Cincinnati. Our mission is to use drama, music and movement to engage children, teens, and adults of all abilities to reach their full creative potential while experiencing, creating and performing art. Incorporated in 2007 as a 501 C-3 non-profit corporation, DK is the only non-profit organization in the area providing performing arts classes designed to include individuals of all abilities for recreational, academic, and therapeutic purposes. (Dramakinetics, 2012, para. 1)

The grants from sponsoring agencies allowed the students, as peer-to-peer trainers, to travel around Ohio conducting trainings at various locations, including group homes, residential facilities, and other agencies that provide services to individuals with

ID and DD. The six peer-to-peer trainers were paid \$8 per hour for each presentation and \$6 per hour during rehearsals and practice time. In addition to practicing the skits during Tuesday classes, Barb also met with the peer-to-peer trainers outside of class time for additional rehearsal and preparation.

A total of six peer-to-peer Health, Safety, and Sexuality trainings were presented around the state of Ohio during the fall semester at TALL. Three trainings were delivered in Cleveland, one in The Plains, near Athens, Ohio, one in Clermont County just east of Cincinnati, and one in Cincinnati. Each of the trainings lasted approximately two and one-half to three hours in duration. The following is a description of the curriculum, followed by a rich, thick description of the complete peer-to-peer Health Safety and Sexuality training based on documented observations from two of the trainings, conducted in Cleveland on November 16, 2012 and in The Plains, Ohio on November 2, 2012. The next section provides a description of the curriculum used to provide the peer-to-peer Health, Safety, and Sexuality training provided by students at The TALL Institute.

**The “Health, Safety, & Sexuality Training for You & Me” Curriculum.** The “Health, Safety, & Sexuality Training for You & Me” curriculum was written in 2008 by Shelly Snyder of Allen County Board of Developmental Disabilities. The curriculum was edited by Barbara J. Thomas, Director of TECS Education Center in Cincinnati, Ohio. The curriculum is a project of the Partners in Justice Disability Resource Network with funding from Ohio Developmental Disabilities Council. The authors of the curriculum also give “special thanks to: People First of Ohio for putting all materials in people first language” (Snyder, 2008). “People first language” means any references to people with

disabilities are phrased to emphasize the individual first and the disability second.

People first language is a clear rejection of the Biomedical Model of Disability that emphasizes the disability first and individual second, with language such as “the blind woman” (Smart & Smart, 2007). Recognizing the power of words, disability advocates now favor the use of language as a tool of empowerment, with disability referred to last instead of the first characteristic that is named, as in “woman with a visual impairment”.

The “Health, Safety, & Sexuality Training for You & Me” curriculum (see Appendix C) consists of 44 PowerPoint slides, oriented in landscape format, written in large font and illustrated using simple color images and icons. The curriculum uses visual tools in the form of icons and illustrations on almost every page. Visual tools have been used in mental health, forensic, and education settings to assist individuals with ID, specifically in situations related to sexuality education and reporting sexual abuse. Research supports the use of visual tools, including pictures, role-play, and live models with individuals with ID, specifically to report incidents of abuse and victimization (Lunsky & Benson, 2000; Valenti-Hein, 2002), although additional research is needed to assess the efficacy of such methods.

The first slide of the curriculum serves as a title page, listing the name of the curriculum, along with the authors and funders of the grant. The next two slides provide a disclaimer, beginning with the words, “We are here to talk about something very important” (Snyder, 2008, p. 2). These two slides briefly introduce the topics that will be covered in the curriculum and offer suggestions for individuals who may have “bad memories” as a result of the material that will be presented (Snyder, 2008, p. 3). The

authors suggest an individual “talk to someone you trust”, “talk to a counselor”, or “talk to one of us at the end of the training” if they wish to seek further assistance with past or current experiences of abuse (Snyder, 2008, p. 3). The image on this slide depicts a face that appears to be worried, with a furrowed brow and a mouth that is shaped in a frown. There is a thought bubble connected to the face that depicts one individual pushing another.

One of the most important concerns related to abuse and victimization of individuals with ID are the mental health implications that may occur as a result. The curriculum used in the peer-to-peer health, safety, and sexuality training broaches this topic in the first two slides, encouraging individuals who experience “bad memories” to seek out someone they trust, including a counselor (Snyder, 2008, p. 2) or one of the peer-to-peer trainers or facilitator at the end of the training. Although limited in scope, previous empirical research found individuals with ID who experience incidents of sexual abuse and victimization are often diagnosed with a variety of mental health disorders, including depression, PTSD, anxiety, dual diagnosis (MR and a co-occurring psychiatric disorder), sexual maladjustment, and dissociation (Champagne, 2007; Matich-Maroney, 2003). Individuals with reported sexual abuse histories were also more likely to have been prescribed psychotropic medication than a comparison group with no reported sexual abuse history (Matich-Maroney, 2003). While the curriculum does not provide detailed information regarding mental health implications, the first two slides generate a brief discussion and encourage individuals to seek further assistance, if needed.

The next 12 slides (Slides 4 through 17) discuss “Incidents that affect your health and safety”, including 1) physical abuse, 2) verbal abuse, 3) neglect, 4) theft, 5) taking



advantage of others, and 6) sexual abuse (Snyder, 2008, p. 4). Each of these incidents is comprised of two or three slides. The first slide for each subtopic lists the name of the incident and asks “What is it?” followed by a definition, without any illustrations (Snyder, 2008, p. 5). The second slide lists examples of the incident, along with relevant illustrations. “Neglect” is the only incident that includes two slides of examples (Snyder, 2008, p. 9).

The six “incidents that affect your health and safety” listed in the curriculum accurately capture potential areas of vulnerability to abuse for members of this population. In 2008, The Bureau of Justice Statistics collected information on violent crimes and property crimes committed against individuals with disabilities, including rape/sexual assault, robbery, aggravated assault, simple assault, household burglary, motor vehicle theft, and other forms of theft (Harrell & Rand, 2010, p. 1). All of these areas are covered in the curriculum, although they are conceptualized using different language (i.e., physical abuse, sexual abuse, theft) in addition to topics of verbal abuse, neglect, and taking advantage (Snyder, 2008).

The next section of the curriculum begins with two title slides entitled, “How do you say no?” followed by “Safety Planning: What can you do?” (Snyder, 2008, p. 18, 19). This section includes a list of eight questions and statements spanning 18 pages covering topics such as understanding risk factors, vulnerability to abuse and victimization, perpetrator characteristics, and factors that prevent or decrease the likelihood that individuals will report abuse. These slides are detailed and illustrated using large fonts and colorful images. These eight questions and statements serve as subheadings for the safety planning section:

- 1) Understand Your Risk Factors
- 2) Understand Why People with Disabilities are Taken Advantage of
- 3) Understand How to Know You are Being Abused
- 4) Understand and Know the Things An Abuser May Do
- 5) Understand Who the Abusers May Be
- 6) Understand What Would Keep You from Reporting Abuse or Telling Someone
- 7) It is Important to Tell Because...
- 8) Who Should You Tell? (Snyder, 2008).

Although the actual prevalence rates of abuse vary depending on the particular study, the authors of the curriculum portray information related to higher rates of victimization for individuals with ID. This is supported by published research by Petersilia (2001), Sobsey (1994) and more recent data collected by the Bureau of Justice Statistics (Harrel & Rand, 2010) showing individuals with ID to be more likely victims of violent crime than their peers without disabilities and compared to individuals with other types of disabilities.

The curriculum also emphasizes the importance of reporting abuse. According to Petersilia (2001), crimes against individuals with ID and other developmental disabilities are underreported and rarely prosecuted by the authorities. The curriculum used in the peer-to-peer health, safety, and sexuality training encourages individuals with ID to report and also provided statistics on the percentages of individuals who fail to report such incidents. Individuals are encouraged to report incidents of abuse to “more than one person” and “keep telling until someone listens and helps you” (Snyder, 2008, p. 38).

The final six slides of the curriculum are sectioned with a title page, “Complete your safety plan.” This section of the curriculum is comprised of nine questions, with minimal images, and encourages individuals to identify a “good safe person” to assist in the creation of a safety plan, while also prompting discussion on the necessary criteria for classifying another person as “safe” (Snyder, 2008, p. 41). These nine questions were written to stimulate self-reflection and critical examination of relationships between individuals with ID and significant others, such as family, friends, staff, and caregivers. These nine questions, listed below, are preceded by the following statement, “Ask yourself these questions. If you can answer ‘no’ to all of them, then you have made a good choice”:

- Has this person ever hurt your body?
- Has this person ever hurt your things?
- Has this person ever made fun of you or embarrassed you?
- Has this person ever called you names?
- Has this person ever borrowed your money without paying you back?
- Has this person ever touched you where you did not want to be touched?
- Has this person ever threatened you?
- If you were alone with this person in a dark room, do you think he/she might do something bad?
- Has this person ever refused to help you?

In addition to addressing relevant topics, the curriculum also addresses potential perpetrators of abuse against individuals with ID. This discussion includes identification of potential perpetrators of abuse, along with discussion of potential actions and

behaviors associated with various forms of abuse. This discussion is described in the literature by Sobsey and Calder's (1999) Multifactorial Model of Violence. This model illustrates victim factors, offender factors, and relationship factors that increase the likelihood of abuse and victimization for individuals with ID. The curriculum encourages individuals to assess quality of relationships between themselves and family members, caregivers and other providers, and relationships with other individuals with disabilities in order to effectively identify and report situations that are inappropriate or potentially abusive.

The final slide contains nine statements with the title, "It is always important to remember..." (Snyder, 2008, p. 44). These statements list rights and responsibilities associated with victimization, such as "Abuse is against the law" and "You have the responsibility to tell someone when you have been hurt" (Snyder, 2008, p. 44). This final slide in the presentation does not have any pictures or illustrations.

While the "Health, Safety, & Sexuality Training for You & Me" (Snyder, 2008) curriculum has several strengths and is supported by previously published literature, one limitation is the word "health" included in the title and throughout the document. A more appropriate title for the curriculum could be, "Safety & Sexuality Training for You & Me" in order to accurately capture the content that is covered. The curriculum primarily addresses incidents that affect safety; however the term "sexuality" could remain because of the emphasis on prevention and reporting of sexual abuse as a critical issue both in the curriculum and in the training. The term "health" is somewhat misleading because it may lead the reader or potential training participant to believe aspects of physical health, such as hygiene, exercise, and nutrition, would be covered by the material. Although incidents

of physical abuse, resulting in injuries to an individual's body, and neglect, such as failure to provide an individual with food, medicine, or assistance with activities of daily living, the primary concern is to provide individuals with ID with tools they can use to be "safe" as opposed to "healthy".

To obtain additional information on the sexuality component of the Health, Safety, and Sexuality Training for You and Me curriculum, the researcher asked Barb to describe her thinking when she decided to include "sexuality" in the title. Barb discussed sexuality as a broad concept that includes abuse prevention, safety, healthy relationships, and knowledge of self, rather than a narrow topic, solely focused on the sex act. Barb shared,

The sexuality piece? Well, to me, understanding about abuse prevention has to do with who you are as a person, and to me, who you are as a person, describes your sexuality. To me, your sexuality is where you are socially, how you express affection, love, and intimacy, your social role, your family role, your body image. All of those things, to me describe your sexuality. And so when I think about this as a health, safety, and sexuality training, to me it means really thinking about who you are as a person and then figuring out how do you say no to someone depending on who you are, that is how you figure out how to say no to someone.

(B. Thomas, personal communication, February 5, 2013)

Human sexuality is a complex construct, covering a variety of topics Barb mentioned above. While the safety and sexuality training program at TALL focuses on one aspect of sexuality, related to abuse prevention and safety planning, other components of sexuality, as described by Dennis Dailey in Schroeder and Kuriansky

(2009), include sensuality, sexual identity, intimacy, and sexual health and reproduction. SIECUS and others use Dailey's model to describe sexuality as more inclusive than the actual sex act. In an individual interview with the researcher Barb discussed the importance of sharing this information regarding sex versus sexuality with participants, but admitted she has not included this information in recent training presentations.

Now I will tell you, it's a really good question. And the reason is for many of the trainings but not for all of the trainings I have talked about the difference between sex and sexuality, at the very beginning. Um but I haven't been doing it and maybe I should be. As the facilitator I kind of, when you're doing the same training over and over again, you try to be a little different, you try to make it appropriate for the particular group and of course because I've got the presenters that are, that have their own intellectual challenges, I do try to kind of do the same thing but for my own brain, sometimes being a little creative and adding things and whatever is a good thing but what I just said there about sexuality and it being [*sic*] kinda defining who you are, I think in order to be healthy and to be safe you do need to know who are. You need to know what makes you feel good and what makes you not feel so good. And um so I think, that's how I think it all goes together. Does that make sense? Do you have my flyer on sex versus sexuality? I should probably give that to you. Since I just said that. [*sic*] Remind me because it's something that I always use or often use when I'm doing trainings and um it's kind of a preface so that people know who I am. And I ask people right off, often teachers and parents if you can buy into this is what sexuality is, it leads you to

understand why um sexuality education is so important to an individual and to their development. I'll give you that so you can see it. (B. Thomas, personal communication, February 5, 2013)

The researcher did not include Barb's handout on sex and sexuality as an appendix. Barb is currently in the process of writing a curriculum on sexuality for individuals with ID and interested readers are encouraged to purchase a copy once the document is available for publication. Future peer-to-peer safety and sexuality trainings could benefit from a statement regarding the difference between sex and sexuality and clarification of safety planning and abuse prevention as one aspect of holistic human sexuality. While this portion of the chapter provided a description of the curriculum, the next section will provide a description of a complete peer-to-peer Health, Safety, and Sexuality training, using data collected from two observations of trainings.

**The "Health, Safety, & Sexuality Training for You & Me" trainings.** The researcher observed two Health, Safety, and Sexuality Training for You and Me presentations: one in an urban area in Cleveland, Ohio at Bridges Rehabilitation Service, and one training presented at Hearts of Hope Institute in The Plains, a rural community in southeast Ohio. Although the researcher originally planned to observe a minimum of three trainings, scheduling conflicts, including one final training presentation that was rescheduled by an agency in Cleveland, prevented additional observations.

Four of the peer-to-peer trainers, Travis, Sam, Heather, and Richard, along with Barb, facilitated the training presentation in The Plains. Pseudonyms are used throughout the case study for confidentiality purposes. Six participants attended the training presentation in The Plains, including four White males, one Black male, and one White

woman. None of the participants used wheelchairs or other mobility devices and two wore glasses. Barb expected the participant group to be as large as 20 to 25 participants, however, agency staff at Hearts of Hope told Barb, after she arrived with her students, that the majority of their clients are at work or attending classes at local colleges and universities during the day. This was the first Health, Safety, and Sexuality Training for You and Me presentation of 2012. Barb and the peer-to-peer trainers were initially shocked and surprised to see a small group of participants because they expected, and are encouraged by the grant, to provide training to groups averaging 30 participants.

All six peer-to-peer trainers (Richard, Heather, Sam, Travis, Amy, and Steven) and Barb facilitated the training in Cleveland. Chris, Barb's husband, also attended. Twenty-five participants attended the training in Cleveland. Fourteen participants were female, 11 were male; five were Black and the remaining 20 were White. Four participants in Cleveland used wheelchairs and five wore glasses. The researcher observed the second presentation delivered at Bridges; the peer-to-peer trainers and Barb provided another training the day before to a different group of participants at Bridges.

Each peer-to-peer Health, Safety, and Sexuality training followed a similar format, following an agenda created by Barb. Agendas were distributed in blue, two-pocket folders that also contained an abbreviated five-page version of the "Health, Safety, & Sexuality Training for You & Me" curriculum, a three-page safety plan, to be completed at the end of the training, and a pink one-page handout, entitled "Ohio Partners in Justice, Team Blue" that provided an overview of the peer-to-peer training program. The agenda contained five broad components, in outline form, with additional



information included under each of the five bullets. Copies of all handouts are included as appendices. The agenda included the following items (actual agenda text is italicized):

1. *Introductions*, followed by the name of each peer-to-peer trainer with Barb's name listed last as facilitator;
2. *Incidents That Affect Your Health and Safety*, followed by the six major incidents that will be covered in the presentation (physical abuse, verbal abuse, neglect, theft, being taken advantage of, and sexual abuse);
3. *Understand*:
  - a. *Your risk factors*,
  - b. *Why people are taken advantage of*,
  - c. *How you know you are being abused*,
  - d. *Group discussion*;
4. *Safety Planning: What can you do?* and
5. *Evaluation*.

Each of the six incidents listed in the second bullet on the agenda were accompanied by one or two brief skits, which included two peer-to-peer trainers serving as actors using minimal props to depict scenes of abuse and victimization. While some of the peer-to-peer trainers memorized their lines, others used four by six inch cards to read their lines while acting out the skits. While the "Health, Safety, & Sexuality Training for You & Me" (Snyder, 2008) curriculum used pictures and icons as visual tools, the peer-to-peer Health, Safety, and Sexuality training also used visual tools in the form of mini-

dramas, or skits, to illustrate the six incidents and safety planning as covered in the curriculum.

Researchers advocate for the use of role-plays and other visual methods when teaching topics related to safety and sexuality (Lunsky & Benson, 2000; Valenti-Hein, 2002). Peer-to-peer trainers served as the actors for the skits and individuals with ID who served as participants in the trainings could likely benefit from seeing their peers encounter scenarios depicting incidents of maltreatment and safety planning. Other visual tools used during the training included a five-page summary of the curriculum distributed to each participant, the inclusion of pictures and icons on participant evaluation forms, and a color, 24 by 36-inch poster that was used during the trainings to highlight key points and agenda items. The six incidents are described in detail in the following section, with their corresponding skits. This description of the trainings follows the format of the five major agenda items.

***Introductions.*** Both of the trainings observed by the researcher began with an introduction of each peer-to-peer trainer, including their first and last names and where they were from, followed by a brief introduction by Barb, as facilitator. Each peer-to-peer trainer had a card, approximately four by six inches in size that contained the information he or she planned to share in their introductions; however, only some of the trainers read their cards during introductions and others memorized the information they planned to share. Next, Barb asked each participant to introduce him or herself. In Cleveland, each participant simply stated his or her name. In The Plains, Ohio, with six participants, Barb facilitated more detailed introductions, including living arrangements, interests, and

employment and leisure activities. In order to protect the confidentiality of training participants, pseudonyms are used.

During introductions in The Plains, Stan introduced himself as a DJ (disk jockey)/producer who works at Personnel Plus, a supported employment agency for people with disabilities in Athens County. Stan has thick, dark hair, wore glasses and a full beard and he wore the hood from his sweatshirt on his head during most of the presentation. Stan also had a large hole in the front of his pants that stretched from the middle of his calf to his mid-thigh on his left leg. Stan is 19 years old, lives alone in a college apartment and attends outings at Hearts of Hope.

Bill did not state his age but he appeared to be the oldest of the group. Bill shared he likes sports, ball games, movies, and does not work but comes to Hearts of Hope every day. Bill told the group he lives with his provider who is a staff member at Hearts of Hope. Bill wore a baseball cap and seemed to have more severe cognitive impairments than the other members of the group. Bill grinned and giggled often and small amounts of dribble escaped from his mouth at times.

Kelly was the only woman in the group at 21 years old. She lives alone was not currently working at the time. Kelly comes to Hearts of Hope five days each week, spends weekends at her parents' house and used to have a cat as a pet. James is 22 years old, lives alone, comes to Hearts of Hope five days each week and shared he "would rather not be here." King is Black and was visting from Maryland. King did not share his age but told the group he likes to skate, swim, and draw. He is the nephew of the agency director. Chase is 21 years old, a former employee of Personnel Plus, a supported

employment agency for individuals with disabilities in Athens County, and lives alone in a house in The Plains.

Each of the peer-to-peer trainers and the facilitator wore cobalt blue collared shirts with a white TALL Institute logo embroidered on the left chest. Barb stood or sat on a barstool while the peer-to-peer trainers positioned themselves around a long rectangular table. Participants who attended the trainings in Cleveland and in The Plains sat around long rectangular tables in a classroom-like setting.

***Incidents that affect your health and safety.*** In Cleveland, immediately following introductions, Barb provided a brief disclaimer saying, “We talk about sensitive stuff” and encouraged students to refrain from sharing information that would be considered too personal, such as past incidents of sexual abuse or using the names of staff and family members when sharing their experiences with others. In Cleveland and in The Plains, Barb transitioned into the second set of agenda items by asking, “What does abuse mean?” Participants in The Plains responded, “burning somebody”, “sadism”, “torturing.” Participants in The Plains and in Cleveland responded to this question with brief, one-word responses and the researcher was unable to capture details regarding specific statements from specific participants. In Cleveland, Barb continued facilitating responses until a participant responded by saying abuse means “to hurt.” Below is a list of the major constructs, as they are defined in the curriculum.

- Abuse: hurt
- Physical abuse: hurting someone else’s body
- Verbal: words

- Verbal abuse: using words or hands or body parts to threaten, scare or make fun of you. Even when you ask or let the person know it hurts, it does not stop.
- Neglect: when getting special help or a special service that you need does not happen
- Theft: stealing or taking things or your money
- Being taken advantage of: “using” another person for their money, body, or other things to satisfy the other person’s needs
- Sexual abuse: someone touching you on your body in a way that makes you feel uncomfortable. Sometimes it might really hurt and other times it might be very confusing. (Snyder, 2008)

***Physical abuse.*** The first incident Barb introduced during both of the observed trainings was physical abuse. In both trainings, Barb called on two peer-to-peer trainers to act out the first skit, depicting a scene of physical abuse, with Travis and Richard as actors. This first skit depicted a father (Travis) yelling and hitting a son (Richard) for allegedly putting away tools on the wrong shelf. Scripts for all of the skits are included in Appendix D. After the skit in The Plains, Barb asked Richard, “How did you feel?” and Richard responded, “Like crap!” King, a participant in The Plains, said, “The father was acting violent.” Barb asked, “What should he do?” and a participant in The Plains responded, “Report to the police.” In addition to physical abuse, Barb asked, “What other kind of abuse is that?” and Chase responded, “Verbal!”

While the father and son skit was the only physical abuse skit included in the presentation in The Plains, Heather and Sam acted out a second physical abuse skit at the training in Cleveland. In the skit, the two women argued briefly about a man who is not

present. Sam pushed Heather on her shoulder, saying, “I don’t know what he sees in you anyway! He should still be MY boyfriend!” After this skit, Barb transitioned into the next incident affecting health and safety – verbal abuse.

*Verbal abuse.* The second incident Barb introduced in The Plains and in Cleveland was verbal abuse. In Cleveland, Barb asked, “What does verbal abuse mean?” and a Black woman who wears glasses responded with, “Calling you, like, ‘retarded’.” Barb then asked, “How many of you have ever been called ‘retarded’?” and almost every one of the 25 participants raised their hands. Barb then asked “Why would someone call you that?” followed by “How does it make you feel?” Participants in Cleveland responded with a wide range of responses including, “Different from everybody else, you got special needs”, “like having a disability”, and “makes me cry”. Barb then facilitated a brief discussion of the recent changes in Ohio, removing the term MR from the names of state agencies serving individuals with ID and DD. One participant in the training in Cleveland described these changes as positive “because the word ‘retarded’ is offensive.”

In The Plains, Barb introduced Heather and Richard to act out a skit depicting verbal abuse, prior to facilitating discussion. Heather and Richard appeared to be a couple involved in an argument. Heather’s character yelled at Richard’s character because he forgot to pick up hamburger meat from the store. Richard’s character appeared reclusive and withdrawn as Heather’s character raised her voice and yelled, “Oh poor baby. Is that what you are? A baby?” After this skit in Cleveland, a Black woman responded, “Now that wasn’t very nice!” She went on to share, “I don’t get a chance, when people tells me things, I don’t get a chance.” Barb asked the participants in both trainings who the two individuals might be. Chase, in The Plains responded “girlfriend and boyfriend” and a

participant in Cleveland stated “could be married.” When Barb asked for one word to describe how Heather was treating Richard in the skit, one participant in Cleveland responded “disrespectful.” This was the first verbal abuse skit presented in The Plains and in Cleveland and a second scene depicting verbal abuse was used in both trainings, described below.

The second skit depicting verbal abuse was role-played by Sam and Richard. This scene took place in a grocery store and opened with Sam struggling to pull two small grocery baskets apart. When Sam saw Richard walking past, she asked for help saying, “These baskets always stick. Can you help me?” Richard’s character responded saying, “If you can’t figure it out, maybe you shouldn’t be here.” Richard then made the “crazy” sign by circling his index finger in the air around his right ear, as he walked away. In Cleveland, Barb processed reactions to this skit, beginning with the statement, “Sometimes we all need help” and a participant from the audience shouted, “It’s nothing wrong with that!” Additional reactions to this skit from participants in Cleveland included “I think it was uncalled for!”, “You gotta treat people the way you wanna be treated.” One Black male in Cleveland shared a personal story of a housemate who was verbally abusive. When asked how he handled the situation, he responded, “Kill them with kindness.”

At this point in the presentation in The Plains, Barb facilitated a discussion on verbal abuse, similar to the discussion in Cleveland, with the question, “How many people have been called stupid, fat, ugly, or retarded?” James laughed when he heard the word “retarded”. Barb asked James how he feels when people use that word to refer to him and he responded, “Sad.” Kelly shared a personal experience and said her brothers

treat her “like that.” Kelly mentioned she and her brother are adopted and her brother calls her “retarded”. At this time, each of the four peer-to-peer trainers shared words they have been called. Richard said he had been called “fat, retarded, dumb ass”, Heather said “bitch, fat, and retarded”, Sam said “stupid, retarded”, and Travis stated “retarded” and “spaz” as words that had been used against them in a negative manner. Sam mentioned some staff and co-workers had been verbally abusive towards her and Stan, a participant, told her the staff members in The Plains are “respectful”.

*Neglect.* In The Plains, Barb transitioned into the third incident by posing a question, “What is neglect?” Chase answered, “Not giving you your meds”. Then Barb and Travis acted out a skit where Travis waited on his ride that was over an hour late to pick him up from an outing and take him home. The second neglect skit in The Plains had Sam and Heather playing the roles of a DD staff person and a client who is a recipient of DD services. In this skit, the staff person forgot to make dinner for the client, encouraging her to “eat a bag of chips” instead. The staff person also forgot to pick up the client’s medication at the pharmacy.

Barb asked the participants in Cleveland what the word neglect means. Two participants responded, “act like they ain’t there [*sic*]”, “ignore” and “black it out”. She then asked what would happen if they didn’t get their medication. They answered, “I go crazy”, “I don’t sleep at night”, “I have a behavior”, “I destroy stuff”, “I don’t sleep at night”, “be depressed all the time”, “You’d get sick”, “feel sick”, “Your whole mood would change”, and “I could be in the hospital”. The participants in Cleveland responded to Travis’s skit and reported feelings of isolation and rejection, saying they would “feel like you’re not wanted”, “ignored”, “stood up”, and “left out”, as if the staff person was



“putting theyself first [*sic*]” before considering the needs of the client. One Black man who uses a wheelchair to assist with mobility mentioned “not getting changed at night” would cause him to feel neglected.

**Theft.** Barb transitioned into this portion of the agenda in The Plains by asking, “What is theft?” King responded immediately, “Someone taking things” and Chase answered with, “Stealing a car.” Bill said, “Going to jail” while Kelly offered, “Shoplifting” and told the group a story of her stealing items from the store as a child. This fourth incident prompted discussion of theft in Cleveland and in The Plains, along with one skit and personal experiences shared by the peer-to-peer trainers. Richard and Travis were in the skit, playing the role of two friends. One friend allowed the other to borrow a DVD that was never returned. When he asked about the DVD, his friend replied, “Maybe I’ll just keep it.” Participants in Cleveland reacted to this skit, saying, “That’s like breaking a promise”. In The Plains, Stan said, “I don’t lend things, I don’t wanna get screwed over”.

In Cleveland, Heather shared a personal experience with theft where a “friend” and former DD staff person stole her iPod, laptop, mp3 player, and Nintendo DS video game from her house and blamed it on someone else. Heather also shared this experience with participants in The Plains and Stan responded with “Wow, that’s intense, shady, sketchy.” In Cleveland, Steven also shared a personal experience related to identity theft where a DD staff person opened a rental account at Blockbuster using his name and information and the names of other individuals who were clients of DD services at the agency where he worked. This staff person would then rent video games and sell them for cash at other stores, including Game Stop. Since Steven was not present at the training in

The Plains, Barb shared his story with the participants there. Personal experiences such as these added to the depth of the training presentations and provided trainers and participants with an opportunity to connect concepts to real experiences and process reactions and lessons learned.

In The Plains, King told the group he let a girlfriend borrow money and never got it back. When Barb asked how he felt, King responded, “Not very happy.” James told King, “I’d go find them.” Chase told King to “call the police.” When Barb asked, “Who can steal?” Chase responded, “anyone”. Barb asked who would feel “100 percent comfortable calling the police” on a family member and everyone in the group responded with a resounding, “No.” This question generated a discussion of the difficulties associated with reporting abuse by family members. Heather told Barb it is difficult for her to report maltreatment by family members because “you love that person.” King told Heather, “I would tell them to get help.” Barb asked, “How many times would you let that happen?” and Chase said “not many.” Then Barb said, “Parents have a hard time calling the cops on their kids” and Travis responded, “Then it keeps on happening.” Kelly told the group a story of her adoptive brother who approached her with sexual advances and Barb redirected saying, “That’s for sexual abuse,” which generated a chuckle from Travis. At this point in The Plains, the time was approaching 10:00 a.m., approximately 30 minutes into the presentation. Stan put his head on the desk, Chase yawned, and King leaned over on the table.

***Being taken advantage of.*** The fifth incident discussed in both trainings centered on people taking advantage of others. In The Plains, Barb asked Stan to define the construct and he responded, “I would jump on that like white on rice!” Barb smiled and

said Stan doesn't look like the type to let people take advantage of him. King introduced the concept of privilege in his definition of taking advantage, "Taking advantage of privileges like not bringing the car back on time." Barb then talked about friends who only call when they need a ride may not be genuine in their friendship.

Participants in Cleveland defined taking advantage as "using somebody", "screwing me over", and "because you want something from that person you be nice to them". In Cleveland, there were two skits associated with this incident, the first with Steven and Sam playing a scene as friends. In this scene, Steven's character was visiting a friend's home and asked if he could have a soda. After hearing, "There's one in the fridge, help yourself" from Sam's character, Steven returned with an entire case of soda. Sam's character responded, "I said you can have ONE, not the whole case." The second skit depicted a staff person and a client in the grocery store, played by Heather and Amy. Heather, playing the role of the staff member, asked if she could put her groceries in with the client's and pay her back later. Amy's character responded, "You're my staff, I shouldn't have to pay for your things."

At this point during the training in Cleveland, Barb shared a story of one of the students at TALL who had a staff person that took advantage of her. According to Barb, the staff person told the client she didn't have enough money to purchase Christmas gifts for her children. The client provided the staff with a sizable amount of money that was never returned. After posing a question asking why these situations were wrong, one participant in Cleveland responded, "'Cause you're at work and you're not allowed to accept gifts."

*Sexual abuse.* The sixth and final incident discussed as part of the second major agenda item was sexual abuse. As Barb transitioned into this part of the trainings, one of the participants in Cleveland shouted, “I was just getting ready to ask about sexual abuse!” Other participants in the room provided definitions of sexual abuse, in response to a question from Barb, including, “touching”, “when someone puts they’re weight on you, you say no, and they still do it” and “rape”. One White woman in Cleveland who wears glasses shared, “I had a boyfriend and he treated me like dirt”. Another woman who is White and uses a wheelchair defined rape as “when somebody forces you to have sex”. Barb told the group, if you don’t want someone to touch you, you have the right to say “no”. The participants then practiced saying “no” together.

In Cleveland, the peer-to-peer trainers provided additional examples including, “human trafficking” (Sam), “voyeurism” (Amy), “peeping Tom” (Richard), “sexting” and “groping” (Scott), and “sexual harassment” (Sam). One of the participants in Cleveland, a young woman, started to recall a personal incident related to sexual abuse by a family member and Barb immediately intervened and redirected.

The skit associated with sexual abuse depicted a scene with a landlord and a tenant who was late on her rent. In The Plains, Barb forgot to introduce the skit, however, in Cleveland, Heather and Travis played the roles for this skit. The landlord, played by Travis, told the tenant, Heather, she can pay her rent the following week if she agrees to have sex with him. When the tenant refused, the landlord threatened to kick her out. Reactions to this skit were mixed and one participant in Cleveland said, “I don’t want to be here right now in this classroom about sexuality”. Barb reassured the participant by telling her they were near the end of this particular part of the discussion. The participant

chose to stay for the remainder of the training. After the skit, Barb asked, “Why was that not good?” A young woman who is White and does not wear glasses said, “because they were gonna have sex” and she asked, “What about kissing all over the place?” Barb facilitated a brief discussion of consent versus coerced sexual activity. In Cleveland, Chris, Barb’s husband, shared a story of a young man who reported being abused by a woman while working at a sheltered workshop.

In The Plains, Barb asked participants to define sexual abuse. James wore a smile and said “rape”. Barb commented on his smile and asked him to define rape. James responded, “A girl says no to sex and you do it anyways.” Chase told James “a woman can do it to a man” and King chimed in, “I know for a fact women are fragile.” At this comment, Barb stood up walked over to where King was sitting and asked, “Do I look fragile to you?” Scott warned King, “You bit off more than you can chew on that one!” At this point Barb gave a brief explanation of several ways that a woman could take advantage of a man, sexually. Barb used classroom-friendly language, void of explicit terms. Barb described the role of power in rape and other forms of sexual abuse, including differences in age and employee versus employee dynamics. Barb told the group there “are lots of sexualized women and that’s not okay either. Men sometimes get a bad rep.” Stan told Barb that it is sometimes harder for men to express their sexuality.

The discussion of male versus female perpetrators continued when Barb said men are not always the perpetrators of sexual abuse, although more men are convicted and in prison. When Chase told Barb, “I don’t believe that”, Barb continued, saying sometimes men are too embarrassed to press charges. Participants and peer-to-peer trainers in The Plains went on to list other kinds of sex crimes, including “sodomy and sexual

harassment” (Stan), “raping them and killing them” (Kelly), “kiddie porn” (Stan), “videotaping, peering Tom” (Heather), “peeing Tom” (Travis), “voyeurism” (Travis), and “looking at boobs” (King). Barb asked about indecent exposure and told a story of a man who flashed his penis at her mother who was waiting for a bus, about 10 or 15 years ago. James told the group he was accused of sexual harassment on the bus in high school. He shared a story, saying a group of “high schoolers kept telling him to touch a younger person.” Stan asked about phone sex and Barb facilitated a brief discussion on the importance of choice.

In The Plains, Barb asked the group to define molestation. Chase responded saying, “Molesting is when you touch someone’s private and they don’t want you to.” This led to a discussion of “private parts” that Barb facilitated in both of the observed trainings. Barb continued, “While we generally think of our ‘private parts’ as those parts of our bodies that are covered by swimming suits”, at this time Barb made a swiping motion in the air in front of her chest and near her hips and rear, “Really our entire body is a ‘private part’ when it comes to touch”. Stan asked Barb, “What is fondling?” and King asked, “flirting?” Barb answered with “touching private parts.”

**Understanding and Group Discussion.** At this point in both trainings Barb announced a five to ten minute break as this marked the halfway point in the training, with approximately one to one and one half hours remaining. After returning from the break, the next item on the agenda was the third major bullet point, entitled, 3) Understanding: a) Your risk factors, b) Why people are taken advantage of, c) How you know you are being abused, and d) Group Discussion. At this point in the training in The Plains, after returning from the break, Barb paused asked, “Why are we here?” and Chase

responded, “So you can help us.” In Cleveland, Barb spoke briefly about the peer-to-peer training program and posed a question to participants, asking, “What makes you different, unique, wonderful? Why are you here at Bridges?” The responses started out more general including responses such as “to meet people”, “to help people”, “It’s nice to get out and get paid”, and “I like making tubes and cups out of newspapers, referring to the tasks they complete at the sheltered workshop. However the responses quickly became more specific, “People help me here” and “I’m a little bit different, I can’t work at other places.” Barb continued, “What makes you guys different?” Another participant responded, “We all have disabilities.” Barb continued, “Do you know what it is?” and this question generated a myriad of responses, including, “my eyes”, “my hands”, “I have ADHD, I have to keep moving”, “seizures”, “I have autism”, “I’m paranoid schizophrenic and chemically imbalanced”, “spina bifida, paralyzed from the waist down”, and “thyroid problems”.

In Cleveland, Barb continued to facilitate a discussion of what it means to have a disability, specifically ID and DD, including difficulties reading and writing, and the use of ISPs and IEPs (ISPs [Individualized Service Plans] and IEPs [Individualized Education Plans] are often used by DD service providers, such as sheltered workshops or vocational rehabilitation agencies, and in education settings to identify goals and track progress of those goals for individuals with disabilities.) At this point, in the Cleveland training the peer-to-peer trainers shared their descriptions of their disabilities. Richard described his disability as “learning challenges”, Amy described her disability as “epilepsy and problems with math and numbers”, Heather described her disability as “slow learner”, Steven described his disability as problems with “following authority and

learn a little slower”, Sam described her disability as “learning disability, ADHD, and joint issues”, and Travis described his disability as “learning disability and anger management”.

At the training in The Plains, the number of participants was smaller with six individuals, compared to an average of 25 to 30 participants in other presentations. Barb was able to ask each participant and peer-to-peer trainer to describe their disability, asking, “What challenges or disabilities do you have?” One participant declined to respond, stating “I’m a private person and people talk in small towns” and he later responded, describing his challenge by saying he has “privacy issues”. Another participant reported he has “ADD, a hard time focusing, easily distracted from certain tasks”. Another participant shared she has “a short fuse” saying, “I might hit. I might blow up.” Two participants responded, “I don’t know” while another said, “getting mad easily. I threaten people.” Travis responded, “I’ve done that before.” The four peer-to-peer trainers at this presentation also provided more detailed explanations of their challenges and shared more specific details than they shared in other trainings. Sam described problems with anxiety that prevent her from being able to drive. Richard described difficulties selecting the right foods and challenges with managing money. In describing his struggle with anger, Travis said, “I’ll censor myself a little bit” and described yelling, cursing, hitting, and other acting out behaviors associated with his temper. Heather said, “I have a learning disability and I learn slower than other people.” Barb also disclosed her struggles with weight and challenges with controlling her temper.

Self-described definitions of disability are a critical aspect of this case study, building on the work of disability advocates who favor a Sociopolitical Model of



disability that emphasizes the individual rather than a specific medical or psychological diagnosis (Smart & Smart, 2007). The opportunity for individuals to openly share their challenges with other individuals seemed to be a unique opportunity, especially for the peer-to-peer trainers, who later discussed their reactions during their individual interviews. In an individual interview, Barb also shared the importance of understanding how individuals with ID describe their challenges.

This morning when I was doing an interview for a student for TALL, asked her what her...she told me that she had gone to this program and the name in the program was disability, so it was easy for me to say to her, 'So what is your disability' and she was able to share that. And it's always nice to find out what people think their challenges are or their disability and also the language that people use is you know, for themselves. 'You know I don't have a disability, but you know, I can't read', or whatever. So um, yeah, it is nice to know exactly what it is you're dealing with. (B. Thomas, personal communication, February 5, 2013)

As an LPC, the researcher postulates an emancipatory feeling that is associated with connecting with others who share similar experiences, challenges, and struggles. It is unknown how often these conversations would occur among individuals with disabilities in other contexts, however at least two of the peer-to-peer trainers in this program expressed their appreciation for this opportunity to listen, share, and connect with others who may understand them in a manner that parents, caregivers, teachers, and agency staff may not be able to do. On the alternative there is still a stigma attached to certain diagnoses and label, and as Barb mentioned, some individuals resist the term disability and prefer to explain their specific challenges or limitations.

After discussing everyone's disabilities and challenges Barb transitioned into a discussion of risk factors associated with abuse and victimization by asking, "Why are you more at risk? Why are you taken advantage of?" Stan, in The Plains responded, "Because they don't know what people are doing to them. People with MRDD get pushed around." In Cleveland and The Plains Barb listed several risk factors associated with abuse of individuals with ID and DD including living arrangements such as living alone or in a group home with agency staff, communication problems, failure of staff and authorities to believe the victim, and failure to report incidents of abuse. Barb asked participants in Cleveland to provide reasons why they wouldn't report abuse. They responded, "Scared somebody might hurt you" and "scared to lose privileges like transportation." This discussion of risk factors has been documented in the literature on abuse of individuals with ID (Sobsey & Calder, 1991; Sobsey, 1994). Petersilia (2001) documents reasons why crimes against individuals with ID are rarely prosecuted, including limited follow up from authorizes and limited reporting of such crimes. This portion of the training is useful in reversing trends related to reporting and prosecution of crimes against individuals with ID.

Prior to beginning the next part of the training in The Plains, Barb asked the peer-to-peer trainers to bring their table closer to the participants' table, creating one large square with participants and trainers seated around all sides of the joined tables. At the presentation in The Plains, King asked, "Is there a such thing as spiritual abuse?" Richard responded, "I do believe that could be a possibility" and he shared a personal story about his uncle "trying to make [him] listen to the Bible over and over". Stan mentioned "I'm earthy, hippy, don't believe in God" and Travis responded, "I'm the same way". Travis

went on to share a story about a DD staff person he had who “was a religious woman and bugged the crap outta [him]”. Travis reported telling her, “Lady, I’m just fine the way I am.” Heather also shared a personal story about a family friend who “tried to put his beliefs on [her]”. This discussion of spiritual abuse was unique to the training in The Plains and did not come up in other training presentations. Although in Cleveland, Sam told the group her staff wouldn’t take her to church and a participant described this as “disrespectful.”

This discussion of spiritual abuse was significant for one peer-to-peer trainer, Travis, who discussed his reactions in his individual interview. For Travis, and for Stan, individual expressions of spirituality (or lack thereof) seemed to be an additional method of demonstrating independence in actions and decision-making. Barb shared her thoughts regarding this discussion in an individual interview with the researcher.

Well I have a definite personal opinion about that that if people want to be spiritual, if they wanna go to church, if they wanna do things certainly they should have access to it but it has been my experience that um more often than not staff take them to their location, their place of worship instead of encouraging people to go to theirs because it’s just easier for them and it’s more convenient for them and it’s what the staff wanna do. I mean, it should definitely be that they’re going to the individual’s place of worship for sure. (B. Thomas, personal communication, February 5, 2013)

While caregivers, parents, and staff who serve individuals with ID often perpetrate a culture of compliance, consideration of individual preference and choice is crucial, even among seemingly harmless situations such as attending religious services or

discussing spiritual topics. The ACA and CRCC Codes of Ethics advise mental health and rehabilitation counselors against imposing their own values and beliefs on clients (ACA, 2005; CRCC, 2009) and the staff who worked with these individuals were likely in violation of the ethical codes for their respective professions.

**Safety planning: What can you do?** The fourth agenda item was entitled “Safety Planning: What can you do?” Barb transitioned into this segment of the training by posing the following question to the participants in The Plains, “If you won the lottery who would be the first person you would call?” This question generated a list of responses including names of friends, family members and other significant relationships, as identified by participants and trainers. One participant jokingly said he would call “Ghostbusters!” Barb then asked “Why wouldn’t you tell those same people if something bad happened to you? They need to know that.” After a brief period of silence, Barb transitioned the group into the discussion of safety planning. The three-page safety plan included a list of four questions, using words and icons, (see Appendix J) asking participants to first identify “a trusted family or friend” including their name, relationship, and phone number. The second question asked if the participant required assistance with activities of daily living such as toileting, medication administration, dressing, mobility, and eating. The third item on the safety plan stated, “If I had to leave home, I could stay with...” with space for three names, addresses, and phone numbers. The fourth item stated, “If I need to leave home I will need to bring...” medication, money, clothes, personal hygiene items, and adaptive equipment. The final page of the safety plan provided a list of local emergency numbers including law enforcement,

shelters, food and clothing assistance, transportation services, and mental health services. There was also space to list names of individuals who may need a copy of the safety plan.

In The Plains the participants completed their safety plans prior to the training and Barb checked for consistencies between the names listed on paper and the names participants provided when asked who they would notify if they won the lottery. The final three skits of the training depicted safety planning with Sam and Richard in the first skit, Travis and Heather in the second skit, and Heather and Barb in the third. The first safety planning skit is a continuation of one of the scenes depicting neglect. In this skit, a daughter is speaking with her father and telling him her staff did not prepare her dinner or pick up her medicine. The father suggests they create a safety plan and “put together all the things you need in a situation like this.” After creating a safety plan, the father agrees to “first we call the agency and get you a new staff”. The second skit depicts a brother and sister who created a safety plan after the brother’s money for bus fare was stolen and he had to call his sister to ask for a ride home. The third skit shows a student at TALL who reviews and uses her safety plan with Barb after leaving her home because she was approached inappropriately by her “Uncle Larry.”

In Cleveland Barb asked the peer-to-peer trainers to share some of the information they have in their safety plans, as examples for the participants. When Barb asked, “If you left home, what is the one thing you need to take with you?” Heather responded, “my glasses” and Travis said, “my cat” which solicited laughs and giggles from participants. Participants responded to the prompt saying they would take “cell phone for emergency”, “money”, “extra meals”, “clothes”, “medicine”, and “keys”.

Barb then asked participants in Cleveland, what it means to trust someone. They responded, “You tell somebody a secret and you know they can keep it,” “choose people wisely”. Barb asked if anyone had family members they don’t trust and asked why family members might lose that trust. Participants responded, “because of a lie” and “because they borrow money and never pay it back” and “because they give kids drugs and stuff”. Barb then asked participants in Cleveland how they could reduce their vulnerability to abuse and they responded, “call 911”, and “pray to God.” Barb encouraged the group to tell and report abuse because “You are worth it!” Before transitioning into the evaluation portion of the training, Barb asked a few quick questions, “What is physical abuse?” and “What is verbal abuse?” Hands shot up across the room and participants stated physical abuse hurts your body while verbal abuse could hurt you mentally. Barb then transitioned the group into the final portion of the agenda.

**Evaluation.** As the trainings in The Plains and Cleveland came to a close, Barb, along with staff members at the agency, distributed 2-page evaluation forms with a total of nine questions and statements, grouped into two categories. The first category of items elicited feedback on the training with statements, illustrated with icons, followed by a happy face and a sad face to indicate agreement or disagreement with the statement: 1) The training was good, 2) The training was easy to understand, 3) The people in the skits did a good job, and 4) I learned something today. The second page included five knowledge questions, also illustrated with icons, followed by “yes” with a thumbs-up icon and “no” with a thumbs-down icon: 1) Is spitting an example of physical abuse?, 2) If someone touches you on the arm and you don’t like it, is that sexual abuse?, 3) Are most abusers strangers, 4) Will a safety plan help you stay safe against abuse and

neglect?, 5) If someone abuses you, is it your fault? Participants in Cleveland and The Plains completed the first version of the evaluation form, created by the researcher, and participants in later trainings completed a second version, amended by Barb to include additional demographic and open-ended items. A copy of both versions of the participant evaluation form, along with a copy of the staff evaluation form, is included in Appendix E. Evaluation reports summarizing data collected from completed evaluations is included in Appendix F.

### **Conclusion**

Behavioral methods of instruction (Utley et al., 2001) and solicitation of feedback from participants (Bullard & Wallace, 1978) are well-established techniques used to teach individuals with disabilities about topics related to health, safety, or sexuality. Utley et al. (2001) used class-wide peer tutoring as a method of teaching health and safety facts to children with DD. Researchers in their study found several of the teaching methods were effective, including immediate feedback, error correction, reinforcement, and participation from the entire group. Although the peer-to-peer Health, Safety, and Sexuality trainings involved adults with ID as trainers and participants, several methods of instruction were similar, including the use of positive reinforcement, and opportunities for all participants to respond. Also, participants and trainers in the peer-to-peer trainings were able to provide immediate feedback after each skit and error correction was used throughout the presentation to prevent the spread of misinformation.

Bullard and Wallace (1978) described a sex and disability training project that was similar to the peer-to-peer training provided by students at The TALL Institute, although the target population in their study was adults with physical disabilities.

Although the target populations were different, several parallels may be drawn between the methods used in each peer-to-peer training program. The Health, Safety, and Sexuality training by The TALL Institute used adults with similar disabilities as the participant population to serve as peer-to-peer trainers, similar to the project described by Bullard and Wallace (1978). Also, the peer-to-peer trainers at TALL participated in their own training where they spent time learning the curriculum in classroom-like settings and conducted shortened versions of the presentations in Cincinnati prior to traveling the state to conduct full trainings. Peer-to-peer trainers in the project described by Bullard and Wallace (1978) also engaged in training sessions, including didactic presentations and role-play among other components, prior to embarking on field placements. Although additional research is needed to assess the effectiveness of the peer-to-peer Health, Safety, and Sexuality program at The TALL Institute, several aspects of the training are supported by relevant published literature on health, safety, and sexuality training programs for adults and children with DD and physical disabilities (Bullard & Wallace, 1978; Utley et al., 2001).

When asked how the trainings could be improved, Barb told the researcher in an interview, she would like to see her students build relationships with the individuals they meet as they travel around the state. While several of the peer-to-peer trainers described the program as an opportunity to meet new people, the meetings do not seem to develop into meaningful friendships or relationships. Barb offered one idea to change this:

I will tell you that one of the things that I wish we could do...it would be nice if the night before we gave a presentation, if we could have a social so that my clients and the presenters, and the people that we're gonna present to could meet



each other. Even if it's just for an hour or like an hour and a half. Something like that. Everybody would come together. 'Hey we're the presenters, we're gonna be there tomorrow.' Um you know, we're just like you, we just like to hang out and have a good time and whatever, 'Hey we'll see you in the morning to do our presentation.' I think to be able to have that would be so nice and we had done it before with a group but it was the other team leader. She had gotten her group together. It was like a People First group or something. And it was really nice that the people got to really talk with so that everybody could see, we're all equal here. You know, we walk in with our own, we're definitely the presenters with our own color on and I think that's fine so that people know who we are and you know but I don't know, I think that would be kind of a cool thing to add to it...I think it would be good for our people. For my presenters. To kind of get to know some people. (B. Thomas, personal communication, February 5, 2013)

A social the day before or even lunch immediately after the presentation could add to the richness of the connections made between the participants and the peer-to-peer trainers. Although the trips across the state include social activities with Barb and the presenters, including dinner and other outings such as karaoke, spending additional time at agencies could provide opportunities for real relationships to develop among individuals.

### **Summary**

This chapter provided a rich, thick description of The TALL Institute and the peer-to-peer Health, Safety, and Sexuality training program provided by students at TALL. The chapter included a description of the curriculum used for the trainings, along

with a description of two complete training presentations, using data collected from two observations of trainings. The next chapter will provide an introduction to each peer-to-peer trainer, using data collected from six individual interviews, observations of trainings, and repeated interactions with peer-to-peer trainers at TALL over a six-month period. The following chapters will explore the experiences of the trainings, from the perspectives of the six peer-to-peer trainers in the Health, Safety and Sexuality training provided by students at The TALL Institute.

## **Chapter 5: The Peer-to-Peer Trainers – Their Stories & Experiences**

The purpose of this chapter is to provide an introduction to each of the six peer-to-peer trainers who were interviewed for the current study. This chapter also includes an analysis of emerging themes from individual interviews with the six peer-to-peer trainers. These introductions and subsequent analysis of interviews, will help answer the second research question posed in this study: 2) How do students at The TALL Institute describe their experiences as peer-to-peer safety, and sexuality trainers for individuals with ID? This chapter contains information generated from six individual interviews with peer-to-peer trainers, two observations of peer-to-peer trainings, and repeated interactions between the researcher and trainers at TALL between August 2012 and January 2013. Pseudonyms are used to protect the identity of the peer-to-peer trainers and participants who attended trainings. Peer-to-peer safety and sexuality training is offered by students at The TALL Institute as one method of decreasing vulnerability to abuse for individuals with ID, however there is no qualitative literature to shed light on this approach. The following pages are an initial step to add to the literature on this topic and to provide support for policy and practical implications along with recommendations for future research. Pseudonyms are used throughout the case study to protect the identity of individuals.

### **Sam**

Sam is a 40 year old White female from Cincinnati, Ohio. Sam is tall, has short reddish-brown hair, wears glasses and uses a cane to assist with mobility. Sam's interests include listening to music by local Cincinnati bands, traveling abroad, and watching Harry Potter movies. Sam describes her disability as "mild cerebral palsy, learning

disability, and ADHD (Attention Deficit Hyperactive Disorder)”. Sam has been taking classes at the TALL Institute for five years. Sam met Barb through a resident in her apartment building who is also a student at TALL. Sam resides in an independent living community in Cincinnati, managed by a DD service provider. This is Sam’s second year to be involved in the Health, Safety, and Sexuality program, however, this year was her first opportunity to travel around the state as a peer-to-peer trainer. After hearing about the training program from Barb, Sam decided to be involved because she thought it would be interesting.

Sam did not report speaking to anyone other than Barb before she made a final decision to be a peer-to-peer trainer in the Health Safety, and Sexuality program, indicating an increased level of independence regarding her ability to choose to participate in certain activities and programs. Sam was not one of the students who reported a need to inquire with parents or caregivers prior to giving consent to participate in the program. Sam is her own legal guardian and made the decision to participate without asking for permission from her parents or staff.

Although Sam made an independent decision to participate as a peer-to-peer trainer, some students at TALL struggled even to share their personal interests related to participating in the program. In August of 2012, when Barb originally approached the students in the Tuesday class and described the peer-to-peer training program, the researcher observed several students who discussed a need to ask permission from parents or caregivers prior to stating their intent to participate as peer-to-peer trainers.

One student in the Tuesday class, a woman with Down syndrome who wears glasses, became visibly upset when Barb asked her if she wanted to participate in the

program as a peer-to-peer trainer. The student kept repeating, “I need to ask my mom” even after Barb reassured her that she was only collecting information regarding their interests, and not making any final decisions. The student continued to respond, “I need to ask my mom.” Barb later shared that although this student is her own legal guardian, she often struggles with independent decision-making. In an individual interview, Barb expressed frustration when recalling the inability of some students to make independent decisions, when expressing thoughts and opinions.

Well, she’s often like that... You know, and so I don’t know how... And the frustration of, ‘Please tell me what you want to do not what your mother’s gonna think and if are you allowed. I mean [this student] is in her 40s you know, her parents are in their 80s like it would be really nice if you could start kinda making some of those decisions for yourself. So it can be kinda tough kinda frustrating.

As society continues to move toward empowerment of individuals with disabilities, through large-scale efforts such as independent living and community integration, as evidenced by the Sociopolitical Model of Disability, some parents still tend to view their adult children with ID as less than capable of making independent decisions (Smart & Smart, 2007).

### **Travis**

Travis is a 34 year old White male who lives alone in an apartment, although he is planning to move and might have roommates in the near future. Travis lives in Lebanon, Ohio, a small predominately White suburb approximately 26 miles northwest of Cincinnati. Travis has short dark brown hair and loves to laugh and tell jokes. Travis enjoys watching wrestling matches and Cincinnati reds professional baseball games.

Travis is also the lead singer in the Garage Band at TALL. Travis describes his disability as “an anger management problem” and he also says “It’s hard to learn some things but I can learn it.” Travis has been taking classes at the TALL Institute for five years. Travis met with Barb for individual counseling at TECS approximately 10 years ago, prior to becoming a student at TALL. Travis reported Barb “was sort of my psychiatrist at Warren County." This is Travis’s second year to travel around Ohio as a peer-to-peer Health, Safety, and Sexuality trainer.

Travis was attracted to the program because of the opportunity to make some extra money, saying "Yeah, it's like, I get paid for this? Okay, I get paid more money for this, I'll go!" Travis appeared to be excited at the opportunity to be compensated for his time and participation as a peer-to-peer trainer. Payment for Barb and the peer-to-peer trainers was provided through grant funds from the Ohio DD Council. Although Travis’s biological parents are his legal guardians, Travis did not report getting his parents’ permission prior to participating as a peer-to-peer trainer. However, Travis’s parents gave consent for him to travel around the state with Barb as a peer-to-peer trainer in the program.

### **Richard**

Richard is a 38 year old White male who lives alone in an apartment in Cincinnati, although he was born in Baltimore, Ohio. Richard is tall, keeps his hair cut bald, and wears dark-rimmed glasses. Richard enjoys music and plays the guitar in the Garage Band at TALL. Richard used to be in a dating relationship, with Amy as his girl friend, however, he now reports to be dating another student at TALL. Richard works part-time at In Return, a non-profit organization that hires individuals with DD and

cognitive limitations as a result of injury to do assembly, light manufacturing, bulk mailing, and similar services. Richard describes his disability as a "learning disability, learning challenge." He reports "troubles with math and sometimes time." Richard has been taking classes at the TALL Institute since 2007 and originally met Barb through a family friend in 1995. This is Richard's second year traveling around the state as part of the Health, Safety, and Sexuality training program. Richard reported he was "selected by Barb" to be a participant in the program. Richard is his own legal guardian and he did not report speaking with anyone else prior to making his final decision to participate in the Health, Safety, and Sexuality program as a peer-to-peer trainer.

In an individual interview, Barb described the process she used to finalize the six-member peer-to-peer trainer team.

Well, Travis and Richard were selected because I really wanted individuals that could speak, that also understood the concepts. So when it came to this class, I guess it was kind of the same thing. You have to be able to speak loud enough. You have to be able to be understood. Like for example, [student] is never... [student] would never be someone that I would bring to actually do the presentation, but he would enjoy coming but he would have to be someone that is handing flyers out or something like that, so I just didn't have the monies available to be able to let people come that are just gonna hang out. I have to really have people that understand the concepts that can share it openly and clearly and concisely. And that's really how and they're without a doubt the ones that speak the best.

Barb made the final decision regarding students who would travel around the state as peer-to-peer trainers in the program, and Travis and Richard clearly stood out among the group, based on their speaking abilities and ability to convey understanding of concepts.

### **Heather**

Heather is a 33 year old White female and lives alone in an apartment in Lebanon, Ohio. Heather is tall, has shoulder-length sandy brown hair, and a bubbly personality. Heather comes to TALL on Tuesdays and Thursdays. Heather spends most of her time working as a cashier, dishwasher, and server at the local 1950s style ice cream parlor in downtown Lebanon, where she has worked for nine years. Heather's supervisor at the ice cream parlor is also her designated payee and assists Heather with managing her finances. Heather describes her disability as a "learning disability" saying, "It's like I learn slower than other people."

Heather has been taking classes at the TALL Institute for one year. Heather met Barb at Production Services Unlimited (PSU), a sheltered workshop for adults with DD in Warren County. Heather also met with Barb in Lebanon for individual counseling sessions. This is Heather's first year to be involved in the Health, Safety, and Sexuality program. When Heather was approached by Barb as a potential participant in the Health, Safety, and Sexuality program, Heather discussed the opportunity with her designated DD representative and "told her what the training was for, what it was about and stuff and she was like, I think it would be a good thing for people to know and so when I, I chose it by myself but I talked to her about it."

### **Amy**



Amy is a 32 year old White female from Cincinnati, Ohio. Amy has long dark, wavy hair and wears glasses. Amy used to live with her mother and father, however due to a recent incident of physical abuse by her father, Amy now lives with a friend and is looking for a permanent residence with a roommate. Amy enjoys shopping, makeup, traveling, and spending time with her best friend Heather. Amy works at the YMCA through the Easter Seals Supported Employment Enclave for five hours per day, five days each week. Amy reports to have epilepsy and she also reports to struggle with math and numbers. Amy has been taking classes at The TALL Institute for one year and this is her first time to participate in the Health, Safety and Sexuality program, as a trainer.

Amy met Barb through a co-worker at the YMCA who is also a student at TALL. Amy comes to TALL "because it was an opportunity for me to meet new people and to make more friends." Amy also wanted to "see like the different kinds of things that Barb had to offer like the classes and activities and stuff that they do." Amy is involved in the Tuesday class and also participates in WALL weekends and Final Fridays and Saturdays. Amy was approached by Barb and asked if she would be interested in participating in the Health, Safety, and Sexuality trainings. Amy reported she spoke with her mother and father "and they said it would be a great opportunity to go ahead and do it."

### **Steven**

Steven is a 29 year old White male from Lebanon, Ohio, although he was born in Spokane, Washington. Steven lives alone in apartment and has a pet cat. Steven has dark hair, a full beard, and often wears a baseball cap, sometimes with sunglasses. Steven works at the Warren County Developmental Disability Grounds Crew Supported Employment Enclave, where he provides landscaping services full-time during spring,

summer, and fall months and snow-clearing services during winter. Steven comes to TALL on Tuesdays and Wednesdays. Steven's interests include learning about wolves and hanging out with his friends. Steven also enjoys using the art of sarcasm to bring a smile to the face of his closest friends. Steven is a true jokester, yet he can be serious when the situation calls for tact. Steven describes his disability as "problems following authority" and he reports that he "learns a little slower than others", at times. Steven has been taking classes at the TALL Institute for about four years. Steven met Barb at PSU, before he was a student at TALL. This is Steven's first year to be involved in the Health, Safety, and Sexuality training. Steven decided to be a part of the peer-to-peer Health, Safety, and Sexuality training as an opportunity to engage and participate in "something new".

Table 2

*Participant Demographics*

<b>Name</b>	<b>Age</b>	<b>Race</b>	<b>Self-described disability</b>	<b>Number of years at TALL</b>	<b>Number of years as a peer-to-peer trainer</b>
<b>Sam</b>	40	White	“ADHD, cerebral palsy, learning disability”	5 years	1 year
<b>Steven</b>	29	White	“problems with authority”, “learn a little slower than others”	4 years	1 year
<b>Amy</b>	32	White	“epilepsy”, “problems with numbers and math”	1 year	1 year
<b>Heather</b>	33	White	“learning disability”	1 year	1 year
<b>Richard</b>	38	White	“learning disability”, “learning challenge”	6 years	2 years
<b>Travis</b>	34	White	“anger management”, “hard to learn some things but I can learn it”	5 years	2 years

**Discussion of Participant Demographics**

To recruit peer-to-peer trainers for the 2012 Health, Safety, and Sexuality Training for You and Me program, Barb made an initial announcement in the Tuesday class, beginning in August, with subsequent discussion until the list of team members was finalized in October. Students discussed their work schedules and other commitments, prior to making decisions to participate. After gathering a list of potential

peer-to-peer trainers, Barb also considered other characteristics including ability to stay on task and engage in appropriate behavior, both during presentations and while traveling, verbal presentation skills, and willingness to participate in the program. After learning who was interested in participating, Barb engaged in further discussion, individually to answer questions regarding the program and ask students if they would be interested in joining the team. All participants were recruited voluntarily, free of coercion. However, a monetary incentive in the form of \$8 per hour, did serve as a motivating factor for at least one student, Travis.

The final team of peer-to-peer trainers consisted of six students from the Tuesday class, identified in Table 2 with the following pseudonyms, Sam, Steven, Amy, Heather, Richard, and Travis. Table 2 also provides a summary of participant demographics, including age, race, self-described disability, number of years as a student at TALL, and number of years as a peer-to-peer trainer. All of the peer-to-peer trainers, and Barb, as facilitator, are White. In The Plains, Ohio on November 2, 2012, one of the six participants was Black and the other five were White. Of the 25 participants who attended the presentation in Cleveland on November 16, 2012, 5 were Black and the others were White. It is unknown whether the racial makeup of the panelists, including the six peer-to-peer trainers and the facilitator, had any impact on the presentation, considering the racial demographics of the participants who attended the training.

The age range of the peer-to-peer trainers appeared to be similar to the ages of the participants who attended the trainings. Both the trainers and participants were adults with varying disability diagnoses, over the age of 21. Although specific ages of

participants in the trainings was unknown to the researcher, the participants in The Plains and in Cleveland appeared to range in age from early 20s to mid 40s, or possibly older.

According to HIPPA regulations and ethical guidelines related to confidentiality, the researcher did not have access to students' files to obtain information regarding their diagnoses; however this information was shared voluntarily as part of the peer-to-peer training presentations. All of the peer-to-peer trainers reported some form of learning challenge, although they preferred to use the term "learning disability" as opposed to ID. Others also chose to share medical, mental health, and behavioral concerns, including "problems with authority", "epilepsy", "ADHD and cerebral palsy", and "anger management". Although Barb confirmed ID diagnoses for all of the peer-to-peer trainers, none of the trainers used the term ID to describe their disability or challenge. This limited disclosure could have stemmed from limited awareness or possibly stigma associated with ID diagnoses.

The importance of obtaining this information directly from the peer-to-peer trainers as opposed to their agency files was an important component of this research. Adherents to the Biomedical Model of Disability (Smart & Smart, 2007) would be more concerned with "legitimate" documented diagnoses as opposed to self-descriptions of limitations in functioning. As a subscriber to the Sociopolitical Model of disability, the researcher in this study "refused to accept the inferior, dependent, and stigmatizing definition of disability" (Smart & Smart, 2007, p. 86). On the contrary, the researcher allowed individuals to define and describe their abilities and limitations as opposed to using labels provided by "experts" and "professionals" (Smart, & Smart, 2007, p. 86).

### **Summary of Introductions**

This section provided an introduction to the six individuals who serve as peer-to-peer trainers in the Health, Safety, and Sexuality training program provided across the state of Ohio by students at The TALL Institute. This section contained information generated from six individual interviews with peer-to-peer trainers, two observations of peer-to-peer trainings, and repeated interactions between the researcher and peer-to-peer trainers at TALL between August 2012 and January 2013. This description of their experiences is a first step to generate new information on peer-to-peer safety and sexuality training, from the perspective of individuals who provide the training. The following section will include an analysis of emerging themes from individual interviews with the peer-to-peer trainers.

### **Emerging Themes**

This section will provide a description of salient themes that emerged during the interviews, in an attempt to generate information to answer the second research question. The researcher used the seven-step strategy for analyzing qualitative data described by Marshall and Rossman (2011): 1) sorted the data, 2) became immersed in the data, 3) coded line by line, 4) generated themes, 5) offered interpretations, 6) searched for alternate explanations, and 7) drafted the final report. The data was analyzed in the context of relevant published literature and using the theoretical framework of the four major models of disability, as described by Smart and Smart (2007), the Biomedical Model, the Functional Model, the Environmental Model, and the Sociopolitical Model.

Data analysis of interview and observation revealed the following eight themes:

1) Benefits of Training, 2) Same & Different, 3) Listening & Learning, 4) Teaching

Peers, 5) Teaching the Youth, 6) Being Approached, 7) Relating & Reacting to Skits, 8) Spiritual Abuse. The following table (Table 3) is a summary of the eight major themes, a relevant quote illustration, a brief description of the theme, and relevant literature or theory, if applicable.

Table 3

*Summary of Emerging Themes*

<b>Theme</b>	<b>Relevant quotation</b>	<b>Brief Explanation</b>	<b>Literature or Theory</b>
<b>1. Benefits of Training</b>	<i>It's kind of opening me up to talk more.</i>	The peer-to-peer trainers described benefits of participation, including speaking up, etc.	Additional research is needed with this population.
<b>2. Same &amp; Different</b>	<i>It's like people that has the same kinds of disabilities that I do, don't do half the stuff I do.</i>	Several of the peer-to-peer trainers described their own capabilities and limitations in comparison to other people, with and without disabilities.	Sociopolitical, Functional, & Environmental Models of Disability (Smart & Smart, 2007)
<b>3. Listening &amp; Learning</b>	<i>I've learned patience. And listening, really listening...</i>	The peer-to-peer trainers described what they learned as a result of participation in the program.	Utley et al., (2001), learning from different sources increases knowledge
<b>4. Teaching Peers</b>	<i>We teach 'em about it's okay to be safe...</i>	Peer-to-peer trainers shared their thoughts regarding the content of the presentations.	Petersilia (2001), Sobsey (1994) discuss vulnerability to abuse
<b>5. Teaching the Youth</b>	<i>Mostly if it was up to me, I would talk to the youth.</i>	One peer-to-peer trainer mentioned he would like to share this information with the youth. Several others agreed.	Shuttleworth (2007) advocated for peer-training, older adults to youth with disabilities.
<b>6. Being Approached</b>	<i>This one guy came by and he started to talk to me about his personal issues and I was like, 'Wait a minute.'</i>	Two peer-to-peer trainers reported hearing others share experiences related to sexual victimization.	Matich-Maroney (2003), mental health implications of abuse
<b>7. Relating &amp; Reacting to Skits</b>	<i>God! The one skit I did not like was the 'Uncle Larry' one!</i>	Two peer-to-peer trainers shared strong reactions to particular skits during their individual interviews.	Not in the literature
<b>8. Spiritual Abuse</b>	<i>Is there a such thing as spiritual abuse?</i>	In one of the trainings, a participant asked a question about spiritual abuse.	ACA & CRCC Codes of Ethics A.4.b. Avoiding value imposition



**Theme 1: Benefits of Training.** The most salient theme that emerged from interviews with peer-to-peer trainers was the benefits peer-to-peer trainers experienced as a result of participation in the program. Analysis of 26 pages of transcripts from individual interviews revealed several benefits of participating in the peer-to-peer training program, as a trainer, including opportunities to gain experience speaking in front of a group, to meet new people, and to travel and spend time with friends. Peer-to-peer trainers also reported learning new things, including learning that abuse can happen to others, learning the different types of abuse covered in the curriculum, and how to create and use their own safety plans. The most salient emerging sub-theme under the larger Benefits of Training theme was Speaking Up. Five of the six peer-to-peer trainers described speaking up and “voic[ing] their opinions”, as described by Richard, as the most beneficial aspect of the peer-to-peer training experience.

*Speaking up.* Three of the peer-to-peer trainers described other opportunities they have to speak in front of large groups, such as at work or at church. When asked about other opportunities she has to speak in front of people, Heather responded,

I work at the ice cream parlor so I talk every day! But it’s so hard to really like, talk loud because you’ve got so many people in there. So when you get to do the presentations, you can talk, and talk, and talk.

Although Heather talks to people every day, as she describes above, she reported struggling, initially, with speaking out during the peer-to-peer trainings. For Heather, the most difficult aspect of the peer-to-peer trainings was “talking to people. It was. Because I had a hard time talking, speaking out, before I came into this. It was hard for me to do that.” Heather goes on to say,

In some of the skits that we do, we have to yell, and I'm not used to yelling, but now that I'm getting comfortable with those skits, I'm getting kind of like, being able to yell it out and talk out loud.

In addition to talking louder, Heather goes on to describe an additional benefit of the training, "It's kind of opening me up to talk more about anything, like about life or something that someone's going through."

While public speaking was the most difficult part of the peer-to-peer training for Heather, Richard listed his favorite part of the training as "just getting out there and talking to the people." Richard said he was not afraid to speak in public and has other opportunities to speak at "church and friends and family and places like that." Amy also enjoyed the opportunity to speak in front of others, saying "I've actually spoken in public before so I mean I'm not that afraid to talk to other people but I like being able to go around and talk to other people." Sam also reports learning to "speak up more" as a result of participating as a peer-to-peer trainer. Although she is in theater, she described a mild fear of public speaking, even in that role, "Yeah, I get scared around theater, I've been doing it for a while but I still get nervous." Travis also shared that he used to be nervous when the group first started doing the trainings, but now his fears are "not that bad as I used to be." Travis continued, "I mean, it was kind of hard at first, I mean the first couple are gonna be hard. Then, like you said, after that, you get used to it, like it's nothing."

Barb also discussed the opportunity to speak up as a benefit of the peer-to-peer training:

I do think that it has definitely given them the self-confidence to be able to speak in from of other people. I think they have really thought about some of the abuses

or challenges that they have had personally in their life with some of the information that we've talked about and they've been able to decipher which ones are appropriate to share and which ones they probably should keep to themselves. So I think that's all good. (B. Thomas, personal communication, February 5, 2013)

Additional research is needed to examine the benefits of peer-to-peer safety and sexuality training for individuals with ID, specifically for the individuals who engage as trainers.

***Meeting new people.*** In addition to speaking up, meeting new people is described here as an additional sub-theme under the broader theme of Benefits of Training. This sub-theme was consistent across two interviews with peer-to-peer trainers. When asked to describe his favorite aspect of the training, Travis stated, "My favorite part, I would say, mostly, meeting the people afterwards, they shake your hands." Heather also related to the benefit of meeting new people as a result of participating in the program, "It's kind of neat to meet new people. It's like I've met new people since I've been. And that's my bigger thing is to try and meet new people." Although these two peer-to-peer trainers reported feelings of satisfaction with meeting new people as a result of participating as peer-to-peer trainers, the initial meetings did not seem to develop into meaningful relationships. During his individual interview, the researcher asked Travis if he stays in contact with anyone he meets, or if he "just kind of meets them and goes on?" Travis responded, "Just meet 'em and go on. I mean I haven't given out my number or anything to 'em." Based on Barb's suggestions, future trainings could incorporate an informal meet and greet social activity to provide an opportunity for peer-to-peer trainers and

training participants to engage with one another, possibly the day before or immediately after training presentations.

### **Theme 2: Same & Different**

The peer-to-peer trainers interviewed in the current study frequently discussed the manner in which they view themselves in comparison to other individuals, with and without intellectual disabilities. As evidenced by the content provided in their interviews, two of the peer-to-peer trainers appeared to view themselves as different from other individuals with intellectual disabilities, while three others felt they could relate, specifically with other students at TALL and with the individuals who attended the Health, Safety, and Sexuality trainings.

*Comparing self to others with disabilities.* One sub-theme that emerged from Theme 2: Same & Different was the manner in which the peer-to-peer trainers compared themselves to others with disabilities. When asked to describe her disability, Amy started to respond by saying, “I would describe it as...” After a brief pause, Amy mumbled “Difference is not really a word,” in a hushed voice. The researcher reassured Amy by saying, “You can say it however you want to say it.” Amy responded with,

Um. Different and sometimes I think I usually have the same disability as some other people that come here. I mean it just depends on who the person is and if they kinda act the same way you do or if they just react differently to things than other people do.

In addition, Amy felt she could relate to the other students at TALL because of shared interests, such as attending concerts, going to the movies, and going out to dinner at area restaurants. As opposed to defining her disability using her ID and DD diagnoses,

Amy used a relative comparison, based on her view of herself in relationship to her peers at TALL. For Amy, having a disability means acting the same or differently than other people who also have a similar label. Amy did not describe her disability using the medical terms for her diagnosis, which would fit with the Biomedical Model of disability, nor did she mention barriers or obstacles to her success, as noted in the Functional and Environmental Models of disability (Smart & Smart, 2007). Amy's view of disability seems to be more social and extrinsic in nature, as opposed to more biological and intrinsic; Amy's description of her disability appears to be similar to the fundamental views associated with the Sociopolitical Model of disability (Smart & Smart, 2007).

While Amy described similarities between herself and the other students at TALL, Heather described the Health, Safety, and Sexuality trainings around the state as opportunities to meet people she views as similar to herself. Heather described one of her favorite aspects of working as a peer-to-peer trainer saying, "It's so hard to meet people kinda like, kinda like me." When the researcher asked Heather what she meant by people "kinda like" her, Heather responded saying "Well, like, people that kinda knows their disabilities and stuff. It's kinda nice to talk to people that knows their disabilities."

Travis also expressed positive reactions toward engaging with other individuals with ID. Travis especially enjoyed the Health, Safety, and Sexuality training in The Plains, about 10 miles outside of Athens, Ohio. Travis said, "I loved the one we did up in Athens. Man, 'cause it was more, like, not in depth, but it was more like we could talk to 'em as people." During this particular training, the audience consisted of six individuals, compared to the other trainings with average attendance of 25 to 30 individuals as participants. After the formal presentation of the curriculum, Barb invited the peer-to-

peer trainers to move their table to join the table where the participants were sitting.

This created a round-table format that was unique to this particular training. Barb also invited the participants to share in a manner that was not possible in the other trainings around the state.

When the researcher told Barb about Travis's comment, Barb responded, Oh! That's interesting. I mean the more personal you can get, the better. I will tell you that the grant states 30 people and so part of our getting the grant is for us to serve as many people as we possibly can. But that's a really good thing to note when I'm doing the report. That we probably could do it would 15-20 people as opposed to 30 and maybe be able to do a better presentation because when there are 30, that's a lot. And to try and hear everybody's opinion and with this clientele, a lot of people wanna give their two cents. Which is good, which is good, but it does mean that you oftentimes don't get to every little thing. So, yeah, it is good to be... You're talking about a pretty intimate topic. So to get intimate with them physically by space is... That makes sense. And that's good, I'm glad Travis said that.

While the peer-to-peer trainers describe their disabilities during each presentation of the curriculum, the training in The Plains provided an opportunity for each participant to describe their disability, as part of the discussion. Two of the six participants responded, "I don't know" when Barb asked them to describe their disabilities. Travis described this moment in The Plains by raising his hand and saying, "Yeah, [they were] saying I have this problem, I have that problem with my disabilities. I have this problem with my disabilities. It's like half of them half the time don't know what their problem

is.”

While Heather appreciated the opportunity to meet individuals who possess some knowledge of their disability, Travis appeared frustrated by the lack of knowledge some individuals appeared to have regarding their disability. Travis reported he was about 18 or 19 when he realized he had an “anger management problem” and he reported “they always had me in disability classes and all of that, I was smarter than that. I just hated school. I was like, ‘Why am I in this class? I’ve already done this before.’ Just get bored easily.” Travis began to participate in one-on-one anger management counseling with Barb around age 24 or 25 and reports becoming aware of his learning challenges when he was in school, as young as he can remember. Travis could have assumed other individuals with disabilities should also be as aware of their limitations.

While the peer-to-peer trainers expressed similarities between themselves and other individuals with intellectual disabilities, they were also clear to emphasize the differences they noticed. Sam, in particular, stated everyone at TALL is “different” with “different wants, different needs, different disabilities, different issues they’re dealing with.” Similarly, Richard stated, “I think of myself as an individual” but he went on to say “Well I think, uh, that we are all equal in one way or another” but not exactly the same because “one person’s strengths may not be the same as another person’s strengths.” Amy shared Richard’s sentiments, saying,

Some of us are pretty much the same and I look at us as just everybody's not as equal as everybody else. You know, people are...just there are some people that are different from other people. And to me, I don't, when I look at somebody, I don't look at ‘em like for what handicap they have or what they look like. I look at

them for who they are. And it's like, if I go and see, 'Oh that person's a really nice person.' Yeah, so that's how I look at it.

Here, Amy's words clearly resonate with the Sociopolitical Model of disability (Smart & Smart, 2007), emphasizing the importance of individual differences and a focus on the person as opposed to the disability.

***Being capable.*** Being capable was a second salient sub-theme under the broad heading of Same & Different. Two peer-to-peer trainers provided detailed descriptions of their abilities and accomplishments when asked how they view themselves as similar or different to others with disabilities. Amy described her perceived differences between herself and the other students at TALL and between herself and the individuals who attended the peer-to-peer Health, Safety, and Sexuality trainings. In regards to the students at TALL, Amy said,

I'm capable of doing things on my own that most of them aren't capable of doing. Like I know how to cook. I know how to clean, I know how to pay my own bills, and I know how to do my own laundry

Regarding the individuals who attended the presentations, Amy said,

I see myself as different from other people that I'm talking to because when we were in Cleveland and we did the presentation that Thursday, and we were talking to the first group that we spoke to Thursday, there was one gentleman that was in a wheelchair. He was just, and I'm not saying anything bad about him, he was different from the rest of us because he was in a wheelchair and we weren't. And then when we went back Friday, there were a couple more of 'em that were in wheelchairs. And some of 'em that... and people who are in wheelchairs are



different from us because they are either able to get out of the wheelchair by themselves or they're either just...they can't get out of the chair by themselves.

And that's why I think people like that are different from people like us. Because we're able to walk on our own two feet and use our hands and our arms and some people like that aren't able to do that.

This emphasis on “skills, abilities, and achievements” is reflective of the Functional and Environmental Models of disability (Smart & Smart, 2007), with an emphasis on external barriers as opposed to internal factors that impede the success of individuals with disabilities. Here, Amy emphasized what she *can* do, as a person with a disability, and what others *cannot* do, as people with disabilities. In her statements, Amy seemed to be disassociating herself from others with disabilities as an individual who is more capable in a variety of activities of daily living, such as mobility, self-care, and managing finances. There appeared to be a sense of pride associated with these statements of capability and Amy wanted the researcher to clearly understand the differences she noticed that differentiated her from others with disabilities.

Similar to Amy, Heather also talked about being capable as something that makes her different from other people, with and without disabilities. Heather reported she was about 12 years old when her father began talking to her about what it means to have ID. For Heather, having ID makes her “kinda different from other people because it's like people that has like the same kinds of disabilities that I do, don't do half the stuff I do. Like work every day, have my own place.” The researcher asked Heather if she considers herself to be more capable than other people with disabilities and Heather responded saying, “Some other people, too, like people without disabilities. Like I can do a little bit

more.” Similar to Amy, Heather seemed to share a feeling of satisfaction when discussing her abilities and accomplishments, as opposed to focusing on things may be difficult for her.

### **Theme 3: Learning & Listening**

Learning & Listening was a third emerging theme, with the following three sub-themes: learning the curriculum, learning from different sources, and creating and using a safety plan.

*Learning the curriculum.* Learning the curriculum prior to traveling around the state was an important aspect of the peer-to-peer training experience. Amy reported some of the information in the Health, Safety, and Sexuality curriculum was new to her, but she developed an understanding through the Tuesday classes at TALL, prior to traveling around the state as a peer-to-peer trainer. Regarding the information in the curriculum, Amy said,

I knew I'm not gonna say that I knew most of it, I didn't really know any, maybe like one or two of them, of the types of abuse, but like all the other ones, I didn't really know anything about. And once we started doing the training we were learning about it and once we got the hang of it, it was like, ‘Oh, wow I didn't realize this could happen to this person or that person.’ So once you learn all that different types of abuse and what could happen to different people, it's like, ‘Wow, that could really happen.’ I feel like I'm learning and I'm teaching something to somebody who doesn't know what the different types of that are.

Amy's words are a clear indication of the peer-to-peer training as an opportunity for trainers to increase their knowledge regarding issues covered in the curriculum.

*Learning from different sources.* Participation in the Health, Safety and Sexuality Training for You & Me program provided opportunities for the peer-to-peer trainers to learn from different sources. For children and adults with ID, obtaining information from multiple sources, including peers and educators, increases the likelihood that information will be retained and generalized to other contexts. One of the peer-to-peer trainers discussed the importance of learning information from Barb while another discussed the importance of learning from the other members of the panel (Barb and the six peer-to-peer trainers) and the participants during peer-to-peer training presentations. Amy shared,

I think some of the tips and information I've gotten from Barb is, I mean it's information well learning because Barb teaches things to us that we've never heard of or that we don't really understand so it's a good thing for us to go and talk to her about that stuff cause she knows a lot more about it than we do.

Richard shared,

I've learned patience. And listening, really listening to other people talk about what they need to. Listening to the people we're talking to and listening to the panel. Really helps you keep in tune with all. Just listening to people voice their opinions makes me feel good.

The peer-to-peer trainers reported learning from different sources, and this will likely increase their ability to contextualize the information and generalize to real-life situations. Utley et al. (2001) found multiple methods of instruction to be helpful in teaching students with DD about health and safety topics. Additional research is needed to confirm, however, to identify the impact of differentiated instructional methods on

peer-to-peer safety and sexuality training for adults with ID.

*Creating and using a safety plan.* Richard said he could relate to the safety plan skits in the trainings because he had to use his safety plan last year when his brother passed away unexpectedly. Richard said he created a safety plan during his first year as a peer-to-peer trainer. Amy also discussed the importance of having a safety plan saying,

One of the things I think that's important is because a safety plan would help somebody who is in a situation that they've never been in before. And it would help them understand, 'Oh I can go call this person and this person would come get me and help me with whatever I need help with.' So I think that's why it's important to have a safety plan.

Travis mentioned he plans to use his safety plan when he relocates to a different apartment in the near future. In his individual interview, Travis's thoughts regarding safety planning also resonated with the others, "Like I said, it's very important cause it's, you gotta learn how to protect yourself and be honest with everything and...everything and everybody." Although additional research is needed to support this claim, peer-to-peer safety and sexuality programs could potentially benefit the trainers, as well as the participants, by increasing their knowledge of the topics covered and potentially decreasing their vulnerability to abuse and victimization through the creation of their own safety plans.

#### **Theme 4: Teaching Peers**

Teaching Peers was a fourth theme that emerged from interviews with peer-to-peer trainers. This broad theme encompasses three smaller sub-themes: sharing their stories, teaching others to stay safe, and getting it/figuring it out.

*Sharing their stories.* For one peer-to-peer trainer, the most difficult part of the trainings was putting all of the pieces together to share her story. One critical component of the trainings involved peer-to-peer trainers sharing real-life personal incidents related to abuse and victimization. Amy shared,

The hardest part is, um, I guess it would be having to...because, like, for different things that have happened to us and we're explaining it to them, I guess that would be the hardest part for me. Because having to explain things that have happened to us and having to go and tell it to them. Because it is more...because it would be more difficult for me to explain to somebody else what has happened to me and them trying...and we're trying to get them to understand what had happened and so then I guess that would be the hardest part for me. It's hard trying to tell that story. Because it's hard trying to be able to put all the pieces together.

Amy appeared to struggle with “putting the pieces together” to describe this aspect of the peer-to-peer training experience. As a woman of many words, Amy paused repeatedly during this part of the interview and furrowed her eyebrows, indicating slight apprehension or difficulty with relaying this part of her experience. Although she described sharing personal stories of victimization as the most difficult aspect of the peer-to-peer training experience, Amy went on to say,

That's the interesting thing and that's the cool thing because you get to explain to other people who don't, who've never had things, something like this happen to them before. So it's interesting being able to go around and tell them what it's all about.

When asked what kinds of things he teaches in the trainings, Steven reported he teaches individuals “how to stay out of trouble” and avoid certain situations he faced. During each peer-to-peer training he attended as a trainer, Steven shared an experience where a DD staff member took advantage of him and other individuals with disabilities. According to Steven, the staff member would take individuals to Blockbuster Movies and open rental accounts in the individuals’ names. Once the accounts were open, the staff member would rent video games and sell them in exchange for cash to other stores, such as Game Stop. Steven reports the staff member was eventually caught and terminated from his place of employment. Despite the difficulties with putting all the pieces together, the peer-to-peer trainers understood the importance of the training they provide, discussed below in the next sub-theme, teaching others to stay safe.

*Teaching others to stay safe.* Although some of the peer-to-peer trainers reported difficulty sharing personal stories of maltreatment by family members and staff, all of the peer-to-peer trainers interviewed for this study emphasized the importance of the work they do. Heather shared,

I think it's important to be on the safe side. Safe of life. You know ‘cause if I was you know, I wish I had somebody to be able to talk to me the way that we talk to other people. Like help, you know, with like doing the skits and stuff like that. So it gets their mind thinking.

Steven also shared that the Health, Safety, and Sexuality trainings are important because of the topics that are covered and “not everyone talks about it.”

Richard shared his thoughts regarding teaching others to stay safe, saying “I feel like I am making a difference when I go out there and train these people, making them

think I'm the eye of the tiger. I wanna make sure people are safe out there." Richard also emphasized the importance of the information provided in the training saying,

God yes, I think it's wonderful to have a resource like this and a resource to give to others who will probably need it in the future or right now cause look at it, there's gonna be people out there that are gonna be lost and they'll need direction in life.

Petersilia (2001) and Sobsey (1994) confirm Richard's views regarding the importance of teaching people with ID to protect themselves and report incidents of abuse. Individuals with ID are at increased risk for abuse and victimization and the peer-to-peer trainers in this study understand the importance of teaching their peers to stay safe, using information in the curriculum and their personal experiences with the topics covered.

*Getting it, figuring it out.* When asked if the participants in the trainings are able to understand the material, Heather responded,

Yeah, because, yeah, I think they do because there was a lot of people that was...you know how Barb goes and asks 'em questions and stuff about different things? They seem like they were getting it. Like the people that we had like Tuesday, they seemed like they were doing it, figuring it out.

The peer-to-peer trainers are confident that the information they are teaching is important. They also seem encouraged to see participants who are engaged, responsive and "figuring it out" during training presentations.

### **Theme 5: Teaching the Youth**

The fourth theme that emerged from the individual interviews related to teaching

young people with ID about safety and sexuality. One sub-theme also emerged, related to when, where, and at what age the peer-to-peer trainers first learned about safety and sexuality topics.

This theme of teaching the youth emerged during the first individual interview with Travis. Early in the interview Travis stated, “Mostly, if it was up to me, I would talk to the youth. I would say that.” Currently the Health, Safety, and Sexuality Training is only delivered to adults with ID and DD. Travis went on to say, “I mean, think about it man, they’ve had it tough, tougher future than us, I mean than we’ve had.” Steven also agreed, saying teenagers are often more sexually active than adults. Regarding the importance of talking to youth, Travis continued, “Right, I mean, yeah, I wish somebody would have done that when I was young. Come up there and did that.” Travis reported learning about safety and sexuality issues from Barb, “Pretty much, went to Barb’s and started learning this stuff.” Amy also reported learning about safety and sexuality primarily from Barb during the classes at TALL, although she also reported learning at school, around age 14, “I learned most of it, I learned some of it at school but then when I first started coming here I learned a big part of it here.”

Amy expressed the importance of teaching young people, similar to Travis’s views,

I think that would be an awesome idea if teenagers got to hear this kind of stuff because there's a lot of there's a big majority of teenagers that don't know about this stuff and some of them, a lot of teenagers end up learning things the hard way. And I think it would be a neat thing for them to learn about this.

Amy also discussed the importance of in-depth discussions in order to convey



safety and sexuality information, such as the content of the Health, Safety, and Sexuality curriculum. Amy stated,

One of the reasons why I think it's important is because for people who don't know about this, they just kind of look at it and say why would I want to waste my time and learn about this? If I wanted to know about this, I could just go to my mom and dad and go to somebody else and they could just give me the short version of it. And to me I don't think kids or teenagers should be getting the short version of it. I think that they should be learning it from where it is. And from the different things that we talk about.

Like Amy, Richard recommended teenage years as the appropriate age to broach sexuality topics with youth. Richard stated,

I think I'm gonna go in a range like 13 to 14 year olds, people that are younger who really need to learn this stuff. And when they get out in the community or out in the world, they're gonna be lost and they're gonna need to know stuff. You know.

Russell Shuttleworth, a major figure in sexuality and disability advocacy through research, recently argued in favor of “more disability peer-support programs for sexuality issues” where “adolescents and young adults can benefit from the experiences of older disabled people (Shuttleworth, 2007, p. 5). Travis’ comments regarding teaching the youth are timely, however, logistical problems associated with parental consent and barriers to entry in P-12 institutions could possibly prevent such opportunities for safety and sexuality training for children and adolescents, using the current model of delivery provided by students at The TALL Institute.

*How, when, where did they learn?* After hearing the peer-to-peer trainers' reactions to Travis' comment regarding teaching the youth, the researcher became interested in the peer-to-peer trainers experiences with sexuality education and abuse prevention. How did they learn? Who taught them? How old were they when they learned about these topics? This information might inform their views of appropriate ages to introduce these topics with others with ID.

Richard mentioned learning from his parents around age 12 and continuing to learn through the classes at TALL. Sam discussed learning about safety and sexuality issues in junior high and she recommended teaching relevant topics to youth as young as 10 to 11 years old. Sam recalled seeing advertisements for the HPV vaccine, targeted at young girls and boys. Developments such as this formed her basis for wanting to speak to children at a younger age than the other peer-to-peer trainers suggested.

Similar to Richard and Sam, Heather also reported learning “the facts of life when we were kids” from her father and also participating in safety education at school.

Heather added,

But I went through school and stuff and they were able to teach us too, and they were telling us too, but they were doing it just in case of a fire or you know somebody breaks in your house or something like that but they didn't tell us about anything else.

Heather went on to highlight the limitations associated with the information she received from school. According to Heather, the safety education at school included fire safety and tornado safety but failed to broach issues related to protection from abuse and victimization. Heather continued,

But I didn't learn, I kind of didn't learn that until I met up with Barb. 'Cause Barb, me and Barb's known each other for a lot of years. And she worked at PSU. And she's kind of the one that kind of helped.

It is clear that the peer-to-peer trainers interviewed in this study would like to convey safety and sexuality information to youth with disabilities. SIECUS, Planned Parenthood and other sexuality education advocacy groups describe the current status of programs as too little, too late, and the situation for children with disabilities is even worse. Additional research could potentially reveal peer-to-peer safety and sexuality training programs as beneficial teaching methods for children, as well as adults with ID and other disabilities.

#### **Theme 6: Being Approached**

The sixth theme that emerged from individual interviews and observations was peer-to-peer trainers who were approached by other individuals who shared their personal experiences as survivors of sexual abuse. The curriculum and program facilitator encourage individuals to speak to one of the panelists after the training, if they experience “bad memories” as a result of the discussion. In their individual interviews, two peer-to-peer trainers shared their reactions to being approached by individuals who shared their experiences related to abuse.

At the beginning of the two observed Health, Safety, and Sexuality training, Barb provided a disclaimer and informed participants that certain thoughts and feelings may emerge as a result of the topics discussed in the training, specifically related to past memories of abuse and victimization. Barb encouraged individuals who participated in the training to speak with her or one of the peer-to-peer trainers after the presentation if

they need more information or assistance with a personal concern. Although Barb provided this information at the beginning of each training presentation, some participants shared personal information during the course of the training. When this happened, Barb redirected and provided reminders of appropriate times and places to discuss personal concerns.

In his interview, Travis recalled times where “people just yell out random things, ‘I was molested,’ and all of that. Yeah, I was like, ‘Dang’.” For example, during one of the sessions in Cleveland, a Black woman, a training participant, shouted that she was molested during the portion of the presentation that covered sexual abuse. Also, while learning the curriculum at TALL, prior to traveling around the state, one White woman with Down syndrome who wears glasses would often voice her past experience of sexual abuse, and then cover her mouth and say, “Ooops! I’m not supposed to talk about that right now, Barb. I’m so sorry. It won’t happen again.” Although Travis reported being surprised initially by such comments, after repeated occurrences, he mentioned he is “used to hearing it by then.”

Similar to Travis, Richard also shared a moment of surprise after being approached by an individual who shared a personal account of abuse and victimization. Richard described the moment saying, “I was just standing there with Travis and this one guy came by and he started to talk to me about his personal issues and I was like, ‘Wait a minute, I gotta go tell Barb and get her to talk to you.’” Richard described his reactions to the incident with mixed emotions, “I felt awkward. Didn’t know what to do. So that’s why I went to Barb.” However, Richard also described feeling a sense of pride that the individual thought of him as a safe person, saying, “I can lead by example, lead them by

example.”

Although being approached is a concept that is included in the curriculum and in presentations, it is not clear whether peer-to-peer trainers are adequately trained to assist individuals who wish to share their experiences or have additional questions. Although Richard referred the individual to Barb when he was approached, it may be helpful to include such information regarding making referrals as part of the training courses students attend prior to conducting presentations around the state as peer-to-peer trainers. Match-Maroney (2003) discussed the mental health implications of sexual abuse for individuals with ID and found a number of negative outcomes related to mental illness that emerged as a result of traumatic experiences of sexual victimization. It may be helpful to increase the amount of time devoted to mental health implications of abuse in the training provided to peer-to-peer trainers and in the actual training presentations.

### **Theme 7: Relating & Reacting to Skits**

The seventh theme that emerged from individual interviews involved peer-to-peer trainers' reactions to specific skits delivered in Health, Safety, and Sexuality trainings. Amy and Travis shared strong reactions to two particular skits, one depicting physical abuse and another involving sexual victimization by a relative.

*The physical abuse skit.* Amy's description of one of the physical abuse skits elicited strong emotions, as evidenced by the following statement, "With like, the physical abuse where the son cleans out the garage and the dad goes back and smacks him, I've been in situation like that, not really cleaning out the garage, but I've been in a similar situation, you know, like that." Amy went on to say, "Yeah, the physical abuse really sticks out to me. Like really far. I mean that's like a big sign that flashes in my face

like, ‘Hello’, right there.” In his individual interview, when asked about his reactions to the physical abuse skit, Travis’s comments resonated with Amy’s, “I don’t know, I mean...the dad, yeah everybody could relate to that.”

The researcher later found out the driving force behind Amy’s strong reactions to this particular skit. In January of 2013, Amy was physically abused by her biological father and decided to move out of her parents’ home. Her reactions to this scene were based on personal experiences as a survivor of physical abuse.

*The Uncle Larry skit.* While Amy reported she could relate to the physical abuse skit, Travis shared a strong reaction to a kit that was rehearsed in the Tuesday class, but not included in the presentations around the state. Travis described a sense of discomfort in one of the original skits where he played “Uncle Larry,” a perpetrator of sexual abuse. In the skit, Uncle Larry approaches his niece and asks for a hug. When she refuses, Uncle Larry responds, “You never complained before.” When Travis was asked if he could relate to any of the skits, he quickly responded, “Some, I could relate with, I mean, yeah. God the one skit I did not like was the Uncle Larry one.” Travis continued, “I was like, ‘No!’ and I was like...I was the one playing Uncle Larry.” Travis also anticipated negative reactions from the training participants, with statements such as, “I was like, ‘Oh man! They’re going to kill me’” and “I was thinking, ‘Oh great! I’m gonna get attacked by a bunch of...’” Although Travis also played a challenging role in a different skit where he depicted a landlord who solicited sex from a tenant with ID in exchange for payment of rent, Travis stated “Uncle Larry was the worst skit I think we ever did.”

Amy described the reactions to the Uncle Larry skit from other peer-to-peer trainers, although she did not have a problem with the skit,

The Uncle Larry one didn't really bother me. Even if they would have left that one in I would have been fine with it. But some of 'em, when we first started doing the training with Dramakinetics, I mean and when a couple of us started doing the Uncle Larry, we were fine with. A couple of us were fine with it, but a couple of us were like, 'I don't like that one, can we do something else, I don't like that one.' So the Uncle Larry one didn't really bother me.

While two of the peer-to-peer trainers shared strong reactions to two of the skits in the presentations, it is possible that participants who attended the trainings also reacted to the skits in a similar manner; however, no reactions were captured using the formal evaluation forms. However, during each training, Barb solicited feedback from peer-to-peer trainers and participants, asking, "How would you feel if that were you?" and "What would you do in that situation?" In addition, the peer-to-peer trainers had multiple opportunities to process reactions during the Tuesday class when they learned the curriculum and rehearsed the skits prior to traveling around the state conducting training presentations.

### **Theme 8: Spiritual Abuse**

The eighth theme that emerged from individual interviews was the discussion of spiritual abuse that emerged during the Health, Safety, and Sexuality training in The Plains, Ohio. After covering several different types of victimization, including physical, verbal, sexual abuse, neglect, theft, and taking advantage, one of the six participants asked, "Is there a such thing as spiritual abuse?" Richard was the first to respond to the young man's question, saying, "I do believe that could be a possibility." In the training, Richard went on to share a story of his uncle who often forced him to "listen to the Bible

over and over.” In his individual interview, Richard shared more about his uncle,

Let's just put it this way, my uncle he kinda abused the Bible a little bit 'cause he's not all there in the head. I mean that in a kind way but he's not mentally stable.

There for a while he called me and was like, I see waterfalls and they're showing the image of Jesus on the wall, saying all kinds of weird stuff.

Richard continued, “And if you have a long enough conversation with him, he will tell you there's people and satellites trying to talk to him and stuff.” Richard then made a “crazy” sign by circling his pointed index finger in the air around his right ear. Richard went on to discuss his uncle’s mental health concerns, which he described as “manic depression schizophrenia.” While Richard’s uncle’s behavior is likely a result of mental illness as opposed to religious fanaticism, Richard shared this story when asked what he thought about spiritual abuse.

Travis also shared strong reactions to the question and comments on spiritual abuse, both during the particular training and later in his individual interview. During the training in The Plains, one of the participants described himself as “earthy and hippy” saying he did not believe in God. Travis agreed with the young man and said, “I’m sort of the same way.” Travis went on to share, “I had a religious woman [referring to a DD staff person], bugged the crap outta me.” Travis recalled telling the staff person, “Lady, I’m fine the way I am.” In his individual interview, when the researcher asked Travis if he found the discussion of spiritual abuse to be interesting, Travis responded, “I actually did. For once I did.” Travis continued,

There's a lot of spiritual abuse. I mean, like I said, you all have your own God that you believe in and everyone has their own thing that they believe in. Nobody can



force you to do that. I mean I had someone that tried to force me to go to church a couple of times.

When the researcher asked Travis how he reacted when staff attempted to “force [him] to go to church”, Travis responded, “I was like, ‘No!’ Not for me. I’m like, ‘No, definitely not for me.’” Travis seems to express his sense of individuality by boldly expressing his aversion to religious coercion by staff. The CRCC Code of Ethics Section A.4.b states

PERSONAL VALUES. Rehabilitation counselors are aware of their values, attitudes, beliefs, and behaviors and avoid imposing values that are inconsistent with rehabilitation counseling goals. (CRCC, 2009, p. 4).

Although Travis’s staff do not include CRCs, this code is listed here as an example of the professional standards that prohibit value imposition by staff onto clients. The ACA Code of Ethics (2005) also includes a statement discouraging value imposition from counselors to clients. Although spirituality is gaining momentum as an important aspect of the counseling process for many individuals, these topics should always center on the views and beliefs of the client as opposed to those of the counselor, in ethically responsible practice.

### **Summary**

As society continues to move towards the Sociopolitical Model of Disability (Smart & Smart, 2007), programs such as the peer-to-peer safety and sexuality training program at The TALL Institute can be used to decrease vulnerability to abuse and violent crime victimization for individuals with ID. The experiences of the six peer-to-peer trainers in the Health, Safety, and Sexuality for You & Me Program at The TALL Institute provide insight into this type of training and provide implications for policy,

practice, and future research as delineated in the final chapter of this case study.

This chapter provided an introduction to participants and a description of salient themes that emerged during the interviews, in an attempt to generate information to answer the second research question posed in this study: 2) How do students at The TALL Institute describe their experiences as peer-to-peer safety, and sexuality trainers for individuals with ID? Individual interviews with peer-to-peer trainers revealed eight emerging themes. These themes included, 1) Benefits of Training, 2) Same & Different, 3) Listening & Learning, 4) Teaching Peers, 5) Teaching the Youth, 6) Being Approached, 7) Relating & Reacting to Skits, and 8) Spiritual Abuse. This chapter included description of these eight themes, using data obtained through individual interviews with the peer-to-peer trainers and observations of two Health, Safety, and Sexuality trainings. The chapter included discussion of published literature to support the emerging themes, including models of disability and relevant ethical codes for counselors. The next chapter will provide lessons learned, including recommendations for future research and implications for policy and practice, and final reflections.

## **Chapter 6: Lessons Learned**

The purpose of this case study was to provide a rich, thick description of the peer-to-peer Health, Safety, & Sexuality Training for You & Me provided by students at The TALL Institute to individuals with ID in Ohio. The current case study used information generated from individual interviews with peer-to-peer trainers, analysis of documents, and observations of peer-to-peer trainings to answer three central research questions: 1) What is the peer-to-peer safety and sexuality training program at The TALL Institute? 2) How do students at The TALL Institute describe their experiences as peer-to-peer health, safety, and sexuality trainers for individuals with ID? 3) How do students at The TALL Institute provide peer-to-peer safety and sexuality training to other individuals with ID? This final chapter of the case study delivers lessons learned, including implications for policy and practice and recommendations for future research.

### **Implications for Practice**

This case study provides a description of the peer-to-peer safety and sexuality training program at The TALL Institute but centers on the experiences of six individuals with ID who serve as peer-to-peer trainers. Based on their descriptions of their experiences, implications for practice are provided. These implications may be applicable to staff and individuals in a variety of practical settings, including but not limited to family homes and independent living communities, residential facilities, sheltered workshops, day treatment facilities, educational centers, and supported employment enclaves in the community. These implications are also relevant to agencies that may consider hosting a peer-to-peer safety and sexuality training for individuals with ID.

The first major implication of this case study is for family, DD staff and service providers, and other caregivers. Family and staff should not assume individuals with ID have already received or will receive information related to safety and sexuality, either at home, at school, or in the community. Parents, staff and caregivers should make concerted efforts to have these conversations, either formally or informally, with individuals with ID, beginning at a young age. Vulnerability to abuse for individuals with ID has been documented in the literature (Harrell & Rand, 2010; Petersilia, 2001; Sobsey, 1994) and parents, staff, and caregivers of individuals with ID often have multiple opportunities to relay safety and sexuality information, as a result of ongoing, if not daily contact and interaction.

The subsequent implications of this case study are for staff and directors of agencies that provide educational and social programming for individuals with ID. Agencies are encouraged to create opportunities for safety and sexuality training within their institutions. Using the program at TALL as a guide, agencies are encouraged to offer such trainings with a few suggestions, based on findings from the current case study. These suggestions could also be used to improve future trainings offered by The TALL Institute. Agencies are encouraged to examine the appropriate number of participants who should attend each training presentation. The trainings offered by The TALL Institute included approximately 25 to 30 participants, with the exception of one conducted in The Plains, Ohio with six participants. Smaller training groups, possibly 15 participants or so, could increase the amount of dialogue between panelists and participants.

In addition, agencies, including The TALL Institute, are encouraged to examine ways to increase socialization between peer-to-peer trainers and training participants. As Barb suggested, a social the evening before the training or sharing lunch or dinner immediately following presentations could increase opportunities for peer-to-peer trainers and participants to increase their social networks with individuals in their city or around the state. Several of the peer-to-peer trainers interviewed in this study shared their personal goals related to meeting new people and making new friends. The peer-to-peer trainers at TALL also enjoyed the opportunity to meet new people through the trainings however, these encounters did not develop into meaningful friendships. Additional time for informal conversation could potentially provide meaningful experiences for all individuals engaged in the trainings.

Future peer-to-peer safety and sexuality trainings for individuals with ID, at TALL and beyond, should also remain sensitive to feedback from peer-to-peer trainers and participants, specifically regarding the content in the trainings and the mental health implications associated with recollections of past abuse experiences. Mental health implications of abuse and victimization have been documented in the literature (Champagne, 2007; Matich-Maroney, 2003; Peckham, Howlett, & Corbett, 2006) and certain topics covered in the curriculum could serve as triggers for bad memories, as documented by the researcher in observations of the trainings conducted by the director and peer-to-peer trainers from TALL. Sensitivity to these concerns, in addition to resources and referral information for local mental health agencies strengthened the trainings provided by the director and peer-to-peer trainers from TALL. These suggestions could strengthen future training presentations offered at TALL and other

agencies that provide educational and socialization programs and services to individuals with ID.

### **Implications for Policy**

Peer-to-peer safety and sexuality training for individuals with ID is crucial as society continues to move toward the Sociopolitical Model of disability (Smart & Smart, 2007). In the U.S., individuals with disabilities experience protected status as a recognized population group that has been historically disadvantaged (Smart & Smart, 2007). It is the responsibility of people without disabilities to continue to dismantle barriers that prevent individuals with ID from being safe at home, at work, and in the community (Functional & Environmental Models of Disability; Smart & Smart, 2007). One way to encourage such change is through advocacy efforts and policy change, discussed below.

While the DD Act of 2000 clearly delineates the rights of individuals to stay safe from incidents related to abuse, neglect, and exploitation, other federal legislation related to individuals with disabilities is lacking in this regard (e.g., IDEIA, 2004; ADA, 1990). Further, the DD Act (200), IDEIA (2004) and ADA (1990) are void of any references to sexuality education or safety training for individuals with disabilities, specifically with ID. Considering the abuse rates compared to other disability groups (Harrell & Rand, 2010), and to people without disabilities (Petersilia, 2001; Sobsey, 1994), the researcher recommends stakeholders engage in broad based advocacy efforts, resulting in legal action related to comprehensive sexuality education and safety training for individuals with ID.

## **Recommendations for Counselor Education Programs**

Counselor Education programs are encouraged to infuse topics related to disability and sexuality throughout all aspects of counselor preparation for all graduate students, not only those in rehabilitation counseling programs. According to the CDC, approximately 1 in 5 Americans, over 50 million individuals, reports having a disability (Centers for Disease Control and Prevention, 2012) and all counselors are likely to engage with individuals with disabilities, regardless of their specialization or practice locale. The profession of counseling, as a whole, could benefit from practitioners who are qualified in all aspects of the human experience, including topics related to sexuality and disability.

## **Recommendations for CRCs and LPCs**

The following recommendations are offered for Certified Rehabilitation Counselors (CRCs) and Licensed Professional Counselors (LPCs) who provide counseling, case management, and related services to individuals with ID:

1. CRCs and LPCs are encouraged to broach issues related to safety and sexuality when providing counseling, case management, and related services to individuals with ID. CRCs and LPCs are then encouraged to make appropriate referrals for sex offender counseling, comprehensive sexuality education, or related services as needed.
2. CRCs and LPCs are encouraged to identify and/or create peer-to-peer safety and sexuality training programs for individuals with ID, possibly using this case study as a model to develop other grant-funded trainings and workshops.

3. If such opportunities exist in their area, CRCs and LPCs are encouraged to refer individuals with ID to participate in peer-to-peer safety and sexuality training programs, either as peer-to-peer trainers or as participants.

### **Recommendations for Future Research**

The current case study generated a rich, thick description of the peer-to-peer safety and sexuality training program for individuals with ID, offered by The TALL Institute. The researcher used qualitative case study design to answer three central research questions: 1) What is the peer-to-peer safety and sexuality training program at The TALL Institute? 2) How do students at The TALL Institute describe their experiences as peer-to-peer health, safety, and sexuality trainers for individuals with ID? 3) How do students at The TALL Institute provide peer-to-peer safety and sexuality training to other individuals with ID? Recommendations for future research, both qualitative and quantitative studies, are provided below.

1. Future qualitative case studies could continue to generate rich, thick descriptions of peer-to-peer safety and sexuality training programs for individuals with ID to add to the body of knowledge on this topic.
2. Future qualitative and quantitative studies could examine the impact of peer-to-peer safety and sexuality training on the sexual knowledge of individuals with ID, including knowledge of topics such as capacity to consent to sexual activity.



3. Future qualitative and quantitative studies could examine the impact of peer-to-peer safety and sexuality training on decreasing vulnerability to abuse and victimization for individuals with ID.
4. Future qualitative and quantitative studies could explore the effectiveness of peer-to-peer safety and sexuality training compared to other teaching methods such as didactic, classroom-style presentations, and other forms of instruction.

### **Conclusion**

The purpose of the current case study was to generate a rich, thick description of the “Health, Safety, & Sexuality Training for You & Me” (Snyder, 2008) program at The TALL Institute to answer three central research questions. Each research question is listed and answered in the following section.

The first research question posed in the current case study was: 1) What is the peer-to-peer safety and sexuality training program at The TALL Institute? While a detailed response to this research question is provided at the beginning of Chapter 4 of this case study, a brief summary is provided here. The “Health, Safety, & Sexuality Training for You & Me” (Snyder, 2008) program is a free three-hour peer-to-peer training provided by students and the director of The TALL Institute in Cincinnati, Ohio to individuals with ID at sheltered workshops, residential facilities, and other DD agencies throughout Ohio. The program follows the “Health, Safety, & Sexuality Training for You & Me” curriculum written in 2008 by Shelly Snyder of the Allen County Board of Developmental Disabilities, and edited by Barbara J. Thomas, M.Ed., Certified Sexuality Educator, Juvenile Sex Offender Counselor, and Director of TECS

Education Center and The TALL Institute. The program was funded by Ohio Developmental Disabilities Council and covered the cost of transportation, meals, lodging, and a small stipend for the peer-to-peer trainers in the program.

The second research question posed by the current case study was: 2) How do students at The TALL Institute describe their experiences as peer-to-peer health, safety, and sexuality trainers for individuals with ID? Chapter 5 provides an analysis of emerging themes, using information gathered through individual interviews with the six peer-to-peer trainers, however a summary is provided below. Eight themes emerged during data analysis and were phrased using direct quotes from individual interviews with the six peer-to-peer trainers in the safety and sexuality program. These themes are: 1) Benefits of Training, 2) Same & Different, 3) Listening & Learning, 4) Teaching Peers, 5) Teaching the Youth, 6) Being Approached, 7) Relating & Reacting to Skits, 8) Spiritual Abuse. These themes are analyzed in relation to relevant literature and theory in Chapter 5, using data from participant interviews and observations to support the researcher's propositions.

The third research question posed in the current case study was: 3) How do students at The TALL Institute provide peer-to-peer safety and sexuality training to other individuals with ID? The methods used to deliver this training are provided at the end of Chapter 4 of the case study, with a description of the "Health, Safety, & Sexuality Training for You & Me" curriculum (Snyder, 2008) and detailed description of two entire training presentation, using data collected from two observations of trainings. To briefly summarize, the peer-to-peer trainers and Director of the TALL Institute as facilitator provide the training using an agenda that is based on the curriculum. The trainings cover

six incidents, including physical, verbal, and sexual abuse, in addition to neglect theft, and taking advantage. The training includes skits to illustrate each incident, with the peer-to-peer trainers serving as actors. The six peer-to-peer trainers share their personal experiences of maltreatment and victimization, related to incidents of theft, verbal abuse, and taking advantage. The peer-to-peer trainers also describe their disabilities, in their own words. Questions are posed by the facilitator while peer-to-peer trainers and participants respond in interactive discussion throughout the training. Participants in the training also complete a written safety plan, complete with emergency numbers and relevant information to use if faced with an incident similar to the ones described in the training. Evaluation forms are distributed and collected at the end of trainings to obtain feedback from participants and agency staff.

The current case study generated a rich, thick description of the peer-to-peer safety and sexuality training provided by individuals with ID at The TALL Institute in Cincinnati, Ohio. This case study is comprised of six chapters. The first three chapters include an introduction, a review of relevant literature, and methodology for the study. The final three chapters answer three central research questions: 1) What is the peer-to-peer safety and sexuality training program at The TALL Institute? 2) How do students at The TALL Institute describe their experiences as peer-to-peer health, safety, and sexuality trainers for individuals with ID? 3) How do students at The TALL Institute provide peer-to-peer safety and sexuality training to other individuals with ID? The last three chapters of the case study answer the central research questions by providing a description of the program, an introduction to the six peer-to-peer trainers, an analysis of emerging themes that emerged from individual interviews with the six peer-to-peer

trainers, and a this final chapter that includes lessons learned. Appendices containing the informed consent documents, a copy of the interview protocol, a copy of the scripts and curriculum, evaluation forms and reports, agenda and handouts from the training, and tables and figures are also provided.

During one of the individual interviews with peer-to-peer trainers, Richard expressed a heartfelt “thank you” to the organizations that provided funding for the Peer-to-Peer Health, Safety, and Sexuality Training program. When the researcher asked Richard what he would like to share with the organization that provided funding for the Health, Safety, and Sexuality trainings, Richard responded,

You are a blessing, you guys are a blessing and I wanna thank you from the bottom of my heart for this and whatever you guys do, please do it more, ‘cause we need you out there. And you guys are angels. True angels.

Peer-to-peer safety and sexuality training is one method used by students and the director at The TALL Institute in Cincinnati, Ohio in an attempt to decrease vulnerability to abuse for individuals with ID in the state of Ohio. Additional research is needed to determine the effectiveness of such trainings and this case study was an important first step to generate qualitative information related to peer-to-peer safety and sexuality training for individuals with ID. The Health, Safety, & Sexuality Training For You & Me program at The TALL Institute was selected as an instrumental case to shed light on this method of training. The case study centered on the voice of the six peer-to-peer trainers and generated a rich, thick description of the safety and sexuality training program. As noted in the comments above by one peer-to-peer trainer in the program at TALL, Richard recognizes the importance of the training he provides and is grateful to the Ohio

DD Council for providing him with this opportunity. The implications for this type of training reach far beyond the boundaries of Hamilton County, and even extend beyond the state lines of Ohio. If practitioners and caregivers who serve individuals with ID, across the nation, create additional opportunities for peer-to-peer safety and sexuality training for members of this population, individuals with ID will have the tools they need to stay safe. Society as a whole would benefit from reductions in violent crime rates, creating a safer place for us all.

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## Appendix A: IRB Approval Form



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F: 740.593.9838  
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The following research study has been approved by the Institutional Review Board at Ohio University for the period listed below.

**Project:** Sexuality and Intellectual & Developmental Disability:  
An Ethnographic Analysis

**Researcher(s):** Natalie Flece Williams

**Advisor:** Mona Robinson  
(if applicable)

**Department:** Counselor Education

Jeff Wancouver, Ph.D., Chair  
Institutional Review Board

9/28/12

Approval Date

9/16/13

Expiration Date

This approval is valid until expiration date listed above. If you wish to continue beyond expiration date, you must submit a periodic review application and obtain approval prior to continuation.

The approval remains in effect provided the study is conducted exactly as described in your application for review. Any additions or modifications to the project must be approved by the IRB (as an amendment) prior to implementation.

Adverse events must be reported to the IRB promptly, within 5 working days of the occurrence.

## Appendix B: Informed Consent Documents

### Ohio University Consent Form

My name is Natalie Williams. I want to learn more about the things you do as a peer-to-peer trainer in the “Health, Safety, and Sexuality Training for You & Me” program at The TALL Institute. If you would like, you can be in my study, as long as you are older than 18 years old and have a diagnosis of ID or DD (intellectual or developmental disability).

If you decide to be in my study, you will spend time talking to me for one hour. We will talk about things you learned and things you do as a peer-to-peer trainer. I will also volunteer at The TALL Institute so I can learn more about what you do there.

When we talk, I will record it and copy to DVD. The DVDs will be locked in 107 McCracken Hall, Ohio University, Athens, OH, for 1 year. Beginning May 2013, the DVDs will remain in my possession and will be destroyed after 2 years (July 2014).

Some of the things we talk about may make you feel sad, upset, or embarrassed. You can say, “I want to stop talking now” to end our talk at any time, if you do not want to continue. If you decide to be in my study OR if you decide not to be in my study, this will not change anything about the services you receive from this agency.

I do not work here; I am only visiting and volunteering to learn more about what you do here. I will not use your real name when I write down the things we talk about.

Barbara Thomas, Director of The TALL Institute, will be present during each interview. If you tell me someone has abused you recently or in the past, or if you tell me you have abused someone recently or in the past, we will make a report to Hamilton County Developmental Disability Services, Major and Unusual Incident Prevention, 24-hour Emergency Hotline 513-794-3308.

If you are interested in more information about sexual abuse and assault prevention services, you may contact the Sexual Assault Program at YWCA, 24-hour Crisis Intervention Assistance Hotline at 800-644-4460. For more information about the program, call 513-732-0450. Also, if you want to talk to a counselor about any abuse, you may call 800-644-4460 and ask for a referral.

This study is important because people with ID and DD are not usually asked to talk to researchers about topics related to health, safety, and sexuality.

If you do not want to be in the study, that's okay. If you do want to be in the study, that's okay, too. If you say, "Yes, I want to be in the study" and change your mind later, that's okay, too. It is your choice. You can stop anytime.

My telephone number is 740-593-4784 (work) and 405-476-6072 (cell) and my email is [nw351909@ohio.edu](mailto:nw351909@ohio.edu). You can call me or email me if you have any questions or decide you do not want to be in the study anymore. I can give you a copy of this paper in case you have questions later.

As a "thank you" for your time/effort, you will receive \$10. You receive \$10, even if you decide to stop the interview.

-----  
By signing below, you are agreeing that:

- you have read this form (or it has been read to you) and all of your questions have been answered
- you are 18 years of age or older
- no one is forcing you to participate in the study
- you may leave the study at any time and if you decide to stop, that is okay, you will be paid for your time

Participant Signature \_\_\_\_\_ Date \_\_\_\_\_

Printed Name \_\_\_\_\_

Version Date: [12/10/12]



## Ohio University Parental/Guardian Consent Form

Title of Research: Experiences as a Peer-to-Peer Health, Safety, and Sexuality Trainer for Individuals with Intellectual and Developmental Disabilities

Researcher: Natalie Williams

You are being asked permission for your adult daughter or son to participate in research. For you to be able to decide whether you want your adult daughter or son to participate in this project, you should understand what the project is about, as well as the possible risks and benefits in order to make an informed decision. This process is known as informed consent. This form describes the purpose, procedures, possible benefits, and risks. It also explains how your adult daughter or son's personal information will be used and protected. Once you have read this form and your questions about the study are answered, you will be asked to sign it. This will allow your adult son or daughter's participation in this study. You should receive a copy of this document to take with you.

### Explanation of Study

This study is being done because I am interested in learning more about your son or daughter's experiences as a peer-to-peer health, safety, and sexuality trainer for people with intellectual and developmental disabilities. I will interview peer-to-peer trainers in the "Health, Safety, and Sexuality Training for You & Me" program at The TALL Institute, so others can understand more about this topic.

If you agree to allow your adult son or daughter to participate, he or she will be asked to participate in 1 individual interview, lasting approximately 1 hour.

Your adult son or daughter should **not** participate in this study if he or she does not have an intellectual or developmental disability **OR** if he or she is younger than 18 years old.

Your adult son or daughter's participation in the study will last up to 3 months.

### **Risks and Discomforts**

Risks or discomforts that your adult son or daughter might experience are feelings of sadness, shame, or anger when talking about topics related to sex and sexuality. Your adult son or daughter may stop the interview at any time and his or her decision will not impact the services he or she receives from this agency.

If your adult son or daughter discloses any information related to past or current sexual abuse or victimization, I am legally mandated to report this information to the appropriate authorities. Barbara Thomas, Director of The TALL Institute, will be present during each interview. Disclosures related to abuse, either as a victim or an offender, will be reported to Hamilton County Developmental Disability Services, Major and Unusual Incident Prevention, 24-hour Emergency Hotline 513-794-3308.

If you or your adult son or daughter is interested in more information about sexual abuse and assault prevention services, you may contact the Sexual Assault Program at YWCA, 24-hour Crisis Intervention Assistance Hotline at 800-644-4460. For more information about the program, call 513-732-0450. Also, if you or your adult son or daughter is interested in mental health treatment as a result of sexual trauma, you may contact the SAP office, above, or a similar resource provider in your area, for a referral for treatment.

### **Benefits**

This study is important because people with intellectual and developmental disabilities are not usually asked to talk to researchers about topics related to health, safety, and sexuality.

Individually, you son or daughter may not benefit from participation in this study.

### **Confidentiality and Records**

Your adult daughter or son's study information will be kept confidential. Only first names will be used during the interview and all names will be changed before reporting results.

Interviews will be audio-recorded electronically and transferred to DVD. The DVDs will be locked in 107 McCracken Hall, Ohio University, Athens, OH, for 1 year. Beginning May 2013, the DVDs will remain in my possession and will be destroyed after 2 years (July 2014).

Additionally, while every effort will be made to keep your adult son or daughter's study-related information confidential, there may be circumstances where this information must be shared with:

- \* Federal agencies, for example the Office of Human Research Protections, whose responsibility is to protect human subjects in research;
- \* Representatives of Ohio University (OU), including the Institutional Review Board, a committee that oversees the research at OU;

### **Compensation**

As a "thank you" for time/effort, your son or daughter will receive \$10. Your son or daughter will receive \$10, even if he or she decides to stop the interview.

### **Contact Information**

If you have any questions regarding this study, please contact ***Natalie Williams (doctoral student) at 740-593-4784 or [nw351909@ohio.edu](mailto:nw351909@ohio.edu) or Mona Robinson (faculty advisor) at 740-593-4461 or [robinsoh@ohio.edu](mailto:robinsoh@ohio.edu)***

If you have any questions regarding your adult son or daughter's rights as a research participant, please contact Jo Ellen Sherow, Director of Research Compliance, Ohio University, (740)593-0664.

---

By signing below, you are agreeing that:

- you have read this consent form (or it has been read to you) and have been given the opportunity to ask questions and have them answered
- you have been informed of potential risks to your adult daughter or son and they have been explained to your satisfaction.
- you understand Ohio University has no funds set aside for any injuries your adult daughter or son might receive as a result of participating in this study
- you are 18 years of age or older
- your adult son or daughter's participation in this research is completely voluntary
- your adult son or daughter may leave the study at any time. If he or she decides to stop participating in the study, there will be no penalty to your adult son or daughter and he or she will not lose any benefits to which he or she is otherwise entitled.

Parent Signature \_\_\_\_\_ Date \_\_\_\_\_

Printed Name \_\_\_\_\_

Participant's Name \_\_\_\_\_

Version Date: *[12/10/12]*

## Ohio University Assent Form

My name is Natalie Williams. I want to learn more about the things you do as a peer-to-peer trainer in the “Health, Safety, and Sexuality Training for You & Me” program at The TALL Institute. If you would like, and if your parent or guardian gives permission, you can be in my study, as long as you are older than 18 years old and have a diagnosis of ID or DD (intellectual or developmental disability).

If you decide to be in my study, you will spend time talking to me for one hour. We may talk one, two, or three times. We will talk about things you learned and things you do as a peer-to-peer trainer. I will also volunteer at The TALL Institute so I can learn more about what you do there.

When we talk, I will record it and copy to DVD. The DVDs will be locked in 107 McCracken Hall, Ohio University, Athens, OH, for 1 year. Beginning May 2013, the DVDs will remain in my possession and will be destroyed after 2 years (July 2014).

Some of the things we talk about may make you feel sad, upset, or embarrassed. You can say, “I want to stop talking now” to end our talk at any time, if you do not want to continue. If you decide to be in my study OR if you decide not to be in my study, this will not change anything about the services you receive from this agency.

I do not work here; I am only visiting and volunteering to learn more about what you do here. I will not use your real name when I write down the things we talk about.

Barbara Thomas, Director of The TALL Institute, will be present during each interview. If you tell me someone has abused you recently or in the past, or if you tell me you have abused someone recently or in the past, we will make a report to Hamilton County Developmental Disability Services, Major and Unusual Incident Prevention, 24-hour Emergency Hotline 513-794-3308.

If you are interested in more information about sexual abuse and assault prevention services, you may contact the Sexual Assault Program at YWCA, 24-hour Crisis Intervention Assistance Hotline at 800-644-4460. For more information about the program, call 513-732-0450. Also, if you want to talk to a counselor about any abuse, you may call 800-644-4460 and ask for a referral.

This study is important because people with ID and DD are not usually asked to talk to researchers about topics related to health, safety, and sexuality.

Your parent or guardian has to give permission for you to be in my study. After they decide, you can decide, too. If you do not want to be in the study, that's okay. If you do want to be in the study, that's okay, too. If you say, "Yes, I want to be in the study" and change your mind later, that's okay, too. It is your choice. You can stop anytime.

My telephone number is 740-593-4784 (work) and 405-476-6072 (cell) and my email is [nw351909@ohio.edu](mailto:nw351909@ohio.edu). You can call me or email me if you have any questions or decide you do not want to be in the study anymore. I can give you a copy of this paper in case you have questions later.

As a "thank you" for your time/effort, you will receive \$10 for each interview. You receive \$10, even if you decide to stop the interview(s).

-----  
By signing below, you are agreeing that:

- you have read this form (or it has been read to you) and all of your questions have been answered
- you are 18 years of age or older
- no one is forcing you to participate in the study
- you may leave the study at any time and if you decide to stop, that is okay, you will be paid for your time

Participant Signature \_\_\_\_\_ Date \_\_\_\_\_

Printed Name \_\_\_\_\_

Version Date: *[12/10/12]*

## Appendix C: Interview Protocol

### *Individual Interviews (Individuals with Intellectual Disabilities)*

1. Basic Demographic Information
  - a. What is your first name?
  - b. How old are you?
  - c. Where are you from?
  - d. How long have you been taking classes at The TALL Institute?
2. Interview Questions
  - a. How would you describe your disability?
    - i. What does this mean to you?
  - b. How long have you been involved with the peer-to-peer training program?
  - c. How did you decide to become a peer-to-peer trainer?
    - i. Was this a choice you made on your own?
    - ii. Did you talk to anyone about it before you made a final choice?
  - d. How many peer-to-peer trainings have you done?
    - i. Where?
  - e. What kinds of things have **you** learned from the training?
  - f. What kinds of things do you **teach** as part of the training?
  - g. What is the **hardest** part about being a peer-to-peer trainer?
  - h. What is your **favorite** part about being a peer-to-peer trainer?
  - i. What was the **most surprising** thing that happened during a peer-to-peer training presentation?
  - j. In your opinion, is it important for people to learn the information in the health, safety, and sexuality program?

**Appendix D: The “Health, Safety, & Sexuality Training for You & Me”  
Curriculum**

Slide 1

# **HEALTH, SAFETY, & SEXUALITY TRAINING FOR YOU & ME**

**Written by:**

Shelly Snyder, Allen County Board of Development Disabilities  
July 2008

**Edited by:**

Barbara J. Thomas, M.Ed., C.S.E., JSOC  
Director of TECS Education Center

**Project of:**

Partners in Justice  
Disability Resource Network

**Funded by:**

Ohio Developmental Disabilities Council



## **WE ARE HERE TO TALK ABOUT SOMETHING VERY IMPORTANT.**

- It is not easy
- It may make people uncomfortable or scared
- It can bring back bad memories
- It is not always easy to understand



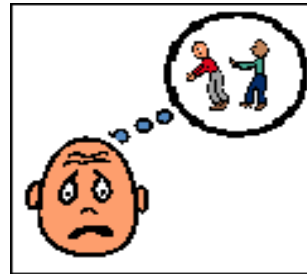
We are going to talk about abuse. It is normal to have these uncomfortable or strange feelings about things that hurt your body or your heart.



## REMEMBER:

If you have bad memories:

- You can talk to someone you trust
- You can talk to a counselor
- You can talk to one of us at the end of this training



# **INCIDENTS THAT AFFECT YOUR HEALTH & SAFETY:**



## **ABUSE = HURT**

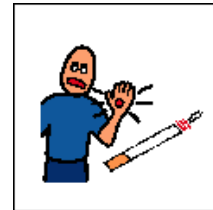
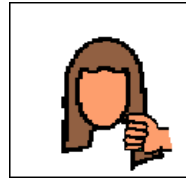
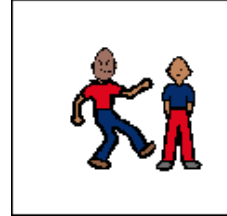
- **PHYSICAL ABUSE**

### **What is it?**

- Hurting someone else's body.

**Examples:**

- Hitting, punching, slapping, pinching, grabbing
- Kicking, making you fall, dragging, pushing
- Burning, no food, jerking, pulling hair and more...



VERBAL = WORDS

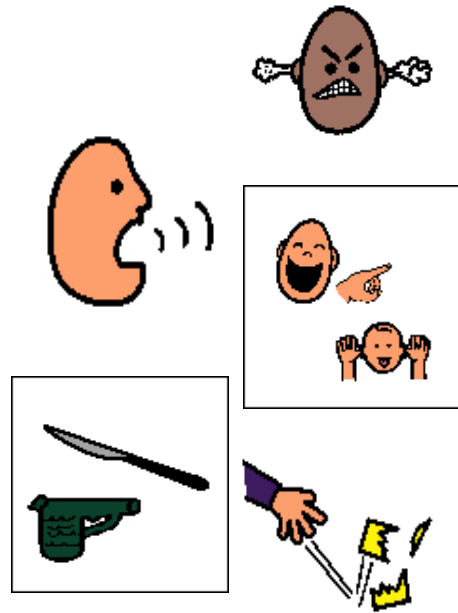
- **VERBAL ABUSE**

**What is it?**

- Using words or hands or body parts to threaten, scare or make fun of you. Even when you ask or let the person know it hurts, it does not stop.

**Examples:**

- Threats such as, “If you don’t do this, I’m going to...” or “If you tell, I’m going to...”
- Lack of respect, calling names or making you feel bad about yourself
- Name-calling, verbal attacks, yelling at you
- Making fun of or talking down to someone
- Raising a fist or showing weapons in a threatening way (gun, knife, etc.)
- Breaking things that belong to you



- **NEGLECT**

**What is it?**

- When getting special help or a special service that you need does not happen.



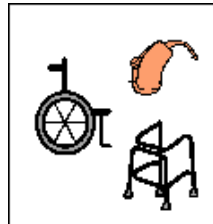
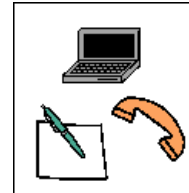
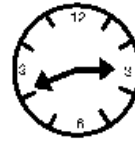
**Examples:**

- Does not provide someone to look after you
- Medical/Dental Care denied
- Does not give you medication on time
- Gives you too much medication
- Does not follow safety rules
- Does not give you basic needs like food or clothes
- Does not provide services outlined in your plan



**Other Examples:**

- Staff not showing up when they are supposed to be with you
- Leaving someone on the toilet too long or failing to help you in the bathroom
- Leaving someone without a way to get their adaptive equipment, telephone, food, etc.
- Failure to give training in areas that would help you do more things on your own
- Does not help or give you what you need for personal hygiene, like toothpaste



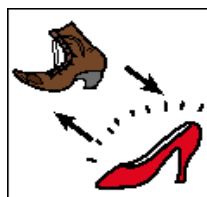
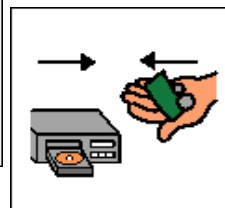
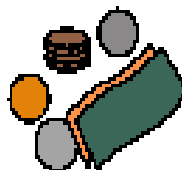
- **THEFT**

**What is it?**

- Stealing or taking your things or your money

**Examples:**

- Stealing money or things that belong to you
- When someone else (Staff, family member, "friend", etc.) uses your money to buy things for themselves
- Selling, buying or trading items for less than they are worth
- Borrowing money and never paying it back
- Trading something that is not worth much money and taking something that cost you a lot of money
- Purposely breaking or taking items that belongs to you



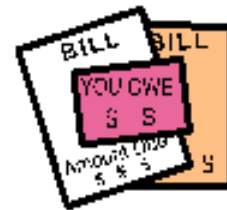
- **BEING TAKEN  
ADVANTAGE OF**

**What is this?**

- “Using” another person for their money, body or other things to satisfy the *other* person’s needs

**Examples:**

- Applying for credit cards or putting bills in someone else's name
- Asking someone to lie to governmental agencies to benefit the other person
- Misuse of someone else's money for personal benefit
- Using another person in a sexual way for personal pleasure



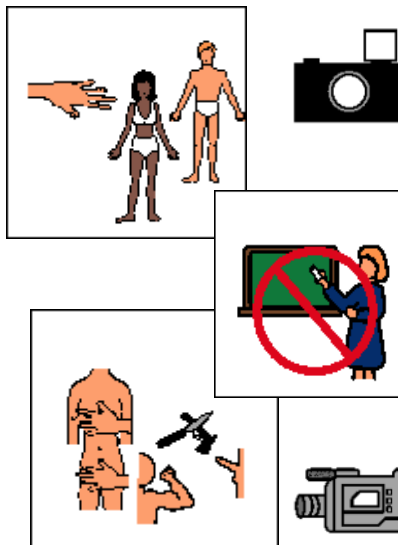
- **SEXUAL ABUSE**

**What is it?**

- Someone touching you on your body in a way that makes you feel uncomfortable. Sometimes it might really hurt and other times it might be very confusing.

**Examples:**

- Touching, grabbing or rubbing you on **ANY** part of your body, including your private areas
- Even after you say “No!” the person keeps touching you
- Penetration (putting a body part or other item inside your body)
- Forced sexual activity (being held down or having words that threaten or scare you into having sex)
- Other types of sex crimes like public indecency or voyeurism, etc., that are done to you
- A “support” person that does not believe you or does not want you to have sexuality education





## HOW DO YOU SAY NO?



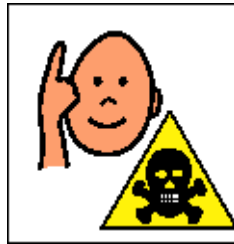
- How can you use your voice to say no?
- How can you use your body to say no?
- What are some other ways you can say no?

# **SAFETY PLANNING**

**What Can You Do?**



# 1. Understand Your Risk Factors



- **People with disabilities are 4 to 10 times more likely to be victims of crime than people without disabilities**

- **Assault: 3 times higher**



- **Sexual Abuse: 11 times higher**



- **Theft: 13 times higher**



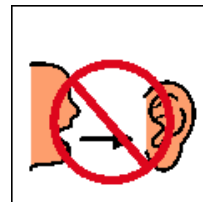
- **90% of persons with disabilities will be sexually abused in their lifetime**



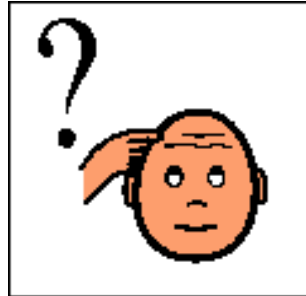
**2. UNDERSTAND  
WHY PEOPLE WITH  
DISABILITIES ARE  
TAKEN ADVANTAGE  
OF**

## Slide 23

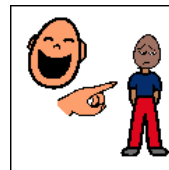
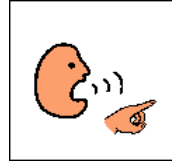
- You might often be alone
- You rely on others for care/assistance
- You are not always able to get what you need (including earning money and/or attending classes to learn new things) due to lack of transportation
- Some people have problems talking or communicating with others
- Others may think that persons with disabilities will not be believed



### **3. UNDERSTAND HOW TO KNOW YOU ARE BEING ABUSED**

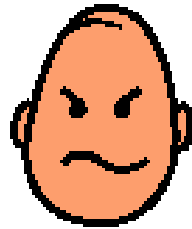


- You are told you are doing something wrong all the time
- You are discouraged from seeing family or friends
- Abuser controls your money, medication and schedule of things you do
- Criticizes or makes fun of you to your face or in front of others
- Is disrespectful to you and/or your personal belongings
- Threatens or actually does hurt you
- Blames you for their temper, anger, yelling



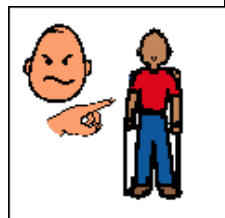
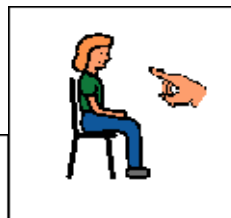
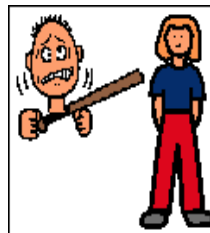


**4. UNDERSTAND AND  
KNOW THE THINGS  
AN ABUSER MAY DO**



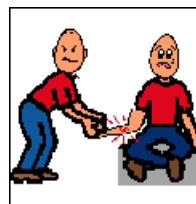
## Slide 27

- Tell you they will punish you or will not be your friend
- Scares you by using looks, words, putting a fist at you, or with guns/knives
- Keeps you from friends, family, phone, TV, news, work, other social places
- Blames you for the abuse
- Uses your money for themselves, you do not get to see your checkbook or bills
- Makes fun of you, does not pay attention to you, or will not do what you want

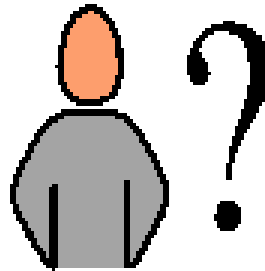


## Slide 28

- Does not follow your personal health and safety rules
- Says they don't have to listen to you
- Hurts you when providing care
- Punishes you if you stand up for yourself
- Uses your phone, TV, laundry, food, and other personal belongings without asking
- Tells you when to sleep, eat, and do other activities
- Says no one will believe you if you report them



# **5. UNDERSTAND WHO THE ABUSERS MAY BE**



- 90% of Abusers know their victims



- They can be...

- Family



- Caregivers/Providers


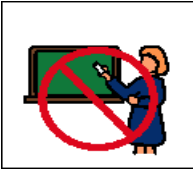

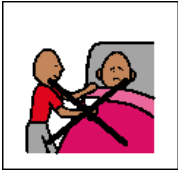




- Other persons with disabilities



## FAMILY

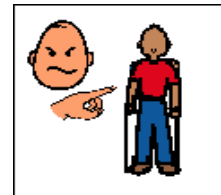
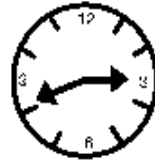
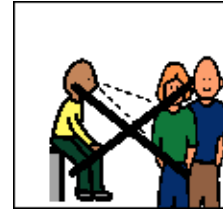
- **Reasons a family member may abuse...**
  - Stress
  - Too much for them to handle
  - Do not get time away
  - Hurt you as a way to “discipline”
  - Lack of training or support
  - Lack of financial resources



## CAREGIVERS/PROVIDERS

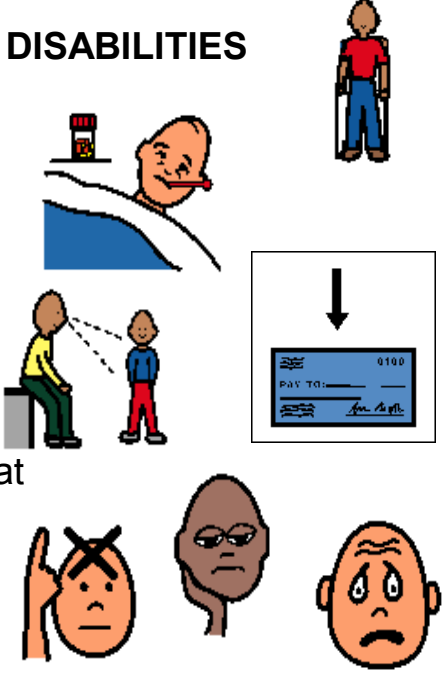
- **Reasons why a caregiver/provider would abuse...**

- Little or no training
- Does not care
- Makes mistakes/does not pay attention to special needs
- Long hours
- Blaming the disability or behavior



### OTHER PERSONS WITH DISABILITIES

- **Why other persons with disabilities would abuse...**
  - Signs of an illness
  - Little money/does not work
  - Loss of control
  - Attention
  - Nothing to do
  - Scared, do not know what to do
  - Problems with knowing what is being asked of them



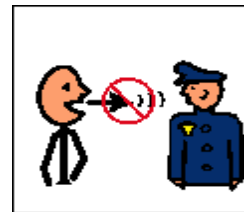
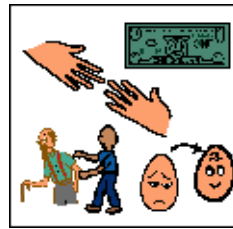
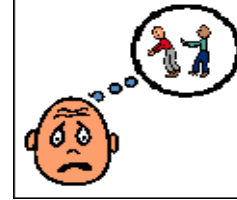
The slide contains several illustrations: a person lying in bed with a thermometer in their mouth and a pill bottle on a table; a person in a wheelchair; a person sitting on a bench talking to a standing person; a check with a downward arrow above it; and three faces showing confusion, anger, and fear.



**6. UNDERSTAND WHAT  
WOULD KEEP YOU  
FROM REPORTING  
ABUSE OR TELLING  
SOMEONE**



- You feel ashamed, somehow to blame or you may feel bad for the person who did something to you
- You don't know what will happen if you report
  - No one will believe you
  - Nothing will be done
  - You might lose a caregiver, privileges or your home
  - Have medication changes
  - Have more restraints
  - Have more abuse
- Dependent on abuser
  - financially, physically, emotionally
- You may feel alone
- You may have difficulty communicating
  - Do not know who to talk to
  - You can't speak or get your point across
  - Unable to use the phone
  - Afraid of the people in charge
  - No safe place to go



## How Many People Did Not Tell

- **40% : mild mental retardation**



- **70% : severe mental retardation**



## **7. IT IS IMPORTANT TO TELL BECAUSE. . . .**

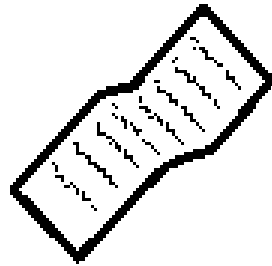
- You have a right to be safe
- You are important
- It will help stop someone else from being abused
- It will help you get support

## 8. WHO SHOULD YOU TELL?

- Tell someone you trust like a caseworker, staff person, friend, parent, police officer
- More than one person
- Keep telling until someone listens and helps you



# COMPLETE YOUR SAFETY PLAN



- Choose someone you trust to help you



- Keep your safety plan in a safe place you can get to



# **HOW DO I KNOW IF A PERSON WOULD BE A GOOD SAFE PERSON?**

Ask yourself these questions.

If you can answer “no” to all of them, then  
you have made a good choice.

? ? ? ? ? ? ? ? ? ?



## **QUESTIONS:**

- Has this person ever hurt your body?
- Has this person ever hurt your things?
- Has this person ever made fun of you or embarrassed you?
- Has this person ever called you names?

## **MORE QUESTIONS:**

- Has this person ever taken or borrowed your money without paying you back?
- Has this person ever touched you where you did not want to be touched?
- Has this person ever threatened you?
- If you were alone with this person in a dark room, do you think he/she might do something bad?
- Has this person ever refused to help you?

## **IT IS IMPORTANT TO ALWAYS REMEMBER:**

- It is wrong for you to be hurt
- Abuse is against the law
- Tell someone when you have been hurt
- You have the right to say no
- You have the right to get help
- You have the right not to be touched
- It is never your fault
- You have the responsibility to tell someone when you have been hurt
- You are a very special person

## Appendix E: Scripts

### First Performing Set – Demonstrating types of abuse

#### Physical Abuse

##### Skit #1

Man 1: Dad, I'm almost done cleaning the garage.

Man 2: You put all the tools on the wrong shelf. (hits Man1) Can't you do anything right? (hits him again) Now put them on the other shelf and don't screw up this time. (hits him again)

##### Skit #2

Woman 2: Greg said to meet him here in front of this store at 4. It's almost 4 now.

Woman 1: I don't know what Greg sees in you. He should still be my boyfriend. (Spits on Woman 2)

#### Verbal Abuse

##### Skit #1

Woman 1: I wish these grocery carts came apart easier. They always stick. (tries to pull out a cart)

Man 2: (enters and watches Woman 2; she doesn't try to help and just watches in disgust)

Woman 1: Can you help me get this cart unstuck?

Man 2: If you're too stupid to get it yourself, maybe you shouldn't be here. (makes a "crazy" sign)

##### Skit #2

Woman 2: (yelling) I can't believe you forgot to pick up the hamburger!

Man 1: I'm sorry. I had a bad day at work.

Woman 2: (yelling) Oh, poor baby. Is that what you are? A baby?

Man 1: No, I'm not a baby.

Woman 2: (yelling) I ask you to pick up one freaking thing at the store and you can't even do that.

Man 1: I'll go get it now.

Woman 2: (yelling) No! I'm not sending a baby to the store. I'll get the hamburger and some baby food for you! (leaves)

## Neglect

## Skit #1

Woman 1: I'm leaving now Lisa.

Woman 2: Did you pick up my medicine Frieda?

Woman 1: No, I was too busy. I'll get it tomorrow.

Woman 2: I'm supposed to have it every day.

Woman 1: Oh, you can wait until tomorrow.

Woman 2: But tomorrow's Sunday and the drugstore is closed.

Woman 1: You'll survive. Oh, and I didn't have time to fix your dinner. Just have a bag of chips.

## Skit #2

Man 1: (looking at watch) Bob was supposed to pick me up an hour ago. The park closed half an hour ago and now it's raining. And I'm hungry ... I should have had dinner by now. (dials cell phone) Still no answer ... I wonder where he is.

## Theft

## Skit #1

Man 2: Can I have my DVD back? I want to watch it with my girlfriend this weekend.

Woman 1: I'll bring it tomorrow.

Man 2: That's what you said last week when my brother wanted to watch it.

Woman 1: I forgot.

Man 2: That's what you said last month. Am I ever going to see it again? It's my favorite movie.

Woman 1: It's my favorite too. Maybe I'll just keep it.

## Skit #2

Hank (Man 1): I can't wait to see what's in my lunch. We had lasagna last night and there were leftovers.

Gina (Woman 2): I want to see what's in the machine. Everything's \$4! That's all I have. Can you buy me a pop?

Hank: I only have enough for a pop and the bus home.

Gina: I thought you were my friend.

Hank: I am. I just don't have the money.

Gina: If you were a real friend, you'd walk home.

Hank: This is all the money I have. (shows her the money)

Gina: (grabs the money) Thanks! See you later. (leaves)

## Being Taken Advantage of

## Skit #1

Woman 1: I'm almost done with my shopping. Let's go to the check out.

Woman2: I need to get a few things. Can I put them in with your things and I'll pay you back later.

Woman 1: Your my staff, I shouldn't have to pay for your things.

Woman 2: I'm a little short this week.

## Skit #2

Man 1: Hey neighbor! Can I have a pop?

Man 2: Sure. There's one in the fridge. Help yourself.

Man 1: Thanks. (goes to get pop, comes back with whole case)

Man 2: I said help yourself to one. Not the whole case.

Man 1: I left one for you. That should be all you need. I have friends coming over.

## Sexual Abuse

## Skit #1

Woman 1: Mr. Jones, my paycheck was delayed. I can't pay my rent until next week. Is that ok?

Man 1: I'll let you pay next week if you will have sex with me.

Woman 1: No, I don't want to.

Man 1: Then I'll kick you out.

## Skit #2

Uncle Larry: Hey Peggy. You're parents are on their way to Baltimore.

Peggy: Okay.

Uncle Larry: How about a hug for you old Uncle Larry?

Peggy: I'd rather not.

Uncle Larry: Come on. I won't bite. (hugs her)

Peggy: Don't touch me there. I don't like it.

Man 2: You've never complained before.

Woman 2: I don't want you touching me at all.

Man 2: Just give me a kiss.

Woman 2: (backs away) No, stay away from me.

Second Performing Set – “How to Say No” Improv

Based on suggestions of situations from the audience, actors will demonstrate ways to say “no”. This will include appropriateness of response in the situation (e.g. who are you saying it to, how was the request made, is an explanation required, etc.)

Third Performing Set – Examples of Making a Safety Plan

## Scene 1 – Neglect by Staff / Trusted person: Parent/Guardian

Lisa – Woman 2

Dad – Man 2

(Knock at door)

Lisa: Hi Dad.

Dad: Hi Lisa. How are you doing?

Lisa: (quietly) Oh, OK I guess.

Dad: What's wrong?

Lisa: Nothing.

Dad: What did Frieda fix you for dinner?

Lisa: I wasn't hungry.

Dad: What?

Lisa: I'm not feeling well

Dad: Lee, what's going on?

Lisa: Frieda didn't have time to fix me dinner. She said to eat a bag of chips.

Dad: That's not dinner. You need a real meal with your medicine.

Lisa: She didn't have time to pick up my medicine. I wish Tina was still my staff.

Dad: Well, unfortunately Tina got married and moved to Tulsa. But we need to make sure this doesn't happen again. We need to make a safety plan. Put together all the things you need in a situation like this.

Lisa: Like my medicine?

Dad: Good. What else?

Lisa: Some food?

Dad: A non-perishable microwave meal would work. And a bottle of water too. What else?

Lisa: Your phone number.

Dad: Exactly. And you'll need a safe place to keep them.

Lisa: How about in my suitcase in my closet?

Dad: Excellent. But first we call the agency and get you a new staff.



## Scene 2 – Extortion by Peer/Friend / Trusted person: Family Member

Hank – Man 1

Marla, Hank's Sister – Woman 1

Marla: Hey bro, I'm glad you called me.

Hank: Thanks for coming. I didn't want to walk all the way home.

Marla: Tell me again what happened.

Hank: Gina didn't have enough money for a pop. She took the money I had for my pop and bus fare.

Marla: Wow. Tell you what; let's make an emergency plan in case this happens again.

Hank: An emergency plan?

Marla: A plan in case this happens again.

Hank: OK.

Marla: What do you think you would need?

Hank: A cell phone to call you.

Marla: Good. But what if I'm not available?

Hank: Ummmm, bus fare?

Marla: Great idea. And how do we keep it safe?

Hank: (thinks about it) We could give it to my supervisor. He can keep it in his office and I can go to him if I need it.

Marla: Sounds like we have a plan!

## Scene 3 – Sexual Abuse by Family / Trusted person: Authority Figure

Barb – Barb or Woman 1

Peggy – Woman 2

Barb: Peggy, what are you doing here? Your class isn't until tomorrow.

Peggy: I need to talk to you.

Barb: I see you're carrying your suitcase. What's wrong?

Peggy: My mom and dad went to California and asked Uncle Larry to stay with me.

Barb: I thought you didn't like your Uncle Larry.

Peggy: I don't. I don't like the way he looks at me and the things he says.

Barb: Is that why you're here?

Peggy: Yes ... and he started touching me and trying to kiss me.

Barb: I'm so sorry. What can we do?

Peggy: I want to use my safety plan.

Barb: Good idea. Do you have your plan?

Peggy: Yes, here it is.

Barb: Let's go through it. (to each of the following, Peggy replies "Check")

- 1) Trusted Person
- 2) Cell Phone
- 3) Emergency Money
- 4) Contact information for Mom & Dad
- 5) Place to go
- 6) Bus Fare
- 7) Medicine
- 8) Extra set of clothes
- 9) Cane

Peggy: Looks like I have everything.


Barb: Yes you do. Good job. Now let's go call your parents and ask them if there is someone else you can stay with.


Peggy: Thanks Barb. I feel much better.













### Appendix F: Evaluation Forms

## Health, Safety, & Sexuality Training for You and Me

*Please answer these questions to help us know if today's training was helpful.*







Agree = 

Disagree = 

<p>1. The training was good.</p> 	 
<p>2. The training was easy to understand.</p> 	 
<p>3. The people in the skits did a good job.</p> 	 
<p>4. I learned something today.</p> 	 

## Health, Safety, & Sexuality Training for You and Me

*Please answer these questions to help us know if today's training was helpful.*

<p>1. Is spitting an example of physical abuse?</p> 	<p> <b>YES</b>     <b>NO</b></p>
<p>2. If someone touches you on the arm, and you don't like it, is that sexual abuse?</p> 	<p> <b>YES</b>     <b>NO</b></p>
<p>3. Are most abusers strangers?</p> 	<p> <b>YES</b>     <b>NO</b></p>
<p>4. Will a safety plan help you stay safe against abuse and neglect?</p> 	<p> <b>YES</b>     <b>NO</b></p>
<p>5. If someone abuses you, is it your fault?</p> 	<p> <b>YES</b>     <b>NO</b></p>

## Partners in Justice / ODDDCouncil

**Evaluation of the Health, Safety and Sexuality Training Program**EvaluationPlease answer these questions to let us know if the training today was helpful:

1. The Training was good:



\_\_\_ YES



\_\_\_ NO



\_\_\_ NOT SURE

2. I was comfortable with the things they were talking about:



\_\_\_ YES



\_\_\_ NO



\_\_\_ NOT SURE

3. I learned something new in the class:



\_\_\_ YES





\_\_\_ NO



\_\_\_ NOT SURE

Can you tell us one thing that you learned?

---

4. The people in the skits did a good job:  \_\_\_ YES  \_\_\_ NO

Comments:

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Please answer these questions to help us know if today's training was helpful:

1. Is spitting an example of physical abuse?

 \_\_ YES  \_\_ NO  \_\_ NOT SURE

2. If someone touches you on the arm, and you don't like it, is that sexual

abuse?  \_\_ YES  \_\_ NO  \_\_ NOT SURE

3. Are most abusers strangers?

 \_\_ YES  \_\_ NO  \_\_ NOT SURE

4. Will a Safety Plan help you stay safe against abuse and neglect?

 \_\_ YES  \_\_ NO  \_\_ NOT SURE

5. If someone abuses you it is your fault?

 \_\_ YES  \_\_ NO  \_\_ NOT SURE

I AM A MALE



\_\_\_\_\_

I AM A FEMALE



\_\_\_\_\_

NAME (OPTIONAL): \_\_\_\_\_

Date: \_\_\_\_\_

**Staff Evaluation for  
Health, Safety, and Sexuality Training**

<b>Strongly Agree</b>	<b>Agree</b>	<b>Disagree</b>	<b>Strongly Disagree</b>			
<b>1</b>	<b>2</b>	<b>3</b>	<b>4</b>			
			1	2	3	4
1.	The information presented was interesting.		1	2	3	4
2.	The information presented was easy to understand.		1	2	3	4
3.	The presentation was well organized.		1	2	3	4
4.	The presenters were engaging.		1	2	3	4
5.	The presenters were knowledgeable of the subject matter.		1	2	3	4
6.	The information presented was relevant to the target audience.		1	2	3	4

**Comments and Suggestions:**

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**Staff Evaluation for  
Health, Safety, and Sexuality Training**

<b>Strongly Agree</b>	<b>Agree</b>	<b>Disagree</b>	<b>Strongly Disagree</b>			
<b>1</b>	<b>2</b>	<b>3</b>	<b>4</b>			
			1	2	3	4
1.	The information presented was interesting.		1	2	3	4
2.	The information presented was easy to understand.		1	2	3	4
3.	The presentation was well organized.		1	2	3	4
4.	The presenters were engaging.		1	2	3	4
5.	The presenters were knowledgeable of the subject matter.		1	2	3	4
6.	The information presented was relevant to the target audience.		1	2	3	4

**Comments and Suggestions:**

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## Appendix G: Evaluation Reports

***“Health, Safety, & Sexuality Training for You & Me”*****Participant Evaluation Report Version 1**

Participants who attended the training were asked to complete evaluation forms, responding to the following prompts. This version of the Participant Evaluation included four items to elicit feedback on the training presentation and five items related to specific concepts covered in the training.

**Last Modified: 02/2/2013**

**1. The training was good.**

#	Answer		Response	%
1	Agree		31	89%
2	Disagree		4	11%
	Total		35	100%

Statistic	Value
Min Value	1
Max Value	2
Mean	1.11
Variance	0.10
Standard Deviation	0.32
Total Responses	35

**2. The training was easy to understand.**

#	Answer		Response	%
1	Agree		33	92%
2	Disagree		3	8%
	Total		36	100%



Statistic	Value
Min Value	1
Max Value	2
Mean	1.08
Variance	0.08
Standard Deviation	0.28
Total Responses	36

### 3. The people in the skits did a good job.

#	Answer	Response	%
1	Agree	35	97%
2	Disagree	1	3%
	Total	36	100%

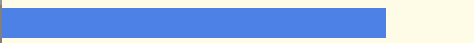

Statistic	Value
Min Value	1
Max Value	2
Mean	1.03
Variance	0.03
Standard Deviation	0.17
Total Responses	36

### 4. I learned something today.

#	Answer	Response	%
1	Agree	35	97%
2	Disagree	1	3%
	Total	36	100%

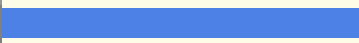

Statistic	Value
Min Value	1
Max Value	2
Mean	1.03
Variance	0.03
Standard Deviation	0.17
Total Responses	36

### 5. Is spitting an example of physical abuse?

#	Answer		Response	%
1	Yes		25	81%
2	No		6	19%
	Total		31	100%

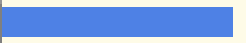

Statistic	Value
Min Value	1
Max Value	2
Mean	1.19
Variance	0.16
Standard Deviation	0.40
Total Responses	31

### 6. If someone touches you on the arm, and you don't like it, is that sexual abuse?

#	Answer		Response	%
1	Yes		24	75%
2	No		8	25%
	Total		32	100%

Statistic	Value
Min Value	1
Max Value	2
Mean	1.25
Variance	0.19
Standard Deviation	0.44
Total Responses	32

### 7. Are most abusers strangers?

#	Answer		Response	%
1	Yes		16	48%
2	No		17	52%
	Total		33	100%

Statistic	Value
Min Value	1
Max Value	2
Mean	1.52
Variance	0.26
Standard Deviation	0.51
Total Responses	33

### 8. Will a safety plan help you stay safe against abuse and neglect?

#	Answer	Response	%
1	Yes	31	97%
2	No	1	3%
	Total	32	100%

Statistic	Value
Min Value	1
Max Value	2
Mean	1.03
Variance	0.03
Standard Deviation	0.18
Total Responses	32

### 9. If someone abuses you, is it your fault?

#	Answer	Response	%
1	Yes	5	15%
2	No	29	85%
	Total	34	100%

Statistic	Value
Min Value	1
Max Value	2
Mean	1.85
Variance	0.13
Standard Deviation	0.36
Total Responses	34

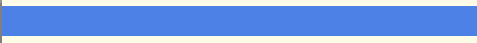


## ***“Health, Safety, & Sexuality Training for You & Me”***

### **Participant Evaluation Report Version 2**

Participants who attended the training were asked to complete evaluation forms, responding to the following prompts. This version of the Participant Evaluation included six items to elicit feedback on the training presentation and five items related to specific concepts covered in the training, in addition to three demographic items.

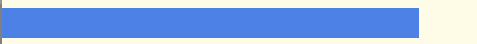


Last Modified: 2/2/2013

#### **1. The training was good:**

#	Answer		Response	%
1	Yes		17	100%
2	No		0	0%
3	Not Sure		0	0%
	Total		17	100%

Statistic	Value
Min Value	1
Max Value	1
Mean	1.00
Variance	0.00
Standard Deviation	0.00
Total Responses	17

#### **2. I was comfortable with the things they were talking about:**

#	Answer		Response	%
1	Yes		14	88%
2	No		1	6%
3	Not Sure		1	6%
	Total		16	100%

Statistic	Value
Min Value	1
Max Value	3
Mean	1.19
Variance	0.30
Standard Deviation	0.54
Total Responses	16

### 3. I learned something new in the class:

#	Answer		Response	%
1	Yes		16	94%
2	No		0	0%
3	Not Sure		1	6%
	Total		17	100%

Statistic	Value
Min Value	1
Max Value	3
Mean	1.12
Variance	0.24
Standard Deviation	0.49
Total Responses	17

#### 4. Can you tell us one thing that you learned?

##### Text Response

modeling  
 no hitting  
 not ok to hit  
 (illegible)  
 peeping Tom  
 That I need help.  
 helping myself  
 angry and mad - tell people how you feel  
 Don't push people around.  
 no arguing  
 do t hit  
 we should not be abused  
 not hit each other  
 not to fight  
 pushing somebody is bad

Statistic	Value
Total Responses	15

#### 5. The people in the skits did a good job:

#	Answer	Response	%
1	Yes	17	100%
2	No	0	0%
3	Not Sure	0	0%
	Total	17	100%

Statistic	Value
Min Value	1
Max Value	1
Mean	1.00
Variance	0.00
Standard Deviation	0.00
Total Responses	17

## 6. Comments:

### Text Response

no  
a very good performance

Statistic	Value
Total Responses	2

## 7. Is spitting an example of physical abuse?

#	Answer	Response	%
1	Yes	16	100%
2	No	0	0%
3	Not Sure	0	0%
	Total	16	100%

Statistic	Value
Min Value	1
Max Value	1
Mean	1.00
Variance	0.00
Standard Deviation	0.00
Total Responses	16



## 8. If someone touches you on the arm, and you don't like it, is that sexual abuse?

#	Answer		Response	%
1	Yes		13	81%
2	No		3	19%
3	Not Sure		0	0%
	Total		16	100%

Statistic	Value
Min Value	1
Max Value	2
Mean	1.19
Variance	0.16
Standard Deviation	0.40
Total Responses	16

## 9. Are most abusers strangers?

#	Answer		Response	%
1	Yes		2	15%
2	No		10	77%
3	Not Sure		1	8%
	Total		13	100%

Statistic	Value
Min Value	1
Max Value	3
Mean	1.92
Variance	0.24
Standard Deviation	0.49
Total Responses	13

## 10. Will a safety plan help you stay safe against abuse and neglect?

#	Answer		Response	%
1	Yes		11	69%
2	No		3	19%
3	Not Sure		2	13%
	Total		16	100%



Statistic	Value
Min Value	1
Max Value	3
Mean	1.44
Variance	0.53
Standard Deviation	0.73
Total Responses	16

## 11. If someone abuses you, is it your fault?

#	Answer		Response	%
1	Yes		4	31%
2	No		8	62%
3	Not Sure		1	8%
	Total		13	100%

Statistic	Value
Min Value	1
Max Value	3
Mean	1.77
Variance	0.36
Standard Deviation	0.60
Total Responses	13

## 12. I am a

#	Answer	Response	%	
1	Male		9	53%
2	Female		8	47%
	Total		17	100%

Statistic	Value
Min Value	1
Max Value	2
Mean	1.47
Variance	0.26
Standard Deviation	0.51
Total Responses	17

## 13. Name (optional)

### Text Response

Names have been removed to protect the confidentiality of participants.

Statistic	Value
Total Responses	10

**14. Date**

## Text Response

12-10-2012

12.4.12

12.4.12

12/4/12

12/4/12

12/12

4

12-4-12

4-27-61

12/4/12

12412

4

Statistic

Value

Total Responses

12

## ***“Health, Safety, & Sexuality Training for You & Me”***

### **Staff Evaluation Report**

Agency staff members who attended the training were asked to complete evaluation forms, responding to the following prompts. This Staff Evaluation included six items to elicit feedback on the training presentation and one open-ended response item.

Last Modified: 2/2/2013

#### **1. The information presented was interesting**

#	Answer		Response	%
1	Strongly Disagree		0	0%
2	Disagree		0	0%
3	Agree		5	20%
4	Strongly Agree		20	80%
	Total		25	100%

Statistic	Value
Min Value	3
Max Value	4
Mean	3.80
Variance	0.17
Standard Deviation	0.41
Total Responses	25

#### **2. The information presented was easy to understand**

#	Answer		Response	%
1	Strongly Disagree		0	0%
2	Disagree		0	0%
3	Agree		6	24%
4	Strongly Agree		19	76%
	Total		25	100%

Statistic	Value
Min Value	3
Max Value	4
Mean	3.76
Variance	0.19
Standard Deviation	0.44
Total Responses	25

### 3. The presentation was well organized

#	Answer	Response	%
1	Strongly Disagree	0	0%
2	Disagree	0	0%
3	Agree	2	8%
4	Strongly Agree	22	92%
	Total	24	100%

Statistic	Value
Min Value	3
Max Value	4
Mean	3.92
Variance	0.08
Standard Deviation	0.28
Total Responses	24

### 4. The presenters were engaging

#	Answer	Response	%
1	Strongly Disagree	0	0%
2	Disagree	0	0%
3	Agree	2	8%
4	Strongly Agree	23	92%
	Total	25	100%

Statistic	Value
Min Value	3
Max Value	4
Mean	3.92
Variance	0.08
Standard Deviation	0.28
Total Responses	25

### 5. The presenters were knowledgeable of the subject matter

#	Answer	Response	%
1	Strongly Disagree	0	0%
2	Disagree	0	0%
3	Agree	3	12%
4	Strongly Agree	22	88%
	Total	25	100%

Statistic	Value
Min Value	3
Max Value	4
Mean	3.88
Variance	0.11
Standard Deviation	0.33
Total Responses	25

## 6. The information presented was relevant to the target audience

#	Answer		Response	%
1	Strongly Disagree		0	0%
2	Disagree		0	0%
3	Agree		3	12%
4	Strongly Agree		22	88%
	Total		25	100%

Statistic	Value
Min Value	3
Max Value	4
Mean	3.88
Variance	0.11
Standard Deviation	0.33
Total Responses	25



## 7. Comments and Suggestions

### Text Response

the whole presentation was great!

Just a couple comments -> will email you. Great to meet the presenters! Great idea!  
great class.

students did a great job of retaining composure & delivering their lines. nice pres.

love the play (skit) idea. good teaching tool.

excellent approach, if a few of the presenters could have their voices amplified, it would be a positive thing. probably difficult to achieve. just a thought.

the presentation was well done. really enjoyed the interaction.

The presentation was great and the individuals did an awesome job. I enjoyed the interaction between Barb & the individuals & hearing how they could relate with their own experiences.

excellent program

very good - got their point across. doing in a relaxed fashion was good.

nicely done - getting the students involved in the Q & A was key

Thank you for letting me watch. Your students are so honest and it seems like you have created a very safe space for them. Though I can't buy your program, I would like if I am taught. It is great.

Statistic	Value
Total Responses	13

## *Certificate of Attendance*

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*Has successfully completed*  
**Health, Safety and Sexuality  
Training for You & Me**

*Presented by the*  
*Partners in Justice Victims Sub Committee*  
*Blue Team*

*A Project of Partners in Justice*  
*Ohio Developmental Disabilities Council*

*Signed:* \_\_\_\_\_

***Blue Team Facilitator:***

*Barbara J. Thomas, M.Ed., C.S.E, JSOC*  
*Chairperson, Partners in Justice Victims Subcommittee*  
*Director, TECS, Education Center and*  
*The TALL INSTITUTE, Thomas Adventures in Lifelong Learning*  
*3950 Edwards Road*  
*Cincinnati, Ohio 45209*  
*513-731-7077*  
*[bjthomas\\_tecs@yahoo.com](mailto:bjthomas_tecs@yahoo.com)*  
*[www.tallinstitute.org](http://www.tallinstitute.org)*

*Date:* \_\_\_\_\_

## Appendix I: Agenda

### Health, Safety & Sexuality Training for YOU & ME

*Presented by Team "Blue" of the Partners in Justice Victims Subcommittee*

#### AGENDA

- I. **Introductions**
  - A. **Presenters & Facilitator**
    - 1. [REDACTED]
    - 2. [REDACTED]
    - 3. [REDACTED]
    - 4. [REDACTED]
    - 5. [REDACTED]
    - 6. Barb Thomas, M.Ed., C.S.E, JSOC
- II. **Incidents that Affect your Health and Safety**
  - A. Physical Abuse
  - B. Verbal Abuse
  - C. Neglect
  - D. Theft
  - E. Being Taken Advantage of
  - F. Sexual Abuse
- III. **Understand:**
  - A. **Your Risk Factors:**
    - 1. 4 to 10 times more likely to be victims of crime than people without disabilities
  - B. **Why people are taken advantage of:**
    - 1. Alone
    - 2. Rely on others
    - 3. Problems with talking/communication
    - 4. May not be believed
  - C. **How you KNOW you are being abused:**
    - 1. Told you are wrong all of the time
    - 2. Discouraged from seeing family/friends
    - 3. Others control your money; medication; activities
    - 4. Criticized; disrespected; threatened; hurt; blamed for others weaknesses
  - D. **Group Discussion:**
    - 1. Who *they* are and What *they* might do?
    - 2. What would keep YOU from reporting?
    - 3. It's Important to Tell Because...
    - 4. Who Should You Tell?
- IV. **Safety Planning: What Can YOU Do?**
  - A. Safety Plan
  - B. Resources in YOUR community
- V. **Evaluation**
  - A. Can you answer these questions?
  - B. NOW WHAT????

## Appendix J: Team Blue – Panel Bios

### Ohio Partners in Justice Team “Blue”

██████████, ██████████, ██████████, ██████████, ██████████ and ██████████ are members of the Ohio Partners in Justice Peer-to-Peer Training Team “Blue”, which is funded by the Ohio Developmental Disabilities Council.

After completing Team training that consisted of working with The TALL INSTITUTE in their Film Making and the Arts Class the “Blue” Team continues their training by meeting for many hours prior to any presentation that they give. This training, facilitated by Barb Thomas, gives the presenters an opportunity to not only review the materials and curriculum but to determine what “life-stories” they may want to add to their presentation. Of course, not all stories should or need to be shared with others while others take on special meaning to the presenters. We determine which ones would benefit the audience and might assist the presenters as they, too, continue to make decisions for themselves in the areas of sexuality and safety education.

The team members, along with their guide, travel throughout Ohio presenting a peer-to-peer education program titled: **Health, Safety and Sexuality Training for You and Me**. The goal is for the Team to address individuals with intellectual and developmental disabilities in making good choices for themselves. ██████████ ██████████ are self-advocates who champion continuing education for adults with intellectual and developmental disabilities. I am proud to be able to work closely with them as they assist others in being **Happy, Healthy and Safe**.

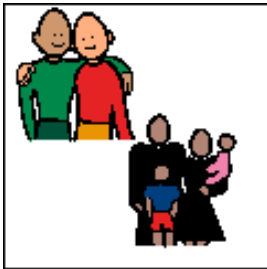
Barbara J. Thomas, M.Ed., C.S.E., JSOC  
“Blue” Team Guide

Appendix K: Safety Plan

SAFETY PLAN

1. A TRUSTED FAMILY OR FRIEND I FEEL SAFE WITH IS:

NAME:	RELATIONSHIP:	PHONE #:
_____	_____	_____
_____	_____	_____
_____	_____	_____
_____	_____	_____
_____	_____	_____



2. I NEED ASSISTANCE WITH THE FOLLOWING:

MEDICATION ADMINISTRATION:	YES	NO
TOILETING:	YES	NO
DRESSING:	YES	NO
USING A TELEPHONE:	YES	NO
MOBILITY:	YES	NO
EATING:	YES	NO
DIET RESTRICTION?	YES	NO



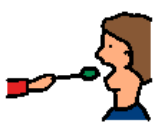
IF YES, EXPLAIN: \_\_\_\_\_

\_\_\_\_\_



OTHER: \_\_\_\_\_

\_\_\_\_\_



**3. IF I HAD TO LEAVE MY HOME, I COULD STAY WITH:**

NAME: ADDRESS: PHONE #:

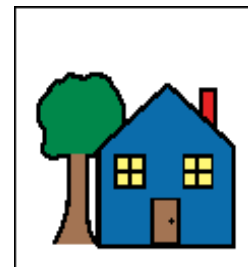
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**4. IF I NEED TO LEAVE MY HOME, I WILL NEED TO BRING:**

MEDICATION/MEDICAL SUPPLIES/  
MY MEDICAL HISTORY YES NO

MONEY YES NO

CLOTHES YES NO

PERSONAL HYGEINE ITEMS YES NO

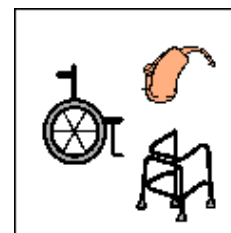
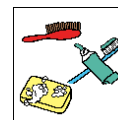
ADAPTIVE EQUIPMENT YES NO

COMMUNICATION DEVICE YES NO

WHEELCHAIR/WALKER/CANE YES NO

OTHER: \_\_\_\_\_ YES NO

OTHER: \_\_\_\_\_ YES NO



**LIST OF INDIVIDUALS WHO ALSO HAVE A COPY OF MY SAFETY PLAN:**

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**IMPORTANT PHONE NUMBERS:**

**911**

**NAME:**

**PHONE NUMBER:**

EMERGENCY \_\_\_\_\_ 911 \_\_\_\_\_

**LAW ENFORCEMENT:**

POLICE DEPT: \_\_\_\_\_

COUNTY SHERIFF: \_\_\_\_\_



**SHELTERS:**

\_\_\_\_\_  
\_\_\_\_\_  
\_\_\_\_\_



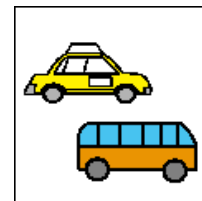
**FOOD/CLOTHING ASSISTANCE:**

\_\_\_\_\_  
\_\_\_\_\_  
\_\_\_\_\_



**TRANSPORTATION:**

\_\_\_\_\_  
\_\_\_\_\_



**MENTAL HEALTH SERVICES:**

\_\_\_\_\_  
\_\_\_\_\_





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