EVALUATION OF THE *SEXUALITY & RELATIONSHIPS* PSYCHOEDUCATION PROGRAM FOR ADOLESCENTS WITH INTELLECTUAL AND/OR DEVELOPMENTAL DISABILITIES AND THEIR PARENTS

Lauren Hamilton

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Approved by:

Grace Hubbard

Cheryl Giscombe

Morgan Parlier

ABSTRACT

Lauren Hamilton: Evaluation of the *Sexuality & Relationships* Psycho-education Program for Adolescents with Intellectual and/or Developmental Disabilities and their Parents
(Under the direction of Grace Hubbard)

The purpose of this DNP project is to evaluate an existing psycho-education program about sexuality and relationships for adolescents with intellectual and/or developmental disabilities and their parents. The clinical problem at the heart of this project is the need to address adolescent psychosexual development in the IDD population. This problem is based on the understanding that sexuality and relationships have an extensive impact on long-term holistic health and individuals with IDD confront unique challenges. Failure to satisfy psychosexual developmental needs results in increased risks and problems in the IDD population. Comprehensive sexuality education equips adolescents and their parents with the knowledge and skills to build the foundation for health and positive experiences in these areas of life. The Context, Input, Process, Product model guides the program evaluation and the alignment of DNP project goals. DNP project participants included the *Sexuality & Relationships* program director and co-facilitators. The program evaluation consisted of two outcome measures: an online survey and semi-structured interview, both conducted after the spring 2018 program series.

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CHAPTER 1: INTRODUCTION

Sexuality and relationships have an extensive impact on long-term health. It is imperative for health care professionals to recognize and address these issues. Adolescence is a critical period for sexual development and development of healthy sexuality is essential for successful navigation of the transition from childhood to adulthood (Chan, & John, 2012; Dewinter, Vermeiren, Vanwesenbeeck, & Van Nieuwenhuizen, 2013; World Health Organization, 2016). Like their peers, adolescents with intellectual and/or developmental disabilities (IDD) experience the physical changes of puberty and express developmentally appropriate interest in sexuality and relationships (Fouquier, & Camune, 2015; Jones, Chatterjee, Anslow, Searle, & Blackhall, 2014; Kok, & Akyuz, 2015). Unique from their peers, adolescents with IDD confront additional challenges. Core features of IDD related to communication, behavior and learning can complicate psychosexual development and impede individuals' ability to acquire developmentally appropriate knowledge and skills related to sexuality and relationships (Foley, 2014; Hannah & Stagg, 2016). The problem is further compounded by negative attitudes surrounding sexuality and IDD that influence adolescents' experiences within families, society and the health care system in ways that interfere with sexuality education and relationship potential (Holmes, et al., 2014; Kellaher, 2015; Thompson, Stancliffe, Broom, & Wilson, 2014). Consequently, the IDD population has an increased risk for sexual health problems and negative sexual experiences, including problematic sexual behavior, exploitation and abuse, as well as decreased personal satisfaction and wellbeing (Chan, & John, 2012; Thompson, et al., 2014).

The current literature offers little information to guide best practices for sexuality education programs targeting the IDD population. The purpose of this DNP project is to evaluate an existing psycho-education program about sexuality and relationships for adolescents with intellectual and/or developmental disabilities and their parents.

CHAPTER 2: REVIEW OF THE LITERATURE

Literature searches were conducted in PUBMED, CINAHL and PSYCHINFO databases. Search terms were used to target the population (e.g. autism, ASD, autism spectrum disorder, Asperger*, attention deficit hyperactivity disorder, ADHD, Down syndrome, intellectual disability, ID, developmental disability, DD, neurodevelopmental disorder, ND, IDD) and combined with the directives "sexual*" OR "sex education" to focus the topic. Filters for human subject, full text availability and publication dates 2012-2017 further narrowed results. Due to the paucity of research, parameters were expanded (i.e. to include perspectives from adults with IDD) and auxiliary searches supplied articles for many topic areas. Initially, 746 articles were identified (i.e. in 322 in PUBMED, 186 in CINAHL and 238 PSYCHINFO). Review of abstracts for relevance and elimination of duplicates resulted in 68 articles for review.

Background and Significance

Intellectual and developmental disabilities (IDD) are described in the fifth edition of the Diagnostic and Statistical Manual. The IDD population includes a broad range of conditions with onset in the developmental period (before age twenty-two years) that impact learning, language, behavior and physical areas of life (American Psychiatric Association, 2013; U.S. Department of Health and Human Services Administration for Community Living, 2017). Data from the National Health Interview Surveys 2006-2008 estimate that neurodevelopmental disorders affect one in six children (15%) in the United States and recent trends indicate the occurrence of childhood disability due to neurodevelopmental disorders is increasing (Boyle, et al., 2011;

Houtrow, Larson, Olson, Newacheck, & Halfon, 2014). Rates increased among children (age 3-17 years) in the United States from 1997 (12.84%) to 2008 (15.04%), largely due to trends in diagnosis of Autism Spectrum Disorder (ASD) and Attention Deficit Hyperactivity Disorder (ADHD) (Boyle, et al., 2011).

The IDD population is comprised of a wide range of neurological, psychiatric and genetic conditions, including autism spectrum disorder (ASD), intellectual disability (ID), attention deficit hyperactivity disorder (ADHD), Down syndrome (DS), Fragile X syndrome (FXS), Angelman syndrome (AS), Prader-Willi syndrome (PWS) and cerebral palsy (CP). Thus, characteristics of individuals within this heterogeneous population are highly variable. For example, autism spectrum disorder (ASD) is characterized by social communication deficits and restrictive or repetitive patterns of behavior, whereas cognitive deficits define intellectual disability (ID) and behavioral hyperactivity/impulsivity is a component of attention deficit hyperactivity disorder (ADHD) (American Psychiatric Association, 2013). Characteristics inherent to specific diagnostic groups (e.g. intellectual disability, autism spectrum disorders, attention deficit hyperactivity disorder) render different challenges and risks.

Challenges Secondary to Characteristics of IDD

Core features of IDD (i.e. deficits in areas of cognition, learning, verbal communication, social communication, social skills, emotional or behavioral self-regulation, restrictive/repetitive behaviors, sensory issues) can influence adolescents' experience and impede the acquisition of knowledge and skills essential for healthy sexual development (Curtiss, & Ebata, 2016; Schaafsma, Kok, Stoffelen, & Curfs, 2015; Tullis, & Zangrillo, 2013). Furthermore, because informal social networks typically contribute to an individual's understanding of sexuality, the

impact of social marginalization must be considered to clearly grasp the challenges confronting the IDD population (Chan, & John, 2012; Hannah, & Stagg, 2016; Jahoda, & Pownell, 2014). For example, recent evidence reveals that adolescents with intellectual disability (ID) have smaller social networks, less access to informal sources of information and inferior sexuality knowledge compared to peers without ID (Aderemi, Pillay, & Esterhuizen, 2013; Jahoda, & Pownall, 2014). Overall, research shows that insufficient sexuality knowledge is a problem throughout the entire IDD population. Compared to typically developing peers, adolescents with autism spectrum disorder (ASD) and Down syndrome (DS) display less understanding of privacy, sexually appropriate behavior and sex education (Ginevra, Nota, & Stokes, 2016). The process of acquiring sexuality knowledge and skills can be especially complicated for adolescents who have deficits in cognitive or social areas. Cognitive deficits present apparent problems with comprehension, especially more complex topics. Social communication deficits (i.e. poor social communication, lack of understanding of social expectations and judgment, impaired ability to detect others' emotions and intentions) interfere with the ability to recognize and interpret nuanced or abstract ideas (Dekker, Hartman, et al., 2015; Dewinter, et al., 2013; Hannah, & Stagg, 2016). Underdeveloped social skills and social marginalization both contribute to challenges by limiting exposure and hindering opportunities to learn. Additionally, behavioral issues related to hyperactivity/impulsivity, sensory issues, restrictive interests and/or repetitive behavior precede certain psychosexual problems and increase the risk for negative consequences.

Themes throughout the literature illustrate that the wide range of characteristics present in the heterogeneous IDD population predispose individuals to different sexuality-related risks and challenges. For example, negative social attitudes and sexual abuse dominate the literature on intellectual disability (ID). In studies exploring lifetime sexual experience, women with ID

expressed problems with negative social attitudes (i.e. disapproval, oppression, over-protectionism), fears, delayed expression, denied experience and lack of self-efficacy (Barnett, & Maticka-Tyndale, 2015; Rushbroke, Murray, & Townsend, 2014). Another small body of research suggests that attention deficit hyperactivity (ADHD) symptoms (i.e. hyperactivity, impulsivity, inattention) predispose individuals to high-risk sexual behavior and subsequent interpersonal violence (Guendelman, Ahmad, Meza, Owens, & Hinshaw, 2016; Hosain, Berensen, Tennen, Bauer, & Wu, 2012; Sarver, McCart, Sheidow, & Letourneau, 2014; White, & Buehler, 2012; White, Buehler, & Weymouth, 2014). The ASD population is a main focus throughout the literature because multiple ASD symptom categories (i.e. social-communication deficits, restrictive interests and/or repetitive behavior, sensory issues) are associated with difficulties with sexuality and relationships (Beddows, & Brooks, 2016; Kellaher, 2015; Fernandes, et al., 2016). Expectedly, a recent study comparing adolescents with ASD, DS and typically developing peers, significantly correlates ASD diagnosis with the lowest psychosexual function (i.e. social behavior, privacy, sex education, sexual behavior, parent concerns) (Ginevra, et al., 2016). Evidence suggests young adults with ASD have significantly lower sexual awareness compared to those without a diagnosis (Hannah, & Stagg, 2016). Studies in adults with ASD reflect anticipated challenges related to social-communication deficits and sensory issues as well as reduced access to peer-based sexual socialization (i.e. exclusion, missed opportunities) and dissatisfaction with inadequate school-based sexuality education (Barnett, & Matika-Tyndale, 2015; Hannah & Stagg, 2016).

Adolescent Development and Healthy Sexuality

Adolescence (e.g. ages 10-19) represents the stage of transition from childhood to adulthood (APA, 2002). Human sexuality encompasses a complex individual experience of

body, mind, relationships and social influences (Dewinter, Vermeiren, Vanwesenbeck, & Van Nieuwenhuizen, 2016[b]). The literature emphasizes three key points relevant to sexual development and adolescence: (1) the importance of addressing human sexual development and sexual health from a lifespan developmental perspective (2) adolescence is a crucial stage in human sexual development (3) addressing needs related to sexual development prevents problems and promotes health during adolescence and into adulthood (Chan, & John, 2012; Dewinter, et al., 2013; Holland-Hall, & Quint, 2017). In addition to the physical changes associated with puberty, adolescent sexual development entails acquisition of knowledge and skills, exploration of values, expression of personal identity and socialization. Psychosexual development requires adolescents to expand social skills to navigate increasingly complex peer socialization and the emergence of romantic relationships (Chan, & John, 2012; Cridland, Jones, Caputi, & Magee, 2014; Dekker, Hartman, et al., 2015). These aspects of sexual development often require additional support and early intervention in the IDD population.

Increased Risk for Sexual Abuse

The increased risk for sexual abuse in the IDD population is a prominent theme throughout the literature. Sexual abuse includes undesired, non-consensual sexual contact in the form of coercion, exploitation, rape and assault. Previous studies have established that children with disabilities are more likely to experience sexual abuse compared to their non-disabled peers (McEachern, 2012). Estimated odds ratios range from three to seven times greater risk; children with speech/language impairments, intellectual disability, mental or behavioral disorders, autism spectrum disorders and other developmental delays are particularly vulnerable (Chan, & John, 2012; Jones, et al., 2012). Though supportive research is limited, the collective literature adds theoretical explanations to describe many factors that contribute to increased risk for sexual

abuse (Martinello, 2014; Normand, & Sallafranque-St-Louis, 2016; Sevlever, Roth, & Gillis, 2013).

Features inherent to IDD such as underdeveloped social skills and cognitive impairments contribute to the IDD population's increased vulnerability to abuse. For example, poor ability to ascertain subtle cues (i.e. safe vs. unsafe) and lack of theory of mind (i.e. judge other's intentions) can lead to the failure to recognize threatening relationships and situations (Dekker, Hartman, et al., 2015; Kim, 2015; Sevlever, et al., 2013). Alternatively, speech-language impairments may prohibit a child from stopping an advance or reporting abuse (Kim, 2015; Martinello, 2014; Sevlever, et al., 2013). The combination of ingrained behavioral compliance training (i.e. manipulation) and dependent relationships with caregivers (i.e. opportunity) makes lower functioning individuals unique targets for abuse (Euser, Alink, Tharner, Van Ijzendoorn, & Bakermans-Kranenburg, 2016; Martinello, 2014; Sevlever, et al., 2013). Stigmatized social perceptions of individuals with ID as unassertive, incapable of self-defense or unreliable witnesses may appeal to perpetrators and factor into heightened vulnerability (Lund, & Hammond, 2014). Specific risk factors also exist for the ADHD subpopulation. Childhood ADHD symptoms correlate with an increased risk of interpersonal violence (IPV) (Guendelman, et al., 2016). Recent studies contribute evidence that attribute risky sexual behavior in ADHD to symptoms of hyperactivity/impulsivity; subsequently, risky sexual behavior is a mediating risk factor for IPV (Hosain et al., 2012; Sarver et al., 2014; White, & Buehler, 2012).

Abuse is particularly concerning due to the damaging physical, emotional and psychological effects (Bellows, &Brooks, 2016; Sevlever, et al., 2013; Walters, et al., 2013). One retrospective longitudinal study in adult women (n=1077) illustrates a cumulative risk trajectory from autistic traits to childhood abuse, trauma victimization and PTSD in adulthood

(Roberts, Koenen, Lyall, Robinson, & Weisskopf, 2015). Conversely, comorbid social and psychological problems (e.g. anxiety, depression, post-traumatic stress disorder, substance use, poor self-esteem, isolation/loneliness, history of abuse, domestic violence, dysfunctional family environments, poverty, academic distress) escalate the risks for exploitation and abuse (Guendelman, et al., 2016; Lund, & Hammond, 2014; Wiggins, Hepburn, & Rossiter, 2013).

Sexual Abuse and Offense

In addition to the increased risk for sexual abuse victimization, the IDD population has an increased risk for perpetrating sexual abuse (Martinello, 2015). Offensive or deviant sexual behaviors often emerge from neglect or violation of socio-cultural rules, norms and conventions (Martinello, 2015; Kellaher, 2015). Individuals with IDD who exhibit harmful sexual behavior may be acting out as a sign of trauma (Sevlever, et al., 2013; Walters, et al., 2013; Wiggins, et al., 2013). Abused individuals are more likely to repeat the cycle of harmful behavior, and this may be especially true for the IDD population (Bellows, &Brooks, 2016; Sevlever, et al., 2013). Research conducted by Put, Asscher, Wissink, & Stams (2014) in the Washington State Juvenile Court system shows an even stronger connection between maltreatment victimization and legal sexual offense in youth with intellectual disabilities compared to peers with normal intelligence.

Consequences of Inadequate Sexuality Education

Numerous consequences are attributed to a lack of sexual knowledge and/or skills. Inadequate understanding of contraception, protection methods or personal hygiene increases the risk for negative sexual health outcomes such as sexually transmitted diseases or undesired pregnancies (Ball, 2012; Holland-Hall, & Quint, 2017; Quint, 2016). Lack of awareness of physical pubertal development leads to anxiety, distress, low self-esteem or negative body image (Cridland, et al., 2014; Holland-Hall, & Quint, 2017; Jahoda, & Pownell, 2014). Poor coping (i.e.

confusion, frustration or anxiety) related to the physical and hormonal changes of puberty and medication effects (i.e. libido) also influences sexual behavior (Beddows, and Brooks, 2016).

Underdeveloped social and relational skills pose barriers to social inclusion (Dewinter, et al., 2013; Gomez, 2012; Lofgren-Martensen, & Sobring, 2015). Social marginalization often compounds difficulties related to social skills deficits and interferes with the formation and maintenance of meaningful relationships (Corona, Fox, Christodulu, & Worlock, 2016; Dekker, Hartman, et al., 2015; Tullis, & Zangrillo, 2013). Consequently, a lack of fulfilling relationships leads to reduced quality of life (i.e. dissatisfaction, loneliness, distress, depression or other mental health problems) and the missed opportunity for personal growth and satisfaction (Chan, & John, 2012; Holmes, Himle, & Strassberg, 2016[b]; Mackin, Loew, Gonzalez, Tykol & Christensen, 2016). In research exploring lifetime sexuality experience, adults with ASD express courtship difficulties, delayed romantic debuts, relationship dissatisfaction, low self-efficacy, struggles with sexual identity and self-expression, among other negative experiences (Byers, Nichols, & Voyer, 2013; Dewinter, Vermeiren, Vanwesenbeeck, & Van Nieuwenhuizen, 2016[a]; Hannah, & Stagg, 2016). A pioneer study by Byers, Nichols, & Voyer (2013) correlates the severity of social impairment in ASD to decreased satisfaction with sexuality and relationships. Poor understanding of socially acceptable and culturally expected norms for psychosexual behavior increases the risk for negative sexual experiences (i.e. awkward encounters, rejection, dissatisfaction, exploitation, abuse) (Dekker, Hartman, et al., 2015).

Furthermore, such misunderstanding can inadvertently lead to social and legal problems in situations where inappropriate, offensive or deviant sexual behaviors emerge from neglect or violation of socio-cultural rules, norms and conventions (Kellaher, 2015; Mackin, et al., 2016; Tullis, & Zangrillo, 2013). Poor social awareness of public/private space and personal

boundaries contributes to inappropriate behaviors such as touching private parts, speaking about sexual activities or masturbating in public (Beddows, & Brooks, 2016). Problems such as excessive or improper masturbation may arise from a lack of practical knowledge and skills (Beddows, & Brooks, 2016). One retrospective analysis examines the relationship of age, verbal ability, symptom severity, intellectual ability and adaptive functioning to inappropriate sexual behaviors in adolescents with ASD. Findings suggest that cognitive function is an influential factor. Inappropriate behaviors are observed in one-fourth of subjects, but problem types differ on the basis of intellectual ability (i.e. public masturbation with ID compared to pedophilia and paraphilia without ID) (Fernandes, et al., 2016).

Findings in the current literature review reinforce previous evidence that inappropriate sexual behaviors are more problematic in the IDD population compared to the general population. Limited evidence stresses that ASD may confer a particularly heightened risk for problematic sexual behavior. Research shows higher incidence of problematic sexual behaviors among adolescents with ASD compared to other groups within the IDD population (e.g. Down Syndrome) and typically developing peers (Ginevra, et al., 2016; Visser, et al., 2017). Stronger evidence comes from a recent study of 1873 youth examining the relationship between autistic traits in childhood (age 10-12) and psychosexual problems (i.e. public exposure, touching genitals excessively, fixation, etc.) in early adolescence (age 12-15) (Dekker, Hartman, et al., 2015). Findings reveal that higher levels of autistic traits correlate with more psychosexual problems and an increase in autistic traits over time predicts more problems. Experts in the literature discuss theoretical explanations for the apparent disproportionate occurrence of inappropriate sexual behaviors in the ASD population. Restricted or repetitive patterns of behaviors, interests or activities (e.g. obsessions/preoccupations) and sensory issues (i.e.

hypo/hyper-sensitivities) impact the experience of sexuality, such that misdirected curiosity about the human body or sexual stimuli may manifest as inappropriate behaviors (Beddows, & Brooks, 2016; Dewinter, Vermeiren, Vanwesenbeeck, Lobbestael, & Van Nieuwenhuizen, 2015; Kellaher, 2015).

Intricate relationships exist between core features of IDD, inadequate sexuality education and a lack of sexuality knowledge with respect to the increased risk for abuse in the IDD population. Both inadequate sexuality education and various core features of IDD lead to insufficient knowledge. Lack of knowledge also functions as an independent risk factor for abuse. A pioneer study by Brown-Lavoie, Viecili, & Weiss (2014) contributes meaningful evidence linking decreased sexual knowledge to increased occurrence of abuse. Overall, the literature affirms that sexual knowledge is a protective factor for abuse, which reinforces the need for proactive sexuality education (Kellaher, 2015).

Sexuality Education Considerations in the IDD Population

The importance of comprehensive sexuality education is well established (Sexuality Information & Education Council of the United States, 2012). Comprehensive sexuality education promotes positive aspects of sexuality and prevents negative consequences (Jahoda, & Pownall, 2014; McEachern, 2012; Wiggins, et al., 2013). Interventions addressing the need for comprehensive sexuality education in the IDD population possess the unique potential to simultaneously address health promotion, risk reduction and harm prevention (Martinello, 2015; McEachern, 2012; Wiggins, et al., 2013). The Sexuality Information and Education Council of the United States (SIECUS) (2004) recommends that sexuality education programs incorporate information, skills and exploration of personal values. SIECUS guidelines outline essential curricula, including thirty-nine topics in six focus areas: human development; relationships;

personal skills; sexual behavior; sexual health; society and culture (2004). In this respect, the sexuality education needs of adolescents with IDD are the same as typically developing peers. However, adolescents with IDD confront many obstacles with respect to sexuality education, including barriers imposed by negative social attitudes and impediments that arise from characteristics inherent to IDD.

Sexuality education for the IDD population is laden with challenges. The nature of sexuality, characteristics of the target population and negative social attitudes intersect with aspects of the health care system to create numerous barriers. Many factors related to acceptance (i.e. attitudes), motivation (i.e. prioritization), preparation (i.e. education, training) and support (i.e. funding, research) function as potential barriers to the implementation and sustainability of sexuality education for the IDD population. Consequently, sex education has traditionally been neglected, inadequate or implemented only in reaction to problems in the IDD population (Holmes, et al., 2014; Sevlever, et al., 2013; Tullis, & Zangrillo, 2013).

The paucity of research on sexuality education in the IDD population is a significant barrier because sufficient quality research is necessary to guide policy development and establish evidence-based practice. Characteristics of the IDD population contribute to the paucity of research. Reluctance to work with challenging IDD characteristics (i.e. cognitive, social deficits) may deter efforts to conduct direct research in the IDD population (Thompson, et al., 2014). Furthermore, the adolescent IDD population is considered vulnerable by two accounts, age and disability. Mirroring society, vulnerable populations are often marginalized in the health care system. For example, increased difficulty with IRB approval may deter research efforts. Broad implications of the marginalization of vulnerable populations include significant oversights and omissions from professional education and research as well as health care policy, finance and

care delivery systems. Accordingly, research is likely scarce due to a cascade of other system level barriers, such as low prioritization and lack of funding.

Sexuality education requires collaboration between multiple stakeholders, including parents, adolescents and multidisciplinary professionals. However, the highly fragmented United States health care system segregates practice specialties and impairs collaboration (Brown-Levey, Miller & deGruy, 2012; Mandersheid & Kathol, 2014). Furthermore, the current specialty-focused structure muddles responsibility for complex multidimensional (i.e. encompasses aspects of physical, mental, emotional, social and spiritual health) issues such as sexuality education causing important aspects of holistic health care to become lost within a highly fragmented system.

Stigma and Misconceptions

Negative social attitudes (i.e. among parents, educators, health care professionals) surrounding sexuality in IDD is a prominent theme throughout the literature. Common myths portray individuals with IDD as childlike, asexual, over-sexualized or sexually aggressive. A legacy of stigmatization contributes to inattention to sexuality-related issues in health care professionals' education and practice (Fouqiuer, & Camune, 2015; Thompson, et al., 2014; Winges-Yanez, 2014). Holmes, et al., (2014) reveal problematic trends in the discussion of sexual health topics between health care professionals and parents of pediatric patients with ASD, such that discussions are avoided entirely or only occur in reaction to problems.

The literature describes how misunderstanding of sexuality in IDD hinders access to adequate sexuality education. For example, a tendency toward overprotection arises from the misconception of individuals as childlike or immature. Research suggests that parents overemphasize protection and undervalue their children's autonomous right to express sexuality

and experience intimate relationships (Ballan, 2012; Dewinter, et al., 2016[a]; Holmes, et al., 2016[b]). Although protection may be based on good-intentions or justifiable fears, shielding individuals with IDD from information about sexuality disempowers them and exacerbates their risks (Holmes, Himle, & Strassberg, 2016[a]; Lofgren-Martensen, 2012; Pownell, Jahoda, & Hastings, 2012). Another misconception is that exposure to sexuality information will "over-sexualize" individuals with IDD, which leads to oppression (Kellaher, 2015; Visser, et al., 2017; Winges-Yanez, 2014). For example, individuals in special education classrooms or residential facilities have historically been excluded from sexuality education (Jones, et al., 2014; Kim, 2015; Lofgren-Martenson, 2012). Critics add that when sexuality education has been offered to the IDD population it is restrictive. Abuse protection and risk avoidance dominate the content and overshadow information that affirms positive aspects of sexuality and encourages healthy psychosexual development (Holland-Hall, & Quint, 2017; Jahoda, & Pownall, 2014; Lofgren-Martenson, 2012). The myth that individuals with IDD are asexual or disinterested in relationships leads to the presumption that sexuality education is irrelevant (Fouqier, & Camme, 2015; Byers, Nichols, & Voyer, 2013).

Conversely, emerging literature espouses the relevance of sexuality and relationships in the lives of individuals in the IDD population (Byers, & Nichols, 2014; Dewinter, et al., 2015; Rushbroke, et al., 2014). Several recent studies convey that parents understand the importance of sexuality and relationships to quality of life and value their children's ability to develop to their full potential (Cridland, et al., 2014; Mackin, et al., 2016; Pownall, Jahoda, & Hastings, 2012).

Teaching Methods

The current literature illuminates the need to provide sexuality and relationships education to the adolescent IDD population in a manner that considers the influence of IDD

characteristics (Ballan, 2012; Curtis, & Ebata, 2016; Tullis, & Zangrillo, 2013). Experts throughout the literature advocate for a shift in attitudes to change the tone of sexuality education from a problem-focused, deficit-centered approach to a strengths-based approach that promotes healthy sexuality and positive experience (Holland-Hall, & Quint, 2017; Jahoda & Pownall, 2014; Lofgren-Martenson, 2012). Professional recommendations exist in lieu of research on effective methods for teaching sexuality education to the IDD population (Chan & John, 2012; Holland-Hall, & Quint, 2017; Tullis & Zangrillo, 2013). For example, Ballan & Freyer (2017) offer examples of sexuality education content delivered through methods commonly used with the ASD population: Applied Behavior Analysis, Social Stories, and Social Behavior Mapping (Ballan & Freyer, 2017). Although none of the sexuality education program evaluations included in this review evaluate teaching methods, several articles report details about the teaching strategies employed in the intervention. Common methods include repetition, active learning (i.e. role-playing) and reinforcement of content through modeling and multimodal representations of material (Corona et al., 2016; Dekker, Van Der Vegt, et al., 2015; Kim, 2015; Holland-Hall, & Quint, 2017; Tullis & Zangrillo, 2013; Wiggins et al., 2013: Visser et al., 2015). Communication strategies are generally described in terms such as simple, clear, tangible, concrete, direct, specific and explicit (Corona et al., 2016; Dekker, Van Der Vegt, et al. , 2015; Holland-Hall, & Quint, 2017; Tullis & Zangrillo, 2013; Wiggins et al., 2013). Other examples include considerations for learners with ASD regarding structure, consistency and positive reinforcement (Corona et al, 2016; Dekker, Van Der Vegt, et al. , 2015; Visser et al., 2017). More outcomes-based research is needed to fully understand how sexuality education can be delivered to effectively empower this population.

Parental Involvement in Sexuality Education

Experts recommend health care professionals support parental involvement in formal sexuality education for the adolescent with IDD, as well as parental engagement in informal discussions about topics related to sexuality and relationships (Ballan, 2012; Holmes, et al., 2014; Mackin, et al., 2016). In the IDD population, this challenging task is exacerbated by social stigmas, elevated risks and the variable influence of IDD characteristics on sexuality, relationships, learning and behavior. Several well-designed studies explore parents' perspectives and highlight common concerns reported by parents with regard to their children's sexual development and educational needs. In general, parent-reported concerns are comparable to the range of issues previously discussed, including: vulnerability to abuse; coping with pubertal development; their child's level of comprehension or emotional maturity; fears that introducing sexual information could lead to perseveration/fixation, overgeneralization or behavioral reactions; fears that social or legal problems could result from inappropriate public behavior or misinterpretation of their child's behavior; risky sexual behavior; negative sexual health outcomes (e.g. unintended pregnancy, STI); their child's limited prospects for romantic relationships and sexual experience; a lack of resources (Ballan, 2012; Cridland, et al., 2014; Gurol, Polat, & Oran, 2014; Holmes, et al., 2016[b]; Lofgren-Martenson, & Sobring, 2015; Mackin, et al., 2016; Pownall, et al., 2012). Baseline information collected in sexuality education program evaluation studies also validates concerns discussed throughout the literature and reinforces the need to provide enhanced support for sexuality education in the IDD population. Parents recognize that their adolescent children with ASD express interest in romantic relationships, but lack an understanding of appropriate strategies to initiate and navigate intimate relationships (Corona, et al., 2016). In spite of previous sex education, parents observe that their

children lack an understanding of important sexuality topics (e.g. sexual hygiene, sexually transmitted diseases and birth control) (Corona, et al., 2016). Additionally, parent reports and clinician referrals indicate the presence of inappropriate behavior and concern for problems with psychosexual development in the IDD population (Dekker, Van Der Vegt, et al., 2015; Kok, & Akyuz, 2015).

Despite heightened concerns, research examining trends in parent-child communication suggests that parents of children with IDD neglect or delay discussions about sexuality and relationships, (Ballan, 2012; Holmes et al., 2016[a]; Pownall, et al., 2012). Parents are more likely to discuss basic information related to sexual abuse prevention, private space and body parts, appropriate touch, personal hygiene, and puberty; whereas relatively mature, complex and abstract topics about dating and sexual activities are the most neglected (Holmes, et al., 2014; Holmes, et al., 2016[a]; Mackin, et al., 2016). This discrepancy is not well understood, but experts hypothesize that both child factors (i.e. IDD characteristics) and parent factors (i.e. attitudes) influence parent-child communication (Ballan, 2012; Dewinter, et al., 2016[b]; Holmes, et al., 2016[a]). For example, research indicates that parents discuss more topics when children have higher cognitive function and fewer topics when children display more severe ASD symptoms (Holmes, & Himle, 2014; Holmes, et al., 2016[a]). Furthermore, Holmes, Himle, & Strassberg (2016[a]) demonstrate a positive predictive relationship between low parental romantic expectations for their children with below average intelligence, greater ASD symptom severity and discussion of fewer sexuality topics. Alternatively, findings from Dewinter, et al. (2016[b]) reveal that parents are unaware of adolescents' actual sexual experience; the authors argue that underestimation of the relevance of sexuality may negatively influence parent-child

communication. More research is needed to capture how parent attitudes influence parent-child communication and the subsequent impact on children's acquisition of sexuality knowledge.

Evaluation of Sexuality Education Programs

The literature search for this review produced six articles containing a program description and evaluation (Corona, et al., 2016; Dekker, Van Der Vegt, et al., 2015; Kim, 2016; Kok, & Akyuz, 2015; Visser, et al., 2017; Wiggins, et al., 2013). Collectively, the participants in these studies are limited to adolescents with ASD, (mild to moderate) ID and their parents. None of the programs represent other diagnostic groups included in the heterogeneous IDD population. Furthermore, beyond topic area content (i.e. based on SIECUS comprehasive sexuality education guidelines), the literature contains no clear standards for sexuality and relationships education targeted to the adolescent IDD population. In addition to the overall paucity of research, the quality of the available research is limited due to small scale and lack of rigorous methodology. For example, only one larger study, the Tackling Teenage Training (TTT) program conducted a power analysis to determine sample size (Visser, et al., 2015). The programs presented in these studies represent a wide-range of different aims, subject characteristics, intervention design, evaluation measures and level of quality. Therefore, it is difficult to make comparisons or draw conclusions from their results. For example, two of the six programs are designed with explicitly narrow aims (e.g. sexual abuse prevention, behavioral management) and a problem-focused approach that exemplify the inadequacy of sexuality education for the IDD population (Kim, 2015; Kok, & Akyuz, 2015). The remaining four programs describe content that includes a comprehensive range of topics. To a certain extent, these four programs attempt to balance attention to population-specific risks and challenges with attention to the holistic dimensions of sexuality (Corona, et al., 2016; Dekker, Van Der Vegt, et al., 2015; Visser, et al., 2017; Wiggins,

et al., 2013). More outcomes-based research is needed to inform program development, implementation and evaluation. Despite these limitations, the available literature provides preliminary evidence to guide future efforts.

These studies establish the feasibility of offering sexuality education programs to adolescents with IDD and their parents. Recruitment methods included voluntary participation, clinician referral or a combination of both. Regardless, the participation response demonstrates acceptance of educational interventions addressing sexuality and relationships in the IDD population. The majority of programs report participant completion rates of 100% (Corona et al., 2016; Kim, 2016; Kok & Akyuz, 2015; Wiggins et al., 2013). One program reports reasons that involve relocation or logistics for completion rates of 82.5-85% (Dekker, Van Der Vegt et al., 2015; Visser et al., 2017). Comparable retention rates are reported for intervention and control groups in the randomized controlled trial (Visser, et al., 2017). Additionally, positive feedback from parents suggests high satisfaction, which may encourage parent-involvement in future programs (Corona et al., 2016; Kok & Akyuz, 2015).

Outcomes and Recommendations

Promising evidence from these studies exemplifies the potential for sexuality and relationships education to benefit the IDD population. For example, two programs designed to increase parent self-efficacy and parent-child communication demonstrate improvements on the respective measures post-intervention (Corona, et al., 2016; Kok, & Akyuz, 2015). Yet, these programs show mixed success for the goal to improve adolescent sexuality knowledge. Dekker, Van Der Vegt, et al. (2015) and Visser, et al. (2017) measure significant improvements post-intervention. However, Corona, et al. (2016) finds no significant change and Wiggins, et al. (2013) does not evaluate a related outcome. Consistent with previous research, two recent studies

correlate younger age (11-16 years) with greater improvements in knowledge (Dekker, Van Der Vegt, et al., 2015; Visser, et al., 2017). Accordingly, intervention during early adolescence may optimize benefits. Beyond strictly cognitive outcomes (e.g. knowledge), the ability to apply knowledge and skills in day-to-day life is an important goal for adolescents with IDD. Kim (2015) evaluates adolescents' ability to generalize protective behavioral skills to real-world settings, but small sample size (n=3), narrow focus (i.e. abuse prevention in females with IDD) and the anecdotal nature of the measure diminish the value of the results. The TTT program is an individual psycho-educational program targeting adolescents with ASD without intellectual disability (Visser, et al., 2015). Research on the TTT assesses social function and problematic sexual behavior with validated measures, but produces mixed results. Parents report generalization of knowledge for 86% of participants in the pilot program, but the randomized controlled trial fails to demonstrate that the acquisition of knowledge translates to commensurate behavioral changes (Dekker, Van Der Vegt, et al., 2015: Visser, et al., 2017). Although data for problematic sexual behavior is not statistically significant, results indicate a change in the positive direction. All adolescents decrease problematic behaviors over the course of the TTT program. Authors attribute the limitation to the individual format and responsively identify the need to facilitate opportunities for adolescents to "practice [social and relational] skills with peers" (Visser, et al., 2017, 847). Concurrently, the included studies all exemplify or discuss the importance of adapting interventions to suit individual needs with respect to pace, delivery style and topic selection. Thus, considerations for the future include investigation of the dichotomous needs for individualization and interactive group experiences, as well as examination of teaching methods and differential impacts on specific subpopulations (i.e. ID, ASD, ADHD, DS).

CHAPTER 3: CONCEPTUAL FRAMEWORK

Program Evaluation

The methodology for this DNP project is a program evaluation. Program evaluations are generally categorized as formative or summative. Formative evaluations refer to evaluations conducted in advance or during a program's implementation for purposes such as program planning, design, development and revision. Summative evaluations refer to a retrospective assessment of a program for purposes such as accountability or goal attainment. Program evaluations serve multiple functions, including both internal and external purposes (Frye, & Hammer, 2012). Internal purposes include program development, quality improvement and sustainability, whereas external purposes include accountability, education and distribution (Frye, & Hammer, 2012). The Context Input Process Product (CIPP) evaluation model can be applied to both formative and summative program evaluations (Frye, & Hammer, 2012).

Context Input Process Product Model

The comprehensive CIPP model enables evaluators to provide multiple stakeholders with useful information and has been used to guide program evaluations in a variety of settings, including health care (Mirzazadeh, et al., 2016; Shams, Golshiri, & Najimi, 2013; Stufflebeam, 1971). The model has been applied extensively for evaluation of educational programs (Mokhtarzadegan, Amini, Takmil, Adamiat, & Sarveravan, 2015; Neyazi, Arab, Farzianpour, & Mahmoudi, 2016). The purpose of evaluation is to improve the program, rather than to prove something about the program. Overall, the CIPP model emphasizes the notion that program

evaluation is a continuous process, in which information about strengths and weaknesses is used to inform ongoing decisions for program improvement (Mokhtarzadegan, et al., 2015; Rooholamini, et al., 2017; Stufflebeam, 1971).

This model has four core components, context (C), input (I), process (P), and product (P), depicting four different aspects of program evaluation (Stufflebeam & Shinkfield, 2007; Stufflebeam, 1971). A context evaluation serves purposes of program planning, development, organization, and management (Frye, & Hammer, 2012; Neyazi, et al., 2016). It is useful to identify needs and problems and to establish program goals (Stufflebeam, 1971). An input evaluation examines different strategies that may be employed to accomplish program goals. It is used to determine the program design and required resources (Frye, & Hammer, 2012; Neyazi, et al., 2016; Stufflebeam, 1971). A process evaluation describes and assesses the program's implementation process. A detailed description of the program process is useful for the purpose of replication. Information about the program's strengths and weaknesses serves ongoing quality improvement (Stufflebeam, 1971). A product evaluation consists of measuring outcomes to assess the program's impact, which is useful for accountability and dissemination purposes (Frye, & Hammer, 2012). For example, application of the CIPP model to an existing program would evaluate the program goals in relation to the identified needs, assess whether or not the content of the program effectively meets the program goals, and identify areas for improvement.

The CIPP model contains three vertical components that represent three steps of program evaluation: (1) delineating (2) obtaining and (3) providing (Mokhtarzadegan, et al., 2015; Rooholamini, et al., 2017; Stufflebeam, 1971.) According to the CIPP model, the first step clarifies different questions and purposes to be addressed for each of the four horizontal components. The second step, obtaining, is important in order to ascertain the source of the

information that will be used to conduct the evaluation for each of the four horizontal components. Obtaining also includes determining how the information will be analyzed. The final step involves analyzing the information and providing it to stakeholders.

CHAPTER 4: PROJECT PLAN AND IMPLEMENTATION

Project Design

The DNP scholarly project is a program evaluation of an existing psycho-education group *Sexuality & Relationships* designed for adolescents with a diagnosis of IDD and their parents (Parlier, & Miller, *n.d*). The CIPP model for program evaluation guides the implementation of the DNP project. The DNP project outcomes align with four overarching questions that correspond to the context, input, process and product aspects of the CIPP model for program evaluation. The outcomes for the program evaluation are: (1) How effective are the program goals in meeting the identified need? (2) How effective is the preparation of group facilitators to lead group sessions? (3) How well does the curriculum content serve the program goals? (4) How well do the group sessions serve the program goals? (5) How effective are the behavioral management strategies? DNP project outcomes and the corresponding CIPP components are represented in APPENDIX A, Tables 1, 2, 3, 4, 5 and 6.

Protection of Human Subjects and Research Ethics

Despite the understanding that projects designed for program evaluation do not commonly meet criteria for university Institutional Review Board (IRB), the DNP project proposal was submitted to the University of North Carolina at Chapel Hill IRB review board in January 2018. As expected, the project proposal was granted exemption under category 2 of the U.S. Department of Health and Human Services "Common Rule," 45 CFR part 46, for the protection of human subjects (University of North Carolina at Chapel Hill, 2016).

Program Description

The *Sexuality & Relationships* psycho-education program is designed to serve as a catalyst for parent-child communication on topics related to sex and relationships for adolescents with intellectual and developmental disabilities and their families. In addition to providing accurate and developmentally appropriate information to increase sexuality knowledge, the program aims to empower youth participants to make good decisions and practice healthy behaviors related to personal relationships and their bodies (Parlier, & Miller, *n.d*). The *Sexuality & Relationships* psycho-education group represents a unique family-system based approach to comprehensive sexuality education. The program aims to equip parents with information, strategies, and resources to support continuous informal sexuality education in the home (Parlier, & Miller, *n.d.*)

History

In 2014 Morgan Parlier and Kylee Miller began developing the *Sexuality & Relationships* program for the Carolina Institute for Developmental Disabilities (CIDD) in response to a service gap identified by the clinic. In addition to her role as clinician and research coordinator at the CIDD clinic, Morgan Parlier, MSW, had previous research experience and interest in issues related to sexuality and relationships. Kylee Miller was a graduate student intern working closely with Parlier at the CIDD clinic while she completed a Ph.D. in School Psychology. The *Sexuality & Relationships* program series commenced in the fall of 2014. This DNP project focuses on the seventh implementation of the *Sexuality & Relationships* program completed in the spring of 2018.

Setting

The setting for this project is an interdisciplinary specialty clinic that primarily serves

children and adolescents with intellectual and developmental disabilities and is affiliated with a large teaching university in the southeastern United States.

Group Leaders

The DNP project participants consisted of the *Sexuality & Relationships* group program leader and co-facilitators. The *Sexuality & Relationships* group program leader is a master's prepared clinical social worker and clinical research faculty member at the clinic. Group co-facilitators include staff, interns and students associated with the clinic.

Group Participants

The group participants consisted of a small group of four adolescents, three boys and one girl, ranging in age from 13 to 19 with ASD and ADHD diagnoses. Each adolescent was accompanied by at least one adult family member. The parent group generally consisted of five adults, including three mothers and two fathers.

Program Implementation

Co-facilitators were prepared to lead group sessions with a variety of orientation resources including an introductory presentation, web-based modules developed for the purpose of training professionals to deliver sexuality education for the IDD population and supplementary articles. These resources were distributed to four of eight co-facilitators in an orientation meeting prior to the start of the program; the remaining co-facilitators received the information and materials via email. Email was also the primary means of communication used to plan details involved in leading each group session. Additionally, co-facilitators were expected to arrive at the clinic approximately one hour prior to each group session. Curriculum resources were stored on an internal network drive; co-facilitators without access to the clinic network relied on other co-facilitators to email resources. Co-facilitators independently obtained

additional resources and circulated them via email. Behavioral management strategies were introduced in the pre-program orientation meeting. Materials from the orientation were distributed to co-facilitators via email. Additional discussion of behavioral management strategies was addressed in pre-session planning emails, specifically in discussion threads amongst the adolescent group leaders.

The *Sexuality & Relationships* program implementation entailed six consecutive weekly sessions, each scheduled for ninety minutes in the evening after regular clinic hours. With the exception of the introduction to the group at the beginning of the first session, each weekly session commenced with the participants divided into adolescent and parent subgroups. Following a brief mid-session break, adolescents and parents joined together to participate in a family activity. To mark the completion of the program series, adolescent participants were awarded certificates in a brief graduation ceremony at the end of the final group session.

CHAPTER 5: EVALUATION DATA

Data Collection and Analysis

Evaluation data was obtained from two outcome measures (refer to APPENDIX B.) A ten question online survey provided quantitative data and a semi-structured interview provided qualitative data. The online survey contained ten total questions in multiple choice or Likert scale format. Four pertained to demographics, two related to context and one question each related to the input, process and product aspects of the evaluation. Five total questions comprised the semi-structured interview, one question relating to each of the four CIPP components and one final open-ended question. Similar to the structure of the outcome measures, the presentation of the evaluation data is based on the CIPP model (refer to APPENDIX D, Figures 1, 2, 3, 4, 5 and 6 for graphic representations of the quantitative results).

Eight individuals who served as *Sexuality & Relationships* group co-facilitators were identified as potential DNP project participants. Participation in the DNP project program evaluation was voluntary, and provision of an email address served as consent to participate in the program evaluation. All eligible participants were invited to participate in the DNP project program evaluation via email.

The online survey was created with *Qualtrics*™ software (http://www.qualtrics.com). Participants accessed the survey through anonymous links sent directly from Qualtrics via the email addresses provided. No information with personal emails was kept with the survey data. Survey links were active for three weeks after the conclusion of the program and required less

than ten minutes to complete. Seven of the eight co-facilitators completed the online survey, for a response rate of eighty-eight percent. No partial responses were recorded. All co-facilitators who participated in the online survey completed the measure in its entirety. Survey participants self-identified as graduate students and professionals from various disciplines, including social work, psychology, speech pathology and nursing. The majority reported one-to-five years experience with the IDD population. Qualtrics™ (http://www.qualtrics.com) software enabled quantitative analysis that was interpreted to rank and compare responses to questions in order to evaluate the programs' strengths and weaknesses.

Semi-structured interviews were conducted by phone during the two weeks following the end of the program. Interviews were scheduled at each participant's convenience and required ten to fifteen minutes to complete. Six of the eight co-facilitators completed the semi-structured interview, for a response rate of seventy-five percent. In original form, the qualitative data consists of notes typed by the DNP Project Leader during phone interviews. Personal identifiers were not linked to the interview data to preserve anonymity beyond the DNP Project Leader.

Thematic Content Analysis

Data collected in the semi-structured interviews was systematically examined and presented based on a common qualitative research method, thematic content analysis (Burnard, Gill, Stewart, Treasure, & Chadwick, 2008; Elo, Kaarianen, Kanste, Polkki, Utriainen, & Kyngas, 2014). The process involves identification and categorization of common themes in the data, followed by selection and presentation of examples of each theme (Burnard, Gill, Stewart, Treasure & Chadwick, 2008; Vaismoradi, Turunen, & Bondas, 2013). While it can be time-consuming, it is a flexible approach that enables a rich, detailed and comprehensive analysis (Burnard, Gill, Stewart, Treasure, & Chadwick, 2008; Vaismoradi, Turunen, & Bondas, 2013).

Validity of the results is established by clearly depicting the steps involved to determine the results (Elo, Kaarianen, Kanste, Polkki, Utriainen, & Kyngas, 2014). Data analysis was conducted independently by the DNP Project Leader. Interview notes were organized in several different ways, based on responses to each of the five semi-structured interview questions, the five DNP project outcomes and the four aspects of the CIPP model. Reorganizing the data enabled the DNP Project Leader to thoroughly review the data from multiple perspectives, resulting in the identification of eight themes (refer to APPENDIX E).

CHAPTER 6: PROGRAM EVALUATION OUTCOMES

Context Evaluation Outcomes

The context evaluation corresponds to the first DNP project outcome: How effective are the program goals in meeting the identified need? In general, the context for the *Sexuality & Relationships* program is explained and supported by the review of the literature. Additionally, the online survey contained two questions (#6 and #7) that explicitly address the context of the *Sexuality & Relationships* psycho-education program. Survey respondents rated problems related to sexuality and relationships in the IDD population as *moderately*, *very* and *extremely significant*. Conversely, most indicated that such problems are given *low* to *medium priority* within their clinical or educational environment. Survey responses indicate that the level of prioritization of problems related to sexuality and relationships is relatively lower than the level of significance. These results bring attention to the gap that exists between the population's needs and the efforts being devoted to those needs.

One of the themes that emerged from the qualitative data pertains to the context evaluation: important issue. Four of the six interviewees explicitly discussed the importance of sexuality and relationships in the IDD population and expressed concern that these issues do not receive sufficient attention, which is clearly illustrated by the quote "*an important issue that is not addressed enough*". Co-facilitators relayed an understanding of the heightened risks for individuals with IDD. For example, one response stressed the importance for these adolescents to be "*knowledgeable and safe*." Overall, co-facilitators expressed appreciation for increased

awareness, knowledge, skills and confidence in this area of life to positively impact adolescents lives. Findings also suggest that the program's existence inspired co-facilitators to develop more interest in the issues surrounding sexuality and relationships in the IDD population. Overall, findings highlight the importance of implementing a program to address sexuality and relationships issues in the IDD population.

Input Evaluation Outcomes

Based on the CIPP model, the second and third DNP project outcomes evaluate the material and human resource inputs required for the *Sexuality & Relationships* program. As discussed below, two themes identified in the qualitative data yielded insightful information for both of these DNP project outcomes. Additionally, one online survey question (#10) directly addressed the second DNP project outcome: How effective is the preparation of group facilitators to lead group sessions? Co-facilitators ranked their perceived level of preparation overall and with respect to different responsibilities: understanding the content; leading activities; managing adolescent behavior. Survey responses indicate that co-facilitators generally felt *very well prepared* to understand the content, manage adolescent behavior and to lead group sessions overall. Understanding the content and managing adolescent behavior were similarly ranked highest in terms of the level of preparedness, closely followed by overall. Leading activities ranked the lowest. Co-facilitators reported that they only felt *moderately well prepared* to lead activities. These findings reveal that preparing co-facilitators to lead activities is a potential area for program improvement.

Two similar themes that emerged from the qualitative data provide useful information for the input evaluation: time constraints (related to preparation) and time constraints (related to group sessions). Due to the large amount of relevant data, two themes were designated to time

constraints as they apply to different aspects of the program. Time constraints were discussed during five of the six total semi-structured interviews in the context of planning and preparation, program sessions and post-processing. During program implementation the post-processing that occurred between each session functioned as planning and preparation for the subsequent session; therefore, for practical purposes, post-processing will be considered along with planning and preparation. Interviewees discussed this barrier from a constructive perspective and offered suggestions for program improvement. For example, one co-facilitator emphasized that it was very helpful to have the prepared power-point presentations (saved from previous program sessions) as a curriculum resource, and suggested more development of similar curriculum resources. Another described the use of email to communicate pre-session plans as "*functional*," but *"it would have been helpful to have had more time to meet as groups of facilitators to prepare, talk in person and run through things."* Recommendations for future sessions include allocating more pre-program planning time to curriculum development and more pre-session preparation time for co-facilitators to rehearse for delivering information and leading activities.

Qualitative data from the semi-structured interview also offered useful information for the input evaluation through feedback represented by a similar theme: time constraints (related to group sessions). Two interviewees recognized challenges related to the large amount of information covered during each session: "*felt like we had to squeeze in a ton of information ...* [which] *took a long time* [and participants] *wanted to discuss more."* Likewise, co-facilitators from both the parent and adolescent groups observed that program participants wanted more time for questions and discussion during group sessions. Accordingly, future program implementation may benefit from streamlining each session's content and/or extending the length of the program (i.e. lengthening or adding weekly sessions).

Process Evaluation Outcomes

Corresponding to the fourth DNP project outcome, online survey question (#8) sought co-facilitators perspective on how well the content of group sessions served the program goals. Content encompasses both the curriculum and activities because they are practically indistinguishable during group sessions. Similarly, the reference to program goals incorporates an element of the product evaluation. Although it is reported in the process evaluation outcomes, it also reflects input and product aspects of the *Sexuality & Relationships* program. Survey responses indicate that the content (i.e. activities and curriculum) of group sessions very effectively supported the primary program goal to serve as a catalyst for parent-child communication on topics related to sexuality and relationships for adolescents with IDD.

Two themes identified from the semi-structured interview data contain feedback relevant to the process of program implementation. Co-facilitators recognized effective approaches that can be enhanced to improve the process of implementing the program session in future program series. One of these, cater to individual needs, was identified based on comments from four of the six interviews. For example, co-facilitators suggested that "*more efforts to individualize the delivery of information*" would be beneficial. Specifically, a "question jar" may be useful to manage parents' specific questions and incorporate families' unique concerns during group sessions in an organized manner. Additionally, it was suggested that it would be helpful to enhance the pre-screening process to further assess individual needs and incorporate this information into future program series.

Another theme was identified as: effective teaching strategies, based on discussion by five of the six interviewees. The co-facilitators who provided feedback in the semi-structured interviews characterized effective teaching strategies as interactive, dynamic and repetitive. They

emphasized the need for a more interactive approach to delivering content and leading activities and suggested incorporating more games, role-play and discussion for program improvement. Two interviewees especially stressed the importance of delivering content "*with different modalities*" and "*repetitively*"; for example, "*teach the same content in different ways."* Although more of the discussions about effective teaching strategies were framed by the challenge to engage the adolescent IDD population during group sessions, these ideas were also applied to the parent group.

Another component of the process evaluation, which was represented by the fifth DNP project outcome, examines the efficacy of the strategies used to manage adolescent behavior. Survey responses indicate that the behavioral management strategies were *very* effective for this population. These findings are reinforced by the previous feedback from the input evaluation, (survey question #10) where the majority of co-facilitators reported they felt *very well* prepared with respect to preparation for responsibilities related to managing adolescent behavior. Based on anecdotal information from direct observation, no significant events related to problematic behaviors occurred during the group sessions. This observation further endorses the efficacy of the behavioral management strategies that were implemented, such as positive reinforcement (i.e. points based reward system) and one-on-one attention. It also serves as a possible explanation for why no major themes pertinent to behavioral management emerged from the semi-structured interviews. Due to the heterogeneity of the IDD population the composition and dynamics among future participant groups will inevitably vary. Therefore, it is recommended to continue to both educate co-facilitators about the common behavioral issues associated with the IDD population and behavioral management strategies that may be useful during the group sessions and to reevaluate the efficacy of these strategies in ongoing program evaluation.

Product Evaluation

Based on the CIPP model, the product evaluation corresponds to the first DNP project outcome: How effective are the program goals in meeting the identified need? Three themes that convey the program's accomplishments were identified in the qualitative data, including new knowledge, cultivated comfort and a catalyst for conversation. Collectively, these themes reflect the principles of one of the main theories (i.e. social learning theory) that support the intervention. The theory anticipates that new knowledge increases a sense of competence and cultivating comfort increases confidence. Thus, it predicts that these conditions will facilitate more discussion of sexuality and relationship topics between adolescents with IDD and their parents. All six of the interviewees discussed changes in awareness, comfort and/ or open conversation from the beginning to the end of the *Sexuality & Relationships* program.

These impressions emerged with respect to both the adolescent and parent participants, as well as the co-facilitators themselves. For example, one co-facilitator observed that initially "*these kids were not aware*" of sexuality "*or how to communicate with your parents*" about it, and it was rewarding to witness their growth during sessions when "*kids discussed trusting adults, when and who to talk to*" about these issues. Other co-facilitators appreciated that the parents appeared to be better equipped, not only with new knowledge and tangible resources for accurate sexuality information, but also intangible resources in the form of a "*community network*" and a sense that this challenging parenting task "*is not insurmountable*." Several co-facilitators affirmed that when confronted with the reality of discussing sex topics in a public forum they initially experienced anxiety and doubt. These same interviewees expressed that throughout the series they acquired a sense of confidence and competence in the ability to address (i.e. discuss and provide education) these topic areas in a professional capacity. The

following quote illustrates how, when it comes to learning, there is no substitute for direct experience. The program "*made it acceptable, less embarrassing... for these teens ... and even for me",* for example, *" talking about something like masturbation,"* from this program "*I felt like I could really talk about it."* Finally, three interviewees explicitly recognized that the program served as a catalyst for conversion about sexuality and relationships. Ultimately, the program's impact manifested as "*fostering that open-dialogue*" among participating families.

Overall Positive Experience

Overall, the six co-facilitators who participated in the semi-structured interviews all described the *Sexuality & Relationships* program as a positive experience. Two quotes from the semi-structured interviews stand out with respect to this program evaluation. One interviewee eloquently captured the essence of the programs' impact: "*it allows for further self-exploration of these kinds of ideas."* Another stated that the program was "*pretty effective overall*", though there is "*plenty of room for growth",* which clearly synthesizes the findings contained in this program evaluation.

CHAPTER 7: PROJECT LIMITATIONS AND STRENGTHS

This DNP project was limited in time and scope. Project weaknesses included the small scope of the project and the limited quantity and quality of research available to guide the development and/or evaluation of programs with comparable goals for the target population. However, given the limited time required from participants to complete both outcome measures, efficiency and convenience were advantages of the outcome measures. Conducting individual interviews by phone was conducive to taking detailed notes, but the lack of verbatim transcripts or recordings is a potential limitation of the qualitative data. Although the methods for collecting data preserved anonymity, the individualized nature of both outcome measures were a disadvantage because they limited the potential for dynamic insight and ideas that can build through group discussion. More important project strengths include the contribution of program evaluation outcomes to existing data for the *Sexuality & Relationships* psycho-educational program, specifically addressing the program's safety (i.e. behavioral management) and efficacy (i.e. program outcomes). The evaluation provides ongoing quality improvement for the long-term goals of the *Sexuality & Relationships* program.

CHAPTER 8: BARRIERS, FACILITATORS AND SUSTAINABILITY

Several logistical aspects of the program are potential barriers to implementation. Time and space constraints exist due to coordination of multiple co-facilitators' and potential clients' schedules in conjunction with the availability of public meeting space within the clinic. Additionally, three interviewees recognized barriers related to affordability and accessibility. In particular, respondents pinpointed the cost for families to participate in the program with the current fee for service pay structure. Based on anecdotal data from observation of the recruitment process, the low enrollment rate for this program series is largely attributable to this barrier. Affordability has the greatest potential to impact program implementation and sustainability because a minimum number of participants (approximately 3 adolescents with 3-6 parents) are required to offer the program. For future series, co-facilitators suggested obtaining additional funding to support the program and/or considering options for billing health insurance.

In order to sustain the program over time a consistent source of volunteers and clinical staff is required. Students' awareness, interest and availability influence the ability to implement the program. Conversely, this potential barrier emerged as a facilitating factor in the program evaluation. Every interviewee emphasized how the *Sexuality & Relationships* program served as a professional growth opportunity. They viewed the exposure to this unique learning experience as a resource for their future careers. Currently, the program relies on students and interns who are involved with the clinic as part of their academic programs to participate as co-facilitators for the group. For example, a total of four survey respondents reported association with the LEND

trainee program, including three from the current academic year and one from a previous cohort. Many students require clinical contact hours for their programs and the unique opportunity to work with the IDD clinical population is appealing to students from education, social work, psychology, nursing, and other related disciplines. Three co-facilitators reported that the ability to satisfy requirements for clinical hours in their respective academic programs influenced the decision to volunteer for the group program. It is reasonable to expect the current method for recruiting co-facilitators to remain sustainable over time. Furthermore, the population served by the clinic is growing and changing, resulting in ongoing demand for the program.

CHAPTER 9: RECOMMENDATIONS

Recommendations for Future Program Series

- Continue to offer the *Sexuality & Relationships* program to address important issues and areas of need for the IDD population.
- Enhance the pre-screening process to further assess individual needs and incorporate this information into future program series.
- Continue to educate co-facilitators about the common behavioral issues associated with the IDD population and behavioral management strategies that may be useful during the group sessions.
- Enhance the co-facilitator orientation with additional material on group leadership.
- Increase the amount of time devoted to pre-program planning.
- Allocate more pre-program planning time to curriculum development.
- Employ a more interactive approach to prepare co-facilitators including time to rehearse delivering material and leading activities.
- Seek additional sources of funding to support the program and/or consider a financial structure that would enable families to utilize health insurance.
- Streamline each session's content and/or extending the length of the program (e.g. lengthening or adding weekly sessions).
- Continue to hold co-facilitator debriefings after each group session to evaluate the efficacy of strategies implemented during each session and anticipate strategies to implement in subsequent group sessions.
- Continue to invest resources to further develop the program.

Recommendations for Ongoing Program Evaluation

- Continue to conduct program evaluation for the purposes of ongoing program improvement.

- Continue to gather post-program feedback from group co-facilitators regarding their perceived level of preparation to lead group sessions in order to inform strategies for future series.

- Continue to gather post-program feedback seeking group co-facilitators perception of how well the group sessions serve program goals in order to inform strategies for future series.

- Continue to include the efficacy of behavioral management strategies in post-program evaluation measures.

- Reevaluate the efficacy of curriculum content with more specific measures in future post-program evaluations.

- Reexamine the outcome measures used to obtain feedback from participating families.

- Re-evaluate future program series with repeat questions from the current Qualtrics online survey for purposes of compiling and comparing data.

- Continue to gather qualitative post-program feedback from group co-facilitators in order to inform strategies for future series.

- Host a formal post-program meeting with co-facilitators to debrief the entire program and discuss suggestions for improvement of future sessions as a group.

APPENDIX A: CIPP, DNP PROJECT OUTCOMES AND PROJECT PLAN

Table 1. Context Evaluation

DNP Project Outcome	(1) How effective are the program goals in meeting the identified need?
Delineate	• Identify the need/problem that the program intends to address • Identify program goals • Are the program goals appropriate to address the need/problem?
Obtain	• Quantitative data from online survey questions in multiple choice and Likert scale formats • Qualitative data from semi-structured interview of group co-facilitators and program director • Anecdotal information from direct observation during program implementation and review of existing program evaluation materials (i.e. adolescent pre/post test; parent pre/post survey)
Provide	• Recommendations for future program sessions • Recommendations for ongoing program evaluation

Table 2. Input Evaluation I

DNP Project Outcome	(2) How effective is the preparation of group facilitators to lead group sessions?
Delineate	• Identify the resources used to prepare group facilitators • How well do these resources serve program goals? • What are the strengths and weaknesses of these resources?
Obtain	• Quantitative data from online survey questions in multiple choice and Likert scale formats • Qualitative data from semi-structured interview of co-facilitators and program director • Anecdotal information from direct observation during program implementation and review of existing program resources used to prepare facilitators to lead group sessions
Provide	• Recommendations for future program sessions • Recommendations for ongoing program evaluation

Table 3. Input evaluation II

DNP Project Outcome	(3) How well does the curriculum content serve the program goals?
Delineate	• Identify the curriculum resources • How well do these resources serve program goals? • What are the strengths and weaknesses of these resources?
Obtain	• Quantitative data from online survey questions in multiple choice and Likert scale formats • Qualitative data from semi-structured interview of group co-facilitators • Anecdotal information from direct observation during program implementation and review of existing program resources for curriculum content
Provide	• Recommendations for future program sessions • Recommendations for ongoing program evaluation

Table 4. Process Evaluation I

DNP Project Outcome	(4) How well do the group sessions serve the program goals?
Delineate	• Describe the process of program implementation for group sessions • Identify the facilitators and barriers for the implementation of group sessions
Obtain	• Quantitative data from online survey questions in multiple choice and Likert scale formats • Qualitative data from semi-structured interview of group co-facilitators • Anecdotal information from direct observation during program implementation
Provide	• Recommendations for future program sessions • Recommendations for ongoing program evaluation

Table 5. Process Evaluation II

DNP Project Outcome	(5) How effective are the behavioral management strategies?
Delineate	• Describe the process of behavioral management for group program implementation • Identify specific elements of the behavioral management strategies used during the program sessions and the context in which they were applied • Are the strategies implemented as intended? • How effective are the strategies in managing behaviors?
Obtain	• Quantitative data from online survey questions in multiple choice and Likert scale formats • Qualitative data from semi-structured interview of group co-facilitators • Anecdotal information from direct observation during program implementation
Provide	• Recommendations for future program sessions • Recommendations for ongoing program evaluation

Table 6. Product Evaluation

DNP Project Outcome	(1) How effective are the program goals in meeting the identified need?
Delineate	• What does the program accomplish? • What are the barriers and facilitators to achieving the program's established goals?
Obtain	• Quantitative data from online survey questions in multiple choice and Likert scale formats • Qualitative data from semi-structured interview of group co-facilitators • Anecdotal information from direct observation during program implementation and review of existing program evaluation materials (i.e. adolescent pre/post test; parent pre/post survey)
Provide	• Recommendations for future program sessions • Recommendations for ongoing program evaluation

APPENDIX B: OUTCOME MEASURES

I. Online Survey

1. Identify your role in the CIDD Clinic

- o Undergraduate student
- o Graduate student
- o Professional/ employee
- o Other (please specify) _____

2. Identify your discipline

- o Social work
- o Psychology
- o Education
- o Nursing
- o Other (please specify) _____

3. Are you a current or former LEND trainee/fellow?

- o Yes, for the current academic year (2017-2018)
- o Yes, for a previous academic year
- o No

4. Which participant group of the Sexuality & Relationships Psycho-education Group did you co-facilitate?

- o Adolescent group
- o Parent group

5. How much experience do you have working with the intellectual and developmental disabilities population?

- o No previous experience
- o 0-1 year
- o 1-5 years
- o 5-10 years
- o 11 years or more

6. Based on your experience, how significant are problems related to sexuality and relationships in the IDD population?

- Extremely significant
- Very significant
- Moderately significant
- Slightly significant
- Not at all significant

7. In your experience, what level of prioritization is generally given to problems related to sexuality and relationships in the IDD population in your clinical or educational environment?

- Essential
- High priority
- Medium priority
- Low priority
- Not at all a priority

8. A primary goal of the *Sexuality & Relationships* psycho-education group program is to serve as a catalyst for parent-child communication on topics related to sexuality and relationships for adolescents with intellectual and developmental disabilities. In your opinion, how effectively did the content (i.e. activities & curriculum) of the group sessions serve this goal?

- Extremely effective
- Very effective
- Moderately effective
- Slightly effective
- Not at all effective

9. Overall, how effective were the behavioral management strategies for this population?

- Not applicable
- Extremely effective
- Very effective
- Moderately effective
- Slightly effective
- Not at all effective

10. Please indicate how prepared you felt to facilitate the group sessions, with respect to each of the following responsibilities:

(a) Understanding the content

- Not applicable
- Extremely prepared
- Very prepared
- Moderately prepared
- Slightly prepared
- Not at all prepared

(b) Leading activities

- Not applicable
- Extremely prepared
- Very prepared
- Moderately prepared
- Slightly prepared
- Not at all prepared

(c) Managing adolescent behavior

- Not applicable
- Extremely prepared
- Very prepared
- Moderately prepared
- Slightly prepared
- Not at all prepared

(d) Overall

- Not applicable
- Extremely prepared
- Very prepared
- Moderately prepared
- Slightly prepared
- Not at all prepared

II. Semi-structured Interview Questions

1. Why were you interested in volunteering to co-facilitate the *Sexuality & Relationships* program? For example, describe your motivation to volunteer and/or what you hoped to gain from the experience. (context evaluation)

2. What would have made you a more effective group leader? (input evaluation)

3. Upon reflection, what would you do differently? (process evaluation)

4. Overall, what do you feel the program accomplished? (product evaluation)

5. What is something you would like to share about this experience, that I haven't asked?

APPENDIX C: CIPP AND DNP PROJECT OUTCOMES

Table 7. Context Evaluation Outcomes

DNP Project Outcome	(1) How effective are the program goals in meeting the identified need?
Delineate	• Adolescents with IDD need to be equipped with knowledge and skills related to sexuality and relationships. • A primary goal of the *Sexuality & Relationships* psycho-education group program is to serve as a catalyst for parent-child communication on topics related to sexuality and relationships • Literature review finds endorsement for parental involvement in sexuality education interventions for the IDD population.
Obtain	• Survey responses indicate that the level of prioritization in clinical and educational environments is relatively lower than the level of significance for problems related to sexuality and relationships in the IDD population. • Theme #1: Important Issue Discussed by 4 of 6 interview respondents
Provide	• Continue to offer the *Sexuality & Relationships* program to address important issues and areas of need for the IDD population. • Continue to conduct program evaluation for the purposes of ongoing program improvement.

Table 8. Input Evaluation I Outcomes

DNP Project Outcome	(2) How effective is the preparation of group facilitators to lead group sessions?
Delineate	• Orientation meeting held to prepare co-facilitators • Orientation resources include a group leader presentation, online course on sexuality education for IDD population, articles • Co-facilitators planned details for upcoming strategies via email • Co-facilitators met for an hour prior to each session
Obtain	• Survey responses indicate co-facilitators felt very prepared to lead group sessions overall, with comparable results reported for responsibilities related to understanding the content and managing adolescent behavior. • Survey responses indicate co-facilitators felt moderately prepared with respect to leading activities. Leading activities is a potential area for improvement. • Theme #2: Time Constraints (related to preparation) Discussed by 5 of 6 interview respondents
Provide	• Enhance the co-facilitator orientation with additional material on group leadership. • Increase the amount of time devoted to pre-program planning. • Consider an interactive approach to prepare co-facilitators including time to practice delivering material and/or leading activities. • Employ a more interactive approach to prepare co-facilitators including time to rehearse delivering material and leading activities. • Continue to gather post-program feedback from group co-facilitators regarding their perceived level of preparation to lead group sessions in order to inform strategies for future series.

Table 9. Input Evaluation II Outcomes

DNP Project Outcome	(3) How well does the curriculum content serve the program goals?
Delineate	• Curriculum resources were stored on an internal network drive • Co-facilitators without access to the clinic network relied on other co-facilitators to email resources • Additional resources were circulated via email • Co-facilitators independently obtained additional resources
Obtain	• Survey responses indicate that the content was very effective at serving the primary goal of the *Sexuality & Relationships* program. • Theme #3: Time constraints (related to group sessions) Discussed by 2 of 6 interview respondents
Provide	• Streamline each session's content and/or extending the length of the program (i.e. lengthening or adding weekly sessions). • Allocate more pre-program planning time to curriculum development. • Reevaluate this aspect of the program with more specific measures.

Table 10. Process Evaluation I Outcomes

DNP Project Outcome	(4) How well do the group sessions serve the program goals?
Delineate	• *Sexuality & Relationships* program implementation entailed six 1.5 hour long evening sessions held on a weekly basis
Obtain	• Survey responses indicate that the group sessions were very effective at serving the primary goal of the *Sexuality & Relationships* program. • Theme #4: Effective teaching strategies Discussed by 5 of 6 interview respondents • Theme #5: Cater the approach to individual needs Discussed by 4 of 6 interview respondents
Provide	• Enhance the pre-screening process to further assess individual needs and incorporate this information into future program series. • Continue to gather post-program feedback seeking group co-facilitators perception of how well the group sessions serve program goals in order to inform strategies for future series.

Table 11. Process Evaluation II Outcomes

DNP Project Outcome	(5) How effective are the behavioral management strategies?
Delineate	• Behavioral management strategies were introduced in the pre-program orientation meeting and distributed to co-facilitators via email. • Additional discussion of behavioral management strategies was addressed in pre-session planning emails, specifically in discussion threads amongst the adolescent group leaders.
Obtain	• Survey responses indicate that the behavioral management strategies were very effective for this population. • Co-facilitators reported that they felt very well prepared for leadership responsibilities related to managing adolescent behavior. • No pertinent themes emerged from the semi-structured interviews. • Anecdotal data from observation during the program implementation suggests that no significant events related to problematic behaviors occurred during the group sessions.
Provide	• Continue to educate co-facilitators about the common behavioral issues associated with the IDD population and behavioral management strategies that may be useful during the group sessions. • Continue to include the efficacy of behavioral management strategies in post-program evaluation measures.

Table 12. Product Evaluation Outcomes

DNP Project Outcome	(1) How effective are the program goals in meeting the identified need?
Delineate	• Not applicable
Obtain	• Theme #6: New Knowledge Discussed by 5 of 6 interview respondents • Theme #7: Cultivated Comfort Discussed by 5 of 6 interview respondents • Theme #8: Catalyst for Conversation Discussed by 3 of 6 interview respondents
Provide	• Continue to invest resources to further develop the program • Re-evaluate future program series with repeat questions from the current online survey for purposes of compiling and comparing data. • Continue to gather qualitative post-program feedback from group co-facilitators in order to inform strategies for future series. • For purposes of ongoing program evaluation, reexamine the outcome measures used to obtain feedback from participating families.

APPENDIX D: QUANTITATIVE RESULTS

DNP Project Participants Background Information

Figure 1. Discipline

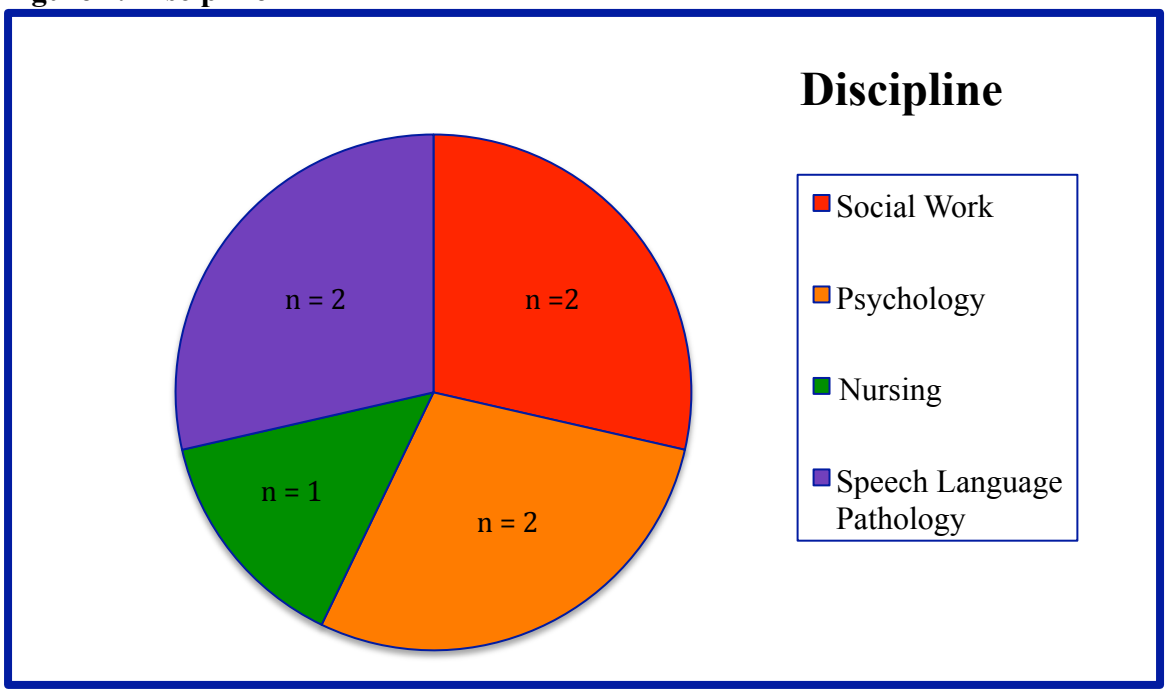
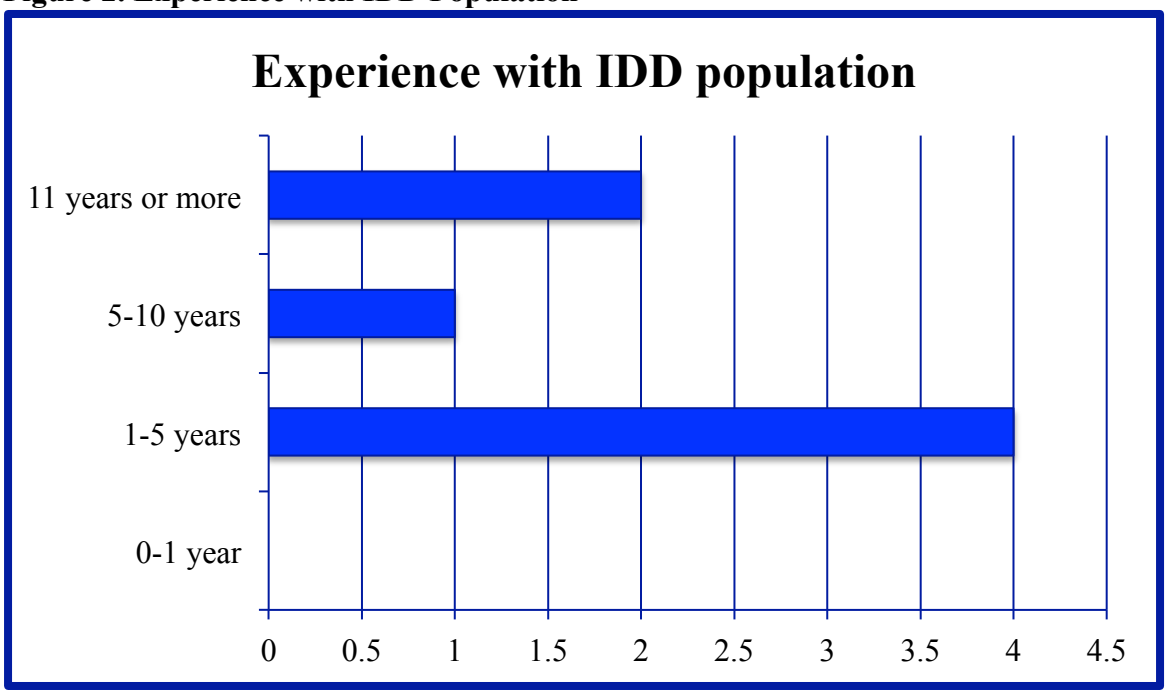
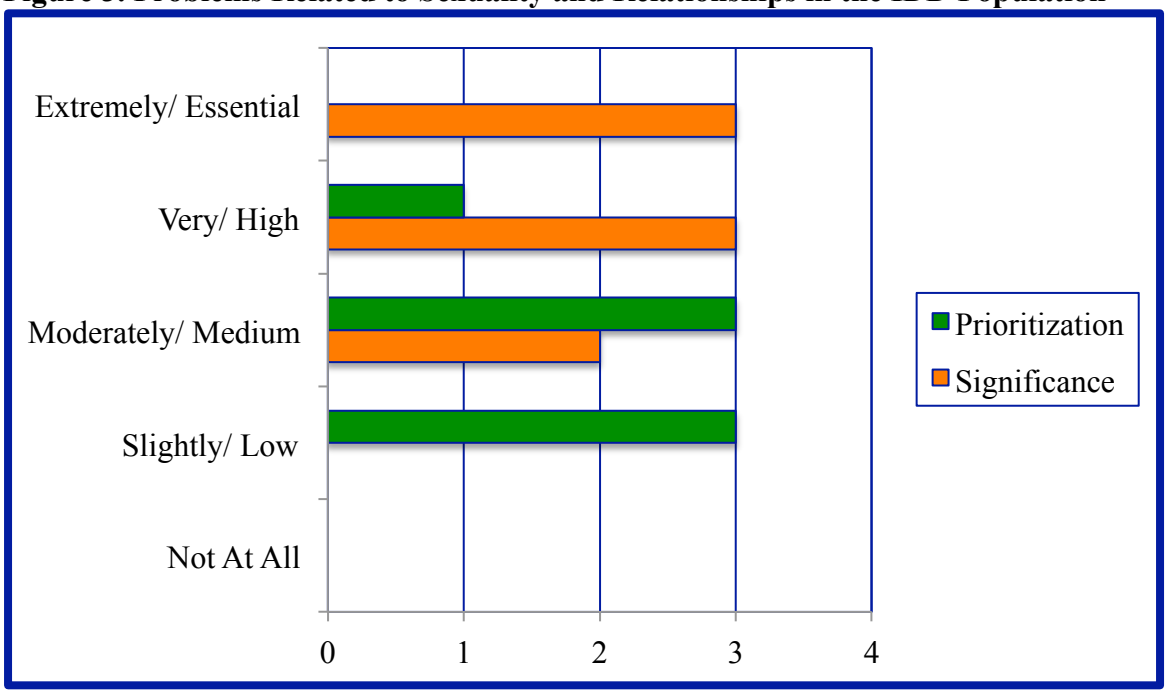


Figure 2. Experience with IDD Population



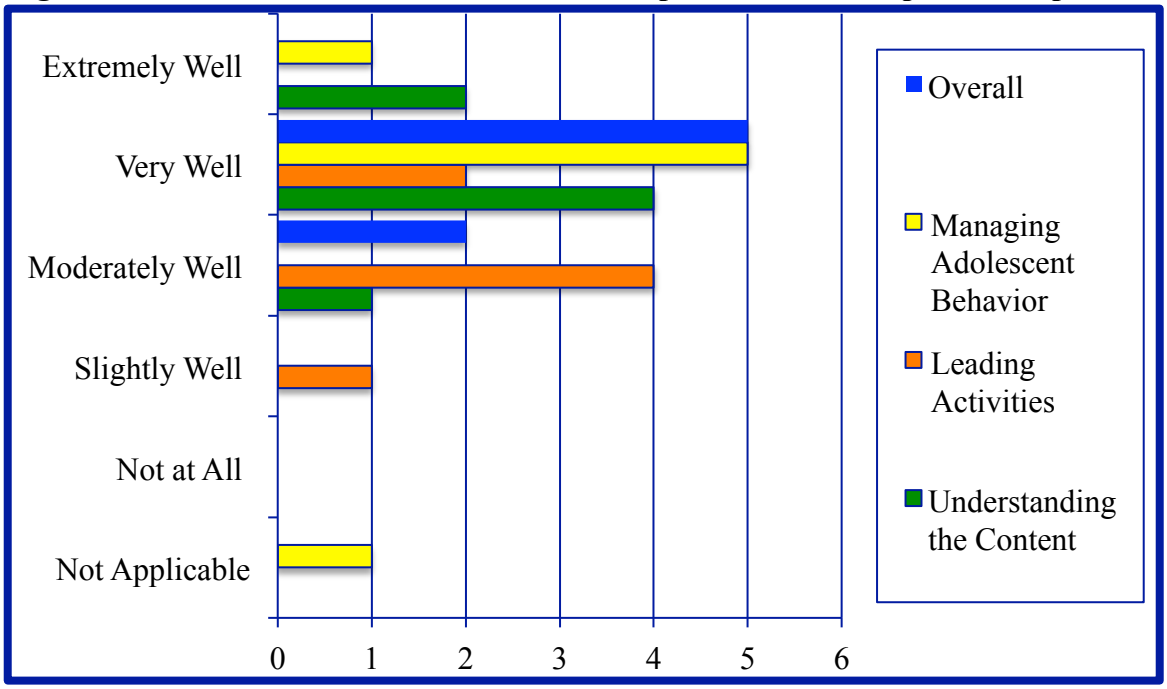
Context Evaluation Results

Figure 3. Problems Related to Sexuality and Relationships in the IDD Population



Input Evaluation Results

Figure 4. Co-facilitator's Perceived Level of Preparation with Respect to Responsibilities



Process Evaluation Results

Figure 5. How Effectively did the Content of the Group Sessions Serve the Program Goal?

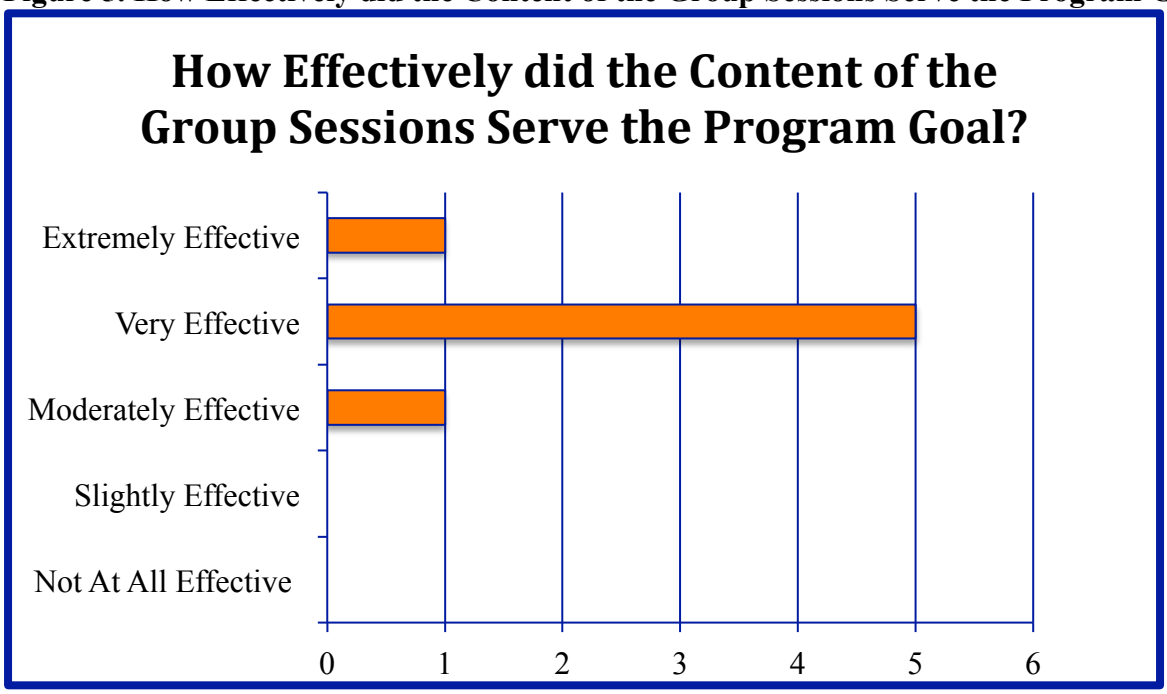
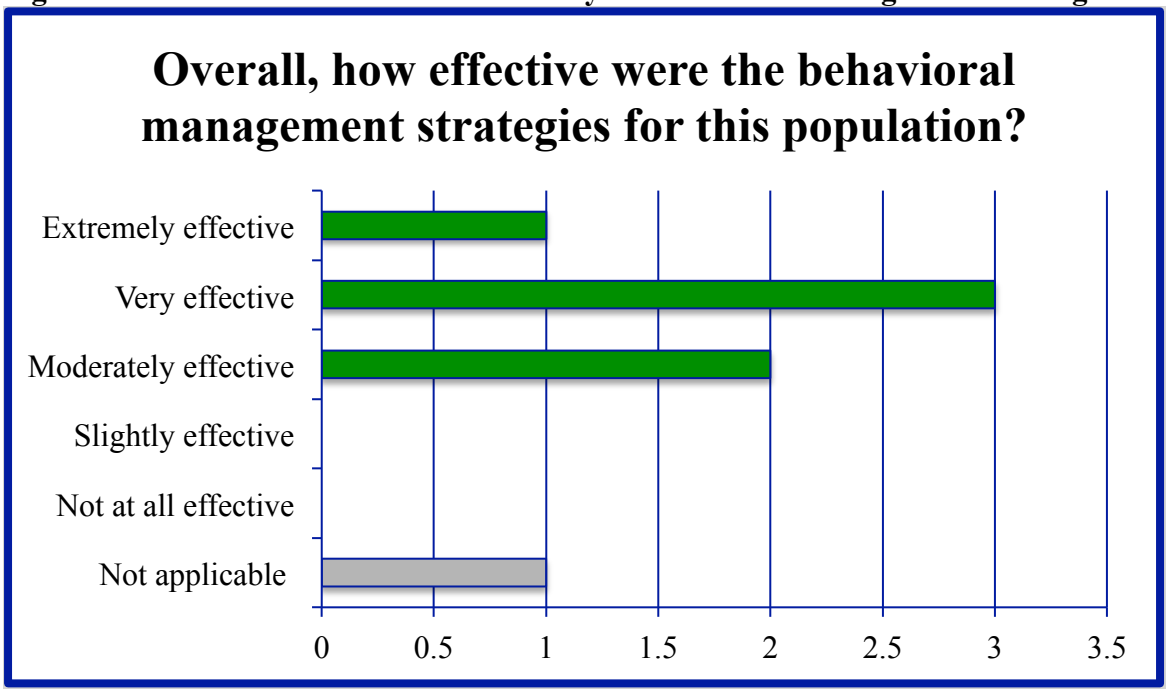


Figure 6. Co-facilitators' Perceived Efficacy of Behavioral Management Strategies



APPENDIX E: QUALITATIVE RESULTS

Table 13: Themes Identified in Qualitative Data

Theme	Frequency	Illustrative Quote
Important Issue	Discussed by 4 of 6 interview respondents	"*This is an important issue that is not addressed enough*"
Time Constraints (related to preparation)	Discussed by 5 of 6 interview respondents	"*It would have been helpful to have had more time to meet as a group of facilitators to prepare, talk in person and run through things."*
Time Constraints (related to group sessions)	Discussed by 2 of 6 interview respondents	"*It felt like we had to squeeze in a ton of information ...* [which] *took a long time* [and participants] *wanted to discuss more."*
Cater to Individual Needs	Discussed by 4 of 6 interview respondents	"*... more efforts to individualize the delivery of information*"
Effective Teaching Strategies	Discussed by 5 of 6 interview respondents	: "*... teach the same content in different ways.... with different modalities.. and repetitively"*
New Knowledge	Discussed by 5 of 6 interview respondents	*"I think everyone who participated ... left with new knowledge"*
Cultivated Comfort	Discussed by 5 of 6 interview respondents	"*... made it acceptable, less embarrassing... for these teens ... and even for me,* [for example], *" talking about something like masturbation,"* [from this program], "*I felt like I could really talk about it."*
Catalyst for Conversation	Discussed by 3 of 6 interview respondents	"*fostering that open-dialogue*"

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