



Walden University  
**ScholarWorks**

---

Walden Dissertations and Doctoral Studies

Walden Dissertations and Doctoral Studies  
Collection


---

2018

# Social-sexual Autonomy, Person-Centered Planning, and Individuals with Intellectual Disabilities

Earlie Simone Brown-Hall  
*Walden University*

Follow this and additional works at: <https://scholarworks.waldenu.edu/dissertations>

 Part of the [Disability Studies Commons](#), and the [Quantitative, Qualitative, Comparative, and Historical Methodologies Commons](#)

---

This Dissertation is brought to you for free and open access by the Walden Dissertations and Doctoral Studies Collection at ScholarWorks. It has been accepted for inclusion in Walden Dissertations and Doctoral Studies by an authorized administrator of ScholarWorks. For more information, please contact [ScholarWorks@waldenu.edu](mailto:ScholarWorks@waldenu.edu).

# Walden University

College of Social and Behavioral Sciences

This is to certify that the doctoral dissertation by

Earlie S. Brown-Hall

has been found to be complete and satisfactory in all respects,  
and that any and all revisions required by  
the review committee have been made.

## Review Committee

Dr. Tracey Phillips, Committee Chairperson, Human Services Faculty  
Dr. Lillian Chenoweth, Committee Member, Human Services Faculty  
Dr. Garth den Heyer, University Reviewer, Human Services Faculty

Chief Academic Officer  
Eric Riedel, Ph.D.

Walden University  
2018

Abstract

Social-sexual Autonomy, Person-Centered Planning, and Individuals with Intellectual  
Disabilities

by

Earlie S. Brown-Hall

MA, Cleveland State University, 1998

BA, Lake Erie College, 1990

Doctoral Study Submitted in Partial Fulfillment  
of the Requirements for the Degree of  
Doctor of Human Services

Walden University

November 2018

## Abstract

Sexual autonomy is the right and capacity of each individual to decide and make choices about whom, when, and how they express themselves sexually. Individuals with intellectual disabilities have frequently been marginalized, oppressed, and left out of discussions about sexuality placing them at risk of abuse, unsafe sex practices, and unplanned pregnancies. The purpose of this qualitative study was to examine the usefulness of person-centered planning techniques in the development of an individual service plan that address the social-sexual needs of individuals with intellectual disabilities. Purposeful sampling was used to select 8 participants for this study. Specific participants were selected because they possessed personal perspectives and experiences regarding person-centered planning techniques. Data collection included semi-structured, open-ended questions with face-to-face interviews and document review. Code development began with systematic organization of narrative data that was thematically analyzed using open-coding. Findings showed the person-centered individual service plan is a tool that can empower and promote social-sexual autonomy for individuals with intellectual disabilities if service and support administrators initiate a conversation about social-sexual activity. Implications for social change include increased advocacy for sexual autonomy, greater social acceptance of relationships, inclusive sexuality programming for individuals with intellectual disabilities and professional development training for service and support administrators.

Social-sexual Autonomy, Person-Centered Planning, and Individuals with Intellectual

Disabilities

by

Earlie S. Brown-Hall

MA, Cleveland State University, 1998

BA, Lake Erie College, 1990

Doctoral Study Submitted in Partial Fulfillment

of the Requirements for the Degree of

Doctor of Human Services

Walden University

November 2018

## Dedication

I would first like to give thanks to my Lord and Savior Jesus Christ for allowing me to start and complete this journey. I know I am a child of God and ALL things are possible through him. I dedicate the completion of this journey and this dissertation to my parents, Earl and Sherry Brown. My father made his transition from this earth on September 19, 2016, and my world was forever changed. I did not think I could go on, but I heard you cheering me on dad, and I made it. My father started his educational journey at a local college in the late 70's, while riding a motorcycle to school, working two jobs and raising four children. He eventually earned a master's degree in 1994, paving the way for his children. My dad constantly stressed the importance of education in our lives and showed my siblings and I that anything is possible with belief in God and hard work. My Uncle, Robert L. Brown, Sr. has supported my dreams all my life. I love you and thank you for being there emotionally and getting me across this stage. I could have never completed this journey without the love, guidance, support and substitute child care my mother provided me. How do you thank someone who gave you life and supported all your dreams? Mama, I could have never made it through this process without your love, support and belief in me. I love you.

## Acknowledgment

My parents planted a seed many moons ago, that education was key to a successful life. Today I would like to acknowledge all their wisdom, encouragement and support that led me to this moment in time. I would like to thank God for allowing me to benefit from an awesome support system starting with my husband, Stephon Hall and my children Carlisle and Stephon Jr. I could have never lived my dream without sacrifices from you all. Stephon you endured my late-night typing, was my sounding board when I had writer's block. You dealt with my emotional ups and downs during this process and understood when I missed social events. I appreciate your support and love you more than ever for it. Kids, I thank you both for understanding mommy had to study or write a paper and could not...I appreciate and love you both so very much. I hope I have inspired you to follow your dreams. I want to be the example of excellence to you that my dad was to me.

I thank my chairperson and committee member, Dr. Tracey Phillips, and Dr. Lillian Chenoweth, for encouraging me. There were many times throughout this process where I was one foot from the ledge, and Dr. Phillips kept throwing me lifelines. For her presences and encouragement in my life during this journey, I am forever grateful. Dr. Chenoweth without your brainstorming session, there would be no qualitative research question. Thank you. Finally, without God's grace and mercy, none of this would have been possible. I am blessed and humbled. To my extended family and friends, I am sorry for missing out on events over these past years. I was on a journey that is finally over.

Thank you for your love, prayers, and support. Dad, you told everyone your baby was going to be a doctor, and now I am.



## Table of Contents

List of Tables .....	v
Chapter 1: Introduction to the Study.....	1
Background.....	1
Operational Definitions.....	3
Research Question .....	4
Purpose of the Study.....	4
Study Framework.....	5
Limitations and Significance of the Study.....	8
Summary.....	10
Chapter 2: Literature Review.....	11
Introduction.....	11
Literature Search Strategy.....	13
Background.....	14
Intellectual Disabilities and Sexual Autonomy.....	17
Intellectual Disabilities and Sexual Relationships.....	19
Person-Centered Approach and Individual Service Plans .....	21
Application of Person-Centered Plans on Diverse Populations.....	25
Disability Services in Cuyahoga County, Ohio .....	26
Summary.....	28
Chapter 3: Research Methodology.....	31
Introduction.....	31

Research Question .....	32
Research for Qualitative Methodology.....	33
Participants and Sample.....	35
Setting .....	36
Data Collection Techniques .....	36
Role of the Researcher .....	38
Procedures.....	39
Data Collection .....	39
Data Management and Analysis Techniques .....	40
Data Management .....	40
Data Interpretation and Analysis .....	41
Code Development .....	41
Identifying Themes .....	41
Review and Reflection.....	42
Coding.....	42
Verification of Trustworthiness and Authenticity .....	42
Additional Ethical Considerations .....	43
Potential Participant Risks and Benefits .....	44
Summary .....	45
Chapter 4: Results.....	47
Introduction.....	47
The setting of the Interview .....	48

Location of the Study .....	48
Disability Services in Cuyahoga County, Ohio .....	48
Participants.....	51
Data Collection .....	54
Interviews.....	54
Document Review.....	54
Digital Recording and Document Review .....	55
Data Analysis Findings .....	56
Interview Question One .....	56
Misconceptions .....	58
Lack of Empowerment.....	59
Interview Question Two .....	59
Lack of Resources.....	62
Interview Question Three .....	62
Autonomy .....	64
Interview Question Four .....	64
Society.....	66
Consent and Capacity .....	66
Summary.....	67
Chapter 5: Interpretations and Recommendations.....	69
Study Purpose and Methodology .....	69
Summary of the Findings.....	69

Limitations of the Study.....	72
Implications for Social Change.....	73
Recommendations for Further Study .....	76
Conclusion .....	78
References.....	80
Appendix A: Study Participant Request .....	100
Appendix B: Interview Questions.....	102

List of Tables

Table 1. Participants Demographic Information..... 53

## Chapter 1: Introduction to the Study

### **Background**

Researchers agree that sexuality begins early in life and continues throughout life regardless of the ability of a person (Bernert & Ogletree, 2013; Travers, Tincani, Whitby, & Boutot, 2014; Hirsch-Walker, 2012). There are approximately 56.7 million people in the United States between the ages of 21, and 64 years old living with some form of physical, developmental, or mental delay that requires the assistance of others to perform one or more daily activities (U.S. Census, 2012). While it is true that some individuals with intellectual disabilities lack common life experiences necessary to develop, and maintain intimate relationships, research has shown that many individuals with intellectual disabilities desire education about appropriate sexual behavior and relationships (Gomez, 2012; Rueda, Linton, & Williams, 2014; Swango-Wilson, 2010). Research has also shown that the attitudes and beliefs of society regarding the development of meaningful romantic relationships among individuals with intellectual disabilities, affects how they view themselves as sexual beings (Brodwin & Frederick, 2010; Keshav & Huberman, 2006).

The lack of meaningful discussions about sexual feelings and emotions that individuals with disabilities have regarding their opportunity to socialize and develop romantic relationships may decrease autonomy and enforce negative social attitudes concerning sexuality in their minds. Pownall, Jahoda, and Hastings (2012) found that the lack of planned social interaction makes individuals with disabilities ashamed or embarrassed about having romantic feelings. Lafferty, McConkey, and Simpson (2012)

showed that delaying sexual education and planning for socialization opportunities for individuals with disabilities to develop intimate relationships arguably increases their vulnerability.

According to Danaher (2013), sexual autonomy is the right and capacity of each individual to decide and make choices about whom, when, and how they express themselves sexually. Researchers have shown that for individuals with intellectual disabilities, sexual autonomy is lacking, and this lack of consideration places them at risk of abuse, unsafe sex practices, and unplanned pregnancies (Brodwin & Frederick, 2010; Richards, Miodrag, & Watson, 2006). Researchers have shown that individualized planning could be a tool to address the sexual needs of individuals with intellectual disabilities; individualized planning can increase sexual autonomy while supporting sexual development (Travers et al., 2014).

The person-centered approach was developed over 50 years ago by Dr. Carl Rogers and originally introduced as a subjective process based on an individual's unique phenomenological perception of the world (Joseph & Murphy, 2013). The goals of person-centered or person-directed plans are to identify attainable goals along with the services needed to achieve those outcomes (Martin & Ouellette-Kuntz, 2014). Outcomes and required services compose the individual service plan, mapping out what is needed to meet a specific goal. However, as constructs of the original person-centered approach developed, it became clear that building partnerships are also important. Working collaboratively within therapeutic relationships, identifying strengths, weakness, intrinsic motivation, and human potential were also important factors of the concept when making

informed choices about the direction of the plan (Joseph & Murphy, 2013; Martin & Ouellette-Kuntz, 2014).

Although the research above regarding person-centered planning illuminates' important findings, I have found limited research that specifically examines the use of person-centered planning and individuals service plans as standardized tools to address the social-sexual needs of individuals with intellectual disabilities. Therefore, further research is necessary to examine the lack of research on the utilization of individual service plans as a standardized tool to address the social-sexual needs of individuals with intellectual disabilities.

### **Operational Definitions**

*Intellectual disabilities*: Defined by the American Association on Intellectual and Developmental Disabilities (AAIDD, 2016), as a disability characterized by significant limitations in both intellectual functioning and in adaptive behavior which covers many everyday social and practical skills. Broader preferred clinical terms, for individuals who have an Intelligence Quotient (IQ) between 70-75, or lower, an intellectual disability, cognitive disability or developmental disability (CCBDD, 2016; DODD, 2016; Luckasson, et al., 1992).

*Service and Support Administrator (SSA)*: Service coordinators or case managers who work with individuals or providers of services to coordinate services. Service and support administrators provide families and individuals with resources and support to ensure the health and safety of the individual receiving services (CCBDD, 2016; DODD, 2016).



*National Core Indicators (NCI)*: A collaborative effort, started in 1997 with the National Association of State Directors of Developmental Disability Services (NASDDDS) and the Human Services Research Institute (HSRI). The purpose of the program is to support member agencies to gather a standard set of performance and outcome measures that can be used to track their performance over time, to compare results across states, and to establish national benchmarks.

### **Research Question**

What are the perspective and experiences of service and support administrators regarding the use of the person-centered approach to develop individual service plans, to address the social-sexual needs of individuals with intellectual disabilities?

### **Purpose of the Study**

In this study I intended to examine the usefulness of the individual service plan as a standardized tool in addressing the social-sexual needs of individuals with intellectual disabilities. The person-centered individual service plan is a tool that could empower and promote social autonomy for individuals with intellectual disabilities; therefore, the experiences of service and support administrators employed with the CCBDD regarding the use of individual service plans were also examined. The CCBDD conducted a customer satisfaction survey in 2013 that examined many areas of the lives of individuals with disabilities that increase autonomy and promote social inclusion. However, information gathered regarding the individual's desire to develop personal relationships was not directly addressed. According to Gregory (2015), social perceptions, in addition to, legal, ethical, and moral considerations may be reasons sexuality for individuals with

intellectual disabilities not being explored more. Ignoring this area means also disregarding the development of sexual identity, a right often denied to individuals with intellectual disabilities (Gregory, 2015).

Individuals with intellectual disabilities have frequently been marginalized, oppressed, and left out of discussions about sexuality (Doyle, 2008; McGuire & Bayley, 2011; Swango-Wilson, 2010; Wings-Yanez, 2014). Simpson, Lafferty, and McConkey (2006) found that avoiding discussions about sexual relationships promotes sexual exclusion and social isolation as they pertain to services, support, and sexual health for individuals with intellectual disabilities. Researchers have shown that providing sexual education to individuals with intellectual disabilities is important to ensure that they have the knowledge and capacity to make informed decisions about sexual activities (Doyle, 2008; Fitcher, 2011; Swango-Wilson, 2010). Sexual expression among people with intellectual disabilities creates challenges on the individual and policy levels for many service providers (McGuire & Bayley, 2011). Capacity is not static and can improve through appropriate individually tailored plans (Dukes & McGuire, 2009).

### **Study Framework**

The social model of disability and Bronfenbrenner's ecological theory of development served as the foundation for this research study. The social model of disability is a civil rights-based approach to disability and developed by individuals with disabilities in the 1970s and 1980s (Langtree, 2015). Historically, disabilities were viewed under the medical model of disability or the social model of disability (Langtree, 2015). The medical model of disability refers to disability as a problem of the person,

directly caused by disease, trauma, or other health condition which requires sustained medical care (Langtree, 2015). According to Parchomiuk (2013), the focus of the medical model of disability is biologism and medicalization of professional, supportive services. The medical model of disability treats sexuality of individuals with disabilities as medical problems, generalizing the lack of sexual interest to all individuals with disabilities (Parchomiuk, 2013). The social model of disability views sexuality and disability from a civil rights context wherein social, cultural, ideological, and environmental barriers are analyzed (Langtree, 2015; Shakespeare, 2000).

Bronfenbrenner's ecological theory of development (1979), addresses human development over time through mutual accommodations, embedded in environmental microsystems, mesosystems, and macro systems that interact with each other, and with the individual to influence the development and achieve futures that are more desirable. Bronfenbrenner's theory offers insight into how environmental systems affect choices made by individuals with intellectual disabilities regarding what relationship boundaries they set for themselves. The theory may also provide insight into possible bias or perceptions that service and support administrators may have regarding planning support services provided to individuals with intellectual disabilities and allows for the involvement of a support system for them.

Bronfenbrenner's ecological theory of development frames this research because the theory aligns with the National Association of Social Worker's (NASW) core value of dignity and worth of a person by supporting self-determination through client participation in decision making and respecting differences (NASW, 2008). Person-

centered planning utilizes mindful practices that involve creativity, available resources, and supports systems within society to assist an individual with intellectual disabilities to live as independently as possible within their community.

Dr. Carl Roger's client-centered psychology approach (also termed person-centered or person-directed approach) asserts that the organismic valuing process is the engine of therapeutic change (Joseph & Murphy, 2013). The core concept of the person-centered theory states that an individual perceives the world in a unique phenomenological way, and places confidence in their ability to control his/her own positive, forward-moving change, while the role of the professional is primarily to support and promote the condition for change (Joseph & Murphy, 2013).

The social disability model is the best approach when discussing sexuality and individuals with disabilities because the condition or disability of the individual should never define the individual with disabilities. Through this lens, economic, social, and physical barriers are examined, and steps can be taken to discourage discrimination in all domains and change can occur (Mackelprang & Salsgiver 2009). Anastasiou (2011) stated that the social model of disability emerged because persons with disabilities wanted to change their lives by having more control and greater participation in civic life.

There are many variations of the basic social disability model in which most models stress the strengths and potential of individuals with disabilities instead of their limitations. However, possibilities and opportunities available to the individuals are stressed more (Burchardt, 2004; Parchomiuk, 2012). One example is making public buildings wheelchair accessible. Wheelchair accessible buildings are huge for individuals

with disabilities because it promotes independence and accessibility for these individuals. The social disability model emphasizes the importance of institutionalized oppression and the devaluation of individuals with disabilities encounter.

### **Limitations and Significance of the Study**

Research is limited to Cuyahoga County, Ohio. This study used a convenience sample. The limitation of a small sample size is the inability to generalize study findings to a larger, more diverse population. However, the decision to limit participation allows for a more in-depth review of the phenomenon studied (Cleary, Horsfall, & Hayner, 2014). Using a larger sample size may provide for wider application but could compromise the quality of what was studied.

The researcher's experience and employment as a service and support administrator with the CCBDD may yield unforeseen bias. Measures were taken to limit any personal biases including the triangulation of data, member checking, and peer-debriefing (Graneheim & Lundman, 2004; Houghton, Casey, & Murphy, 2013). The peer-debriefing was performed by an academic who had no vested interest in the study or the topic under research.

Shakespeare (2000) stated that it is easier to discuss and tackle issues of physical access and discriminations faced by individuals with disabilities than it is to discuss sexual aspects of their lives. Previous research has shown that societal, parental, and professional views towards sex and the disabled effect and influences how new life skills, and appropriate sexual behavior is learned (Brown & Pirtle, 2008; Doyle, 2006; Gardiner & Braddon, 2009; North Carolina Council on Developmental Disabilities, 2012). A lack

of education and knowledge, leads to little or no exposure to sexuality and disability, narrowing society's understanding of the need for appropriate planning and support (Esmail, Darry, Walter, & Knupp, 2010). A team approach promoting sexual autonomy for individuals with intellectual disabilities may allow human services professionals, caregivers, and family members insight into what individual with intellectual disabilities feel is important to them, and what is important for a successful plan outcome in terms of sexual and relationship development (Brodwin & Fredrick, 2010; Gilmore & Brooke, 2010; Lumley & Scotti, 2001; Pownall et al., 2012).

Utilizing individual service plans as a tool for promoting sexual autonomy for individuals with intellectual disabilities may give professionals in the human services field insight into what activities are important to the individual and what is important for them to participate in their community while remaining healthy and safe. Refusal to acknowledge individuals with intellectual disabilities as sexual beings increase the chance of victimization (Keshav & Huberman, 2006). Per McGuire and Bayley (2011), fear of possible legal sanctions, ethical and moral conflicts are at the heart of prohibitive attitudes on both the individual and organizational level. Utilizing a tool that is client-driven like the individual service plan, legal and moral fears should be alleviated, because it is the individual who makes informed decisions, often with the involvement of a support system versus the support administrator dictating services and supports. The result of this study may enlighten human service professionals and organizations about the effectiveness of the individual service plan tool as an approach to increase sexual autonomy for individuals with intellectual disabilities.

## **Summary**

Sexual expression is a natural component of everyone's life. Researchers have shown that individuals with disabilities desire intimate relationships that are healthy and safe (Bernert & Ogletree, 2013; Brodwin & Frederick, 2010; Doyle, 2008; Futcher, 2011; Swango-Wilson, 2010). This study was designed to explore the perceptions of service and support administrators regarding sexuality and individuals with disabilities, as well as, the use of individual service plans to meet the needs of individuals receiving supports. Chapter 2 provides a review of the literature to support the problem statement and need for this research. Chapter 3 provides information on the research method and design.

## Chapter 2: Literature Review

### **Introduction**

Historically, services and supports for individuals with intellectual disabilities have been deficit-based instead of goal-oriented (Trainor, 2007; Travers et al., 2014). Researchers have shown that for individuals with intellectual disabilities, taking an integrated approach, collaborating with the person's circle of support results in more effective outcomes and can improve their quality of life (Buntinx & Schalock, 2010; Lafferty et al., 2012; Martin & Carey, 2009). Providing for the health and safety of individuals with intellectual disabilities in all aspects of their lives is of the utmost importance to all who are closest to them. The health and safety of these particular individuals is also a major concern for service providers (Healy, McGuire, Evans, & Carley, 2009).

Many individuals with intellectual disabilities enjoy the same range and diversity in socializing opportunities that other individuals enjoy when it comes to developing intimate relationships (Brodwin & Frederick, 2010; Eastgate, 2011; Esmail et al., 2010). However, opportunities for those with intellectual disabilities to interact and socialize becomes more of a production than a natural occurrence (Cuskelly & Gilmore, 2007; Healy et al., 2009). Stewart (2009) stated there are groups of individuals who are fortunate enough to have good support systems within the care facility or home environment, and they are successful at gaining friendships. However, for others, access to leisure services still largely depends on the involvement and support the individuals receive from their support system.



This study intended to examine the effectiveness of the individual service plan as a standardized tool in addressing the social-sexual needs of individuals with intellectual disabilities. The scholarly research and peer-reviewed literature discussed in this review focused on the utilization of individual service plans, person-centered plans, and the development of intimate relationships for individuals with intellectual disabilities. This study specifically examines the utilization of person-centered techniques to develop individual service plans that address the social-sexual needs of individuals with intellectual disabilities in Cuyahoga County, Ohio.

Friendships and relationships are intrinsic to all human beings. However, for persons with intellectual disabilities, there are often limited opportunities to socialize outside of the supported living environment (Eastgate, 2011; Healy et al., 2009; Obe, 2009). There are even fewer discussions about what the individual wishes and what steps would be taken to fulfill their wishes (Stewart, 2009; Swango-Wilson, 2008). Lafferty et al. (2012), showed that delaying sexual education and planning for socialization opportunities to develop intimate relationships, increases vulnerability for individuals with intellectual disabilities. However, sexual expression among people with intellectual disabilities can create challenges on the individual and policy levels for many service providers (McGuire & Bayley, 2011).

A team approach to promoting sexual autonomy for individuals with intellectual disabilities may allow human services professionals, caregivers, and family members understanding regarding the desires of the individual and required services and supports

required for a successful plan outcome. (Brodwin, 2010; Gilmore & Brooke, 2010; Lumley & Scotti, 2001; Pownall et al., 2012). Therefore, the goal of this chapter was to examine the existing literature related to the utilization of person-centered therapy and individual service plans as possible standardized tools for human service professionals when discussing social-sexual services and supports needed for individuals with intellectual disabilities.

### **Literature Search Strategy**

The literature reviewed brings focus to this research study and shares with the reader results of other studies, fills in gaps in the literature, and extends prior studies (Marshall & Rossman, 2006; Randolph, 2009). In an attempt to find literature that specifically examined ways to assist individuals with intellectual disabilities plan for and develop appropriate intimate relationships, I used a broad search strategy. Library database searches for peer-reviewed and scholarly research was conducted using the following keywords: *intellectual disabilities*, *intellectual disabilities and sexuality*, *transitional plans*, *mental retardation and sex*, *dating and intellectual disabilities*, *intellectual disabilities and intimate relationships*, *sex resources for individuals with intellectual disabilities*, *person-centered theory*, *social model of disability*, *caregiver and societal attitudes towards sex and individuals with intellectual disabilities*, as well as, *individuals with intellectual disabilities and sexual health*. Search engines used to find literature for this study include Google Scholar, Human Services and Multidisciplinary databases from Walden University Library, such as PsycINFO, Soc-Index with Full Text, Education Research, ProQuest Central, ScienceDirect and Academic Search Complete

reviewed. The researcher also reviewed statistical and local data from the Ohio Department of Developmental Disabilities, the AAIDD, National Core Indicator, and the Ohio Self-Determination Association.

The review of the literature crossed several academic disciplines and yielded many articles which contained a variety of research topics. Research topics focused on individuals with developmental disabilities and their experiences with victimization, sexual dysfunctions, and other medical conditions. The literature I reviewed focused on societal attitudes, legal rights, and ramifications concerning sexual rights of individuals with intellectual disabilities, the role of family, caregivers, and professionals, as well as, sexual education for individuals with intellectual disabilities. I also used Boolean identifiers such as *individual service plans and intellectual disabilities*, *service delivery tools and individuals with intellectual disabilities*, and *sexual planning for individuals with intellectual disabilities*. After a thorough search for scholarly literature, I was unable to find any information regarding the use of both person-centered therapy and individual service plans to address the social-sexual needs of individuals with intellectual disabilities (Robertson et al., 2007).

### **Background**

Traditionally, sexuality among individuals with disabilities holds stigmas within North American societies. Other countries such as Ireland, Great Britain, Canada, Nigeria, South Africa, and Poland, have historically had sexuality policies in place. Research conducted into the sexual education of individuals with intellectual disabilities abroad (Esmail et al., 2010; Kijak, 2010; Lafferty et al., 2012). The openness to discuss

sexuality issues in other countries may be due to cultural differences. Healy et al. (2009) discussed how many services for individuals with intellectual disabilities historically operated under the auspices of religious organizations in Ireland, because of how Catholic teachings have a major influence on the education curriculum and social policy including those concerning individuals with intellectual disabilities.

Before the 1970s, there was minimal research on the topic of sexuality and disability (Esmail et al., 2010). When the topic of sexuality and disability was discussed or researched, sexuality was typically researched from a medical perspective and rarely without any consideration for the emotional connection made between two people (Esmail et al., 2010). Societal views regarding individuals with intellectual disabilities and social integration have improved and changed significantly over the past 20 years, with greater segments of society accepting individuals with disabilities as sexual beings (Parchomiuk, 2012; Thompson, 2011). The AAIDD (2016) classified individuals with intellectual disabilities as those who have an intelligence quotient score between 70-75. Moein, Rivard, Crocker, Boursier, and Caron, (2013), also showed more acceptance for higher functioning individuals, however, the lower the functioning level of the individual, the less social supports individuals with disabilities received regarding establishing romantic relationships.

Worldwide, The United Nations Convention on the Rights of People with Disabilities declared the right of all individuals to full participation and inclusion in society, and in their communities without distinction, and to be actively involved in decision-making processes (Amado, Stancliffe, McCarron, & McCallion, 2013; Buntinx

& Schalock, 2010; United Nations, 2006). Advancements in sexuality and individuals with intellectual disabilities are attributed to their demand for full inclusion into a society where social and intimate relationships are valued (Esmail et al., 2010; Gerowitz, 2007; Lafferty et al., 2012). Self-determination and autonomy require that an individual has the capacity, opportunities, and positive self-perception to make decisions (Travers et al., 2014). However, rights are not sufficient if not accompanied by opportunities to exercise those rights (Buntix & Schalock, 2010).

In the United States, the Individuals with Disabilities Education Act (IDEA), enacted in 1990, and re-authorized in 2004, ensures services, as well as, a free, appropriate public education to all children with disabilities (IDEA, 2016). However, social views in the United States regarding adult individuals with disabilities still lean towards viewing these individuals as child-like, and less capable of understanding sexual concepts (Finlay, Rohleder, Taylor & Culfear, 2015; Swango-Wilson, 2010). McRuer and Mollow (2012), stated that “rarely are disabled people regarded as either desiring subjects or objects of desire” (p.1). Therefore, they are excluded from typical sex education planning and programming (Swango-Wilson, 2010). These attitudes are changing, and access to sexually related education is becoming more available to young adults with disabilities who are transitioning into adulthood (Gougeon, 2009; Pownall et al., 2012). Partially credited for this surge of interest are international influences, and the accessibility and accommodation laws for individuals with disabilities enacted in the United States (Swango-Wilson, 2010; Taylor, 2014). These laws have allowed individuals with disabilities more access to the wider community, allowing them more

interaction with their nondisabled peers (Hayashi, Arakida, & Ohashi, 2011; Taylor, 2014; Swango-Wilson, 2010).

Pownall et al. (2012) found that the lack of planned social interaction makes individuals with disabilities ashamed or embarrassed about their romantic feelings. Research has shown that individualized planning can be used as a tool to impact transitions positively when discussing realistic expectations (Kaehne & Beyer, 2014; Travers et al., 2014). Travers et al. (2014) showed in their research how specializing services could increase sexual autonomy while supporting sexual development for individuals with developmental disabilities, but also recognized that more research was needed to develop policies and individualized plans for sexual development.

### **Intellectual Disabilities and Sexual Autonomy**

Civil rights for individuals with disabilities focused initially on deinstitutionalization, community inclusion, and basic human rights. Once deinstitutionalization occurred, issues related to appropriate and accessible housing, employment, education, self-advocacy, and self-determination surfaced, because the ability to make informed life decisions is an important component of everyday living (Devi, 2013). Individuals with intellectual disabilities wanted the equal opportunity to socialize, maintain intimate relationships, marry, and even start families just like nondisabled individuals (Esmail et al., 2010; Gerowitz, 2007; Lafferty et al., 2012; Obe, 2009). However, societal views involving this vulnerable segment of the population acted as a barrier and had a negative impact on these individuals' ability to fulfill their desire to love and be loved (Franco, Cardoso, & Neto, 2012; Fletcher, 2011).

Per Danaher (2013), sexual autonomy is the right and capacity of individuals to decide and make choices about whom, when, and how they express themselves sexually. In 2002, the Declaration of Sexual Rights prepared by the World Association for Sexual Health and accepted by the World Health Organization stated that “Sexuality is an integral part of human personality...Sexual rights are universal human rights. Sexual health results from the society that recognizes, respects and applies these sexual rights. Rights to sexual equality apply to all forms of discrimination irrespective of sex, sexual orientation, age, race, social class, religion, physical or emotional disability” (Kijak, 2010, p 72). Healy et al. (2009) examined social, cultural, and service provider perceptions of impediments to achieving sexual autonomy for individuals with intellectual disabilities. Service providers felt that individuals with intellectual disabilities are often required to demonstrate achievements of autonomy and self-determination, in aspects of life that are beyond some of their abilities such as homeownership or banking. From a service provider’s perspective, the inability to complete tasks can negatively impact a person’s ability to advocate for themselves (Healy et al., 2009).

Researchers have shown that a lack of social-sexual information, opportunity, support, and acceptance from society also act as barriers to sexual autonomy for individuals with intellectual disabilities (Hirsch-Walker, 2012; Juda, 2012). Researchers have shown that for adult individuals with intellectual disabilities, lack of knowledge, and sexual autonomy exist. Since individuals with intellectual disabilities are not viewed as sexual beings, there is rarely a discussion about a typical social-sexual activity like dating or attending social events. Many discussions about sexuality surround inappropriate

sexual activities or behaviors. Avoiding typical social-sexual topics does not empower sexual autonomy. In fact, this lack of consideration and planning places individuals at risk for sexual abuse, sexually transmitted infections, and unplanned pregnancies (Brodwin & Frederick, 2010; Finlay et al., 2015; Grieve, McLaren & Lindsay, 2007; Jahoda & Pownall, 2014; Richards, Miodrag, & Watson, 2006; Stevens, 2011). However, researchers also showed that the development of self-advocacy in disability services might empower individuals to communicate their desires to operationalize changes in services (McGuire & Bayley, 2011).

### **Intellectual Disability and Sexual Relationships**

There are approximately 9.6 million people in the United States between the age of 21 and 64 years old who live with some form of physical, developmental, or mental delay which requires the assistance of others to perform one or more daily activities (Brault, 2012). Having paid staff, family members, and family friends as their social circle, individuals with intellectual disabilities have limited opportunities for personal friendships (Stewart, 2009). Some individuals with intellectual disabilities have difficulty translating behavioral cues within social environments. Previous researchers have also shown that many individuals with intellectual disabilities have the desire to be educated about appropriate sexual behavior and relationships (Gomez, 2012; Rueda, Linton, & Williams, 2014; Swango-Wilson, 2010).

Sexuality for individuals with intellectual disabilities continues to be shrouded in myths and prejudices (Franco et al., 2012). Researchers agreed that sexuality begins early in life and continues throughout life, regardless of the ability of a person (Bernert &



Ogletree, 20113; Hirsch-Walker, 2012; Travers et al., 2014). While it is true that some individuals with intellectual disabilities lack common life experiences necessary to develop, and maintain intimate relationships, many would like the opportunity to socialize (Bernert & Ogletree, 2013). Tavares and Payne (2012), felt that this lack of experience could have detrimental outcomes regarding sexual expression for individuals with intellectual disabilities.

Barclay (2011) suggested that society may not be able to fix all injustices individuals with disabilities encounter. However, society could fund services and supports that would make participation in activities easier for individuals with intellectual disabilities. Funding for services that provide alternative sex education communication formats like the use of pictures, translators, adaptive equipment or sound and touch simulators. Funding assistance from government-run human services programs would benefit individuals with intellectual disabilities greatly regarding developing and accessing sex education programs that emphasize instructional intervention, self-determination, and self-advocacy (Travers et al., 2014).

Professionals, caregivers, and family members often assume that individuals with intellectual disabilities are not capable of understanding the specifics of many conversations. Their assumption further alienates the individuals by taking away their ability to make informed choices, giving control of their lives to someone else (Lafferty et al., 2012; Travers et al., 2014; Swango-Wilson, 2010). Swango-Wilson (2011) provided information regarding the desire of persons with intellectual disabilities to develop intimate relationships, against the social myths that individuals with intellectual

disabilities have no interest in sexual relationships (Brodwin & Frederick, 2010; Franco & Neto, 2012).

Swango-Wilson (2008) conducted a qualitative, descriptive inquiry regarding what individuals with intellectual disabilities expected from a sex education program in Anchorage, Alaska. Wilson identified three themes: Information about the development of friendships, the development of lasting relationships and marriage, and safe intimacy dispelling the myth about individuals with disabilities being asexual. Swango-Wilson's again focused on what participants felt would be important for a sex education program. However, there was no discussion about supports available to the participants that would allow them to participate in a sex education program (Swango-Wilson, 2008).

### **Person-Centered Approach and Individual Service Plans**

The person-centered approach was developed over 50 years ago, by Dr. Carl Rogers, and originally introduced as an individual process, based on the individual's unique phenomenological perception of the world (Joseph & Murphy, 2013). The goals of person-centered or person directed plans are to identify attainable goals along with the services needed to achieve those outcomes (Martin & Ouellette-Kuntz, 2014). Outcomes and required services are then developed into an individual service plan mapping out what is needed to meet a specific goal. Person-centered planning allows for the development of a goal orientated plan based on the future (Shurack & Rolings, 2014; Travers et al., 2014). Working collaboratively within therapeutic relationships, identifying strengths, weakness, intrinsic motivation, and human potential were also

important aspects when making informed choices about the direction of the plan (Joseph & Murphy, 2013; Martin & Ouellette-Kuntz, 2014).

Brown and Brown (2009) discussed the ability to make informed choices by individuals with intellectual disabilities, as making choices related to the quality of life, self-determination, or integration. Brown and Brown suggested a four-step strategy that encourages individuals with intellectual disabilities to become invested in the choices they make and how professionals working with them ensure their choices are put into practice (p.15). The four-step strategy for integrating choice into daily practice as outlined by Brown and Brown includes the following steps: (a) assessing the acceptance of choice in the environment, (b) determining ways opportunities can be made broad and familiar, with numerous opportunities and opportunities that promote autonomy and independence, (c) determining ways freedom, initiative and skills can increase in choice-making for individuals with intellectual disabilities, and (d) increase skill of support personnel and family members.

Examples of acceptance include available opportunities for choice and choice-making activities, written mission statement, and policy that includes a commitment to choose. Professionals who are knowledgeable of methods that promote choice, and ongoing assessment and evaluation of choice by individuals with intellectual disabilities. Skills can increase for individuals with intellectual disabilities by providing opportunities that are familiar, and that promote autonomy and independence. Increasing free and frequent access to opportunity, ongoing support in developing and expanding skill that expresses choice, and receiving support for choices made, so individuals with intellectual

disabilities develop consistent and long-term support of choices made and what choices cannot be made (Brown & Brown, 2009). Brown and Brown (2009) stated that following these steps would assist practitioners to move forward with developing individualized strategies.

The literature review showed that there are advantages for service providers when services are planned around what an individual wants versus what slot they fit into (Adnanes, Ose, & Kalseth, 2015; Kaehne & Beyer, 2014; Martin & Carey, 2009; Stewart, 2009). Martin and Kuntz (2014) conducted qualitative research in Ontario to better understand the lived experience of planning team members, including the individual with intellectual disabilities, families, staff and planners/facilitators. The research showed the importance of the person with intellectual disabilities having a voice and making informed, meaningful choices (Martin & Kuntz, 2014). PCP removes the power to make decisions concerning services or supports, from providers or staff, and gives the power to make these decisions back to the consumer or their family (CCBDD, 2015; Healy et al., 2009; Kaehne & Beyer, 2014). PCP and the development of individual service plans ensure that individuals are receiving services and supports that would best benefit them and their situation (CCBDD, 2015; Kaehne & Beyer, 2014). Research in both the United States and the United Kingdom also indicated that PCP could lead to improvements in lifestyle-related outcomes if the core principles of PCP, choice, independence, inclusion, and communication are followed (Martin & Carey, 2009; Martin & Kuntz, 2014; Robertson et al., 2007).

There have been several studies on the utilization of person-centered therapies to assist individuals with intellectual disabilities set and meet life goals (Buntinx & Schalock, 2010; Joseph & Murphy, 2013; Kaehne & Beyer, 2014; Martin & Carey, 2009; Robertson et al., 2007). Person-centered plans provide structure, orientation, direction and movement toward goal attainment (Forest, Pearpoint, & Snow, 1992; Mansell & Beadle-Brown, 2004; Martin & Carey, 2009; Pearpoint, O'Brien, & Forest, 1991; Thompson & Cobb, 2004). Thompson and Cobb (2004) showed the integration of person-centered plans has numerous advantages, especially the collaboration among a person's circle of support. Planning Alternative Tomorrow with Hope (PATH): McGill Action Planning System (MAPS): and Essential Lifestyle Planning (ELP) are just a few examples of person-centered plans used by Human Service professionals. The Planning Alternative Tomorrow with Hope (PATH), and the McGill Action Planning System (MAPS) are two structured action-planning systems that are conducive to the integration of an individual's sexuality (Travers et al., 2014). ELP is a written description of what is important to the person, how issues of health, safety or risk are addressed, and what steps need to occur to support the person live the life they want (Smull et al., 2009). Each tool has a different focus, but they all focus on what is important to the person and what is necessary to help an individual stay safe. Plans are presented in a colorful, interactive way (CCBDD, 2015; Smull et al., 2009; Travers et al., 2014). While these PCP programs exist, there was very little literature to support the use of individual service plans as a primary tool when assisting individuals with intellectual disabilities plan for their sexual needs and education.

History and research have shown that individuals with intellectual disabilities are commonly viewed as asexual and child-like people, who do not have any sexual desires, or as sexual deviants who should stay away from the opposite sex (Futcher, 2011). During their study on the application of person-centered planning during transitional planning, Kaehne and Beyer (2014), suggested that a person-centered approach can have a positive impact on planning and must have consistent involvement with all relevant stakeholders, assisting the individual with planning. Although the study did not examine specific areas of support, the outcome of the study supported the utilization of the person-centered approach.

Negative attitudes and restrictive practices from family members, staff or other professionals assisting the individual can impede sexual freedom for individuals with intellectual disabilities, thus affecting the individual's service plan (Healy et al., 2009). When discussing individual preferences and social integration, Amado, Stancliffe, McCarron, and McCallion (2013), asked how individuals with intellectual disabilities can make informed decisions concerning social integration if the individuals spent most of their lives in community environments of their disabled peers where they may have had little exposure or experience with relationships.

### **Application of Person-Centered Plans on Diverse Populations**

Researchers have shown that person-centered plans have the potential to be useful for individuals with intellectual disabilities who are from culturally and linguistically diverse backgrounds (Kijak, 2010; Robertson et al., 2007; Trainor, 2007). Disability, in some non-western cultures, views the disability as a manifestation of misfortune caused

by others (Brodwin & Fredericks, 2010). Understanding that cultural awareness is required with any therapeutic approach, the person-centered approach allows for individualization of service(s). Therefore, cultural roles can be respected and individual service plans developed (Trainor, 2007).

Another tool that is utilized to identify the service needs of individuals with significant disabilities is the Supports Intensity Scale. While useful in addressing friendships and intimate relationships, the Support Intensity Scale emphasizes the monitoring of inappropriate behavior(s) and not the development of intimate relationships (Travers et al., 2014).

### **Disability Services in Cuyahoga County, Ohio**

Cuyahoga County Board of Mental Retardation, established in 1967, because of strong lobbying efforts of parents whose local school districts refused to enroll their children. In 1975 federal law mandated that children with disabilities receive a free and appropriate public education. In the early 1980's the legislature added 'developmental disabilities' to the name and responsibilities, and in 2009 Legislature removed the term 'mental retardation' from the name and the agency became known as the CCBDD (CCBDD, 2015).

The CCBDD offers a full range of services to over 10,000 residents of Cuyahoga County, Ohio, that include in-home early intervention programs, leisure programs for seniors, specialized therapies (speech-language, occupational and physical), psychological services, support administration, family resources and respite care, supported living, vocational training, community employment, rehabilitation engineering,

and crisis intervention (CCBDD, 2015). Operational funding for services and supports provided by the CCBDD comes from three sources: (a) countywide property tax, (b) state, and (c) federal funding (CCBDD, 2015). Countywide property tax rates are computed in mills. One mill per the Cuyahoga County 2014-2015 Budget Plan (2015) is the equivalent of \$1 of tax for each \$1,000 in property value. For example, if a home has a property market value of \$100,000 and the assessed value of \$35,000, one mill would generate \$35 in tax (Parks et al., 2015). Usually, levies are voted on by residents every four years. However, continuing levies are continuous and are not subject to the 4-year voting process. Continuing levies also provide the same financial funds to the entity annually unless there is a public request for and approval of the change(s) (Parks et al., 2015). In November 2013, residents of Cuyahoga County, OH, approved a 3.9-mill continuing levy to the CCBDD. This approval is significant as local taxes account for 60% of the CCBDD primary support (Parks et al., 2015).

The CCBDD is composed of a seven-member, unpaid board who oversees overall operations. The Cuyahoga County Executive appoints five members, and the presiding Judge of Probate Court appoints two members, with at least three of appointed board members being either parent of or immediate family an enrollee (CCBDD, 2015). Each board member serves a four- year term, with the possibility of two additional appointments for a maximum of 12 years of service (CCBDD, 2015).

The mission of the CCBDD is to support and empower people with developmental disabilities to live, learn, work and play in the community (CCBDD, 2015). Service and support administrators employed by the CCBDD utilizes person-



centered planning tools like the ELP to assist in the development of an individual service plan. These individual service plans address six domains of an individual's life; transportation, mealtime, communication, health and safety, employment, and community involvement. Although the community section often addresses social activity participation, no discussion about sexual needs. There is no area in the individual service plan utilized in Cuyahoga County, OH, that specifically addresses the development of, or the maintenance of social and intimate relationships for the individuals with intellectual disabilities receiving served by the county board (CCBDD, 2015).

The CCBDD has access to a sex educator. However, assessments and evaluations are the only services currently offered. Developing a person-centered service plan that specifically addresses the social-sexual needs of individuals with intellectual disabilities and collaborating as a team to ensuring their health and safety is the goal (Callicott, 2003; Fanstone, 2010; Gardiner & Braddon, 2009; Gougeon, 2009; Tavares & Gavidia-Payne, 2012; Trainor, 2007).

### **Summary**

Society is coming to terms with individuals with disabilities being sexual beings. Before the 1970s, there was little, or no research focused on the sexuality of individual with intellectual disabilities (Di Giulio, 2003). Today, research is developing in this area with individuals who have intellectual disabilities at the forefront of the conversations. Public policy changes and attitudes have resulted in improved opportunities for individuals with intellectual disabilities. However, social attitudes about the

acknowledgment of individuals with intellectual disabilities as sexual beings remains in a negative light (Advocates for Youth, 2016).

Researchers supports the need for sexual education and inclusion for individuals with intellectual disabilities (Futcher, 2011; Parchomiuk, 2012; Smith & Windsor, 2013; Stewart, 2009; Swango-Wilson, 2011; Travers et al., 2014; Walker-Hirsch, 2012; Ward, Atkinson, Smith, & Windsor, 2013). Autonomy, regardless of an individual's abilities, should be upheld. The voices of individuals with intellectual disabilities must be heard, and their preferences placed at the forefront of any decisions made by team members such as family, medical professionals, educators, social service professionals, advocates or others vested in the health and safety of the individual (Taylor, 2014). Gomez (2012) stated that protection of a person's sexual rights must include service providers input on how to implement policies to support individuals with intellectual disabilities life planning around sexual expression.

Many studies reviewed examined the need for sex education programs, sexual interventions, barriers to sexual exploration, sexual inclusion, and laws about sex and individuals with disabilities (Brown & Pirtle, 2008; Lafferty et al., 2012; Pownall et al., 2012). Several studies showed that for individuals with intellectual disabilities, sexual autonomy is lacking. Lack of sexual autonomy places individuals with intellectual disabilities at risk of abuse, unsafe sex practices, and unplanned pregnancies (Brodwin & Frederick, 2010; Richards, Miodrag & Watson, 2006). To effect change and empower individuals with intellectual disabilities to advocate for themselves, a conversation about the individuals and their social-sexual needs must occur. The lack of meaningful

discussions about sexual feelings and emotions that individuals with disabilities have regarding their opportunity to socialize and develop romantic relationships decreases autonomy and reinforce negative social attitudes concerning sexuality in their minds (Pownall et al., 2012).

Starting the discussion into the need for sex education can begin with individual service plans, based on person-centered and person-directed planning. I was unable to locate literature that specifically utilized person-centered therapies to develop individual service plans that focused on the target population's social-sexual needs. The hope is that with communication and education, collaborators can meet each other halfway to keep individuals with intellectual disabilities safe from sexual abuse, victimization, and exploitation. Individuals with intellectual disabilities can be as sexually functioning as any non-disabled person with appropriate services and supports (Brodwin & Frederick, 2010).

This research examined the usefulness of the individual service plan tool used by service and support administrators employed by the CCBDD in Ohio, as a useful tool to address the social-sexual needs of individuals with intellectual disabilities who receive services from a professional perspective. Chapter 3 outlines the methodology utilized.

## Chapter 3: Research Methodology

### **Introduction**

Chapter 3 provides details of the research method and design used for this study. This study intended to examine the usefulness of the individual service plan as a standardized tool in addressing the social-sexual needs of individuals with intellectual disabilities. The person-centered individual service plan is a tool that could empower and promote social autonomy for individuals with intellectual disabilities. Therefore, the research focused on the perceptions and experiences of service and support administrators employed with the CCBDD regarding the use of the person-centered approach to developing individual service plans, and how its approaches could be utilized to address the social-sexual needs of individuals with intellectual disabilities. Currently, individual service planning is utilized by the CCBDD to address other areas of an individual's life. However, during the planning process, social-sexual needs and supports are omitted.

Dr. Carl Roger's client-centered psychology approach also termed the person-centered or person directed approach, asserts that the organismic valuing process is the engine of therapeutic change (Joseph & Murphy, 2013). The core concept of the person-centered theory states that individuals perceive the world in unique ways and places confidence in the individual's ability to control his or her own positive, forward-moving change, while the role of the professional is primarily to support and promote the condition for change (Joseph & Murphy, 2013). Researchers have shown that providing sexual education to individuals with intellectual disabilities is important to ensure these

individuals have the knowledge and capacity to make informed decisions about sexual activities (Doyle, 2008; Fitcher, 2011; Swango-Wilson, 2010). Service providers experience challenges on the individual and policy levels when discussing sexual expression among individuals with intellectual disabilities (McGuire & Bayley, 2011). Capacity is not static and can improve through appropriate, individually tailored plans (Dukes & McGuire, 2009).

The CCBDD, in 2013, examined many areas of the lives of individuals with disabilities that increased autonomy and promote social inclusion. However, information gathered regarding the individual's desire to develop intimate relationships was not directly addressed. According to Gregory (2015), social perceptions, as well as legal, ethical, and moral considerations are some of the reasons why sexuality for individuals with intellectual disabilities is not explored more.

Individuals with intellectual disabilities have frequently been marginalized, oppressed and left out of discussions of sexuality (Doyle, 2008; McGuire & Bayley, 2011; Swango-Wilson, 2010; Wings-Yanez, 2013). Simpson, Lafferty, and McConkey, (2006) found that avoiding discussions about sexual relationships promotes sexual exclusion and social isolation as it pertains to services, supports, and sexual health for individuals with intellectual disabilities. In the agreement, Gregory (2015) stated that ignoring a person's sexuality impedes the development of the individual's sexual identity.

### **Research Question**

Rubin and Rubin (2012) stated that individuals who are professionally knowledgeable, who has first-hand experience with the phenomenon studied, and whose

combined views present a balanced perspective on a topic are appropriate research study candidates. These individuals can add credibility to the research topic. In Cuyahoga County, Service and Support Administrator are the primary plan writer and has a unique perspective as to the effectiveness of person-centered planning. This was the rationale for selecting service and support administrators to answer the following research question: What are the perceptions and experiences of service and support administrators regarding the use of the person-centered approach to develop individual service plans, to address the social-sexual needs of individuals with intellectual disabilities?

## **Research Design**

### **Rationale for Qualitative Methodology**

I employed a qualitative descriptive exploratory case study using a holistic approach to obtain a rich, in-depth understanding of a person, program, or situation, by exploring a phenomenon, individual, or groups ascribed to a social or human problem (Connelly, 2016; Rudestam & Newton, 2007). This approach allowed me to explore experiences of service and support administrators who serve individuals with intellectual disabilities. The use of a descriptive case study allowed for the exploration of person-centered individual service planning as a phenomenon in the real-life context in which it occurs, to address the social-sexual needs of individuals with intellectual disabilities (Yin, 2012). Yin (2012) stated that other research methods would most likely not yield the rich description or insightful explanations that arise from case study research. A case study design should be considered when the focus of the study is to answer how and why questions, and when one cannot manipulate the behavior of those involved in the study

(Yin, 2012). Case studies have been found to be useful in the social sciences and practice-oriented fields such as education, management, and social work (Starman, 2013). According to Yin (2009), when there are few definitive hypotheses on a topic and little is known about the nature of the phenomenon, a qualitative inquiry is a reasonable approach to begin research.

Qualitative descriptive research is appropriate when a rich description or insightful explanations are desired to examine a phenomenon within its real-world context (Hatch, 2002). Starman (2013) stated that a case study is important for developing different views of reality. Case studies can contribute to the professional development of the researcher and case studies can provide concrete, context-dependent experiences (Flyvbjerg, 2006; Starman, 2013). Based on the search for meaning and understanding, the researcher is the primary instrument of data collection and analysis, and descriptive results, a case study methodological approach was deemed most appropriate (Merriam, 2009).

According to Rudestam and Newton (2007), an exploratory methodology intends to explore the research question and does not intend to offer a final and conclusive solution to the existing problem. Qualitative exploratory research leaves room for future research while investigating a contemporary phenomenon within its real-life context (Anastas, 1999; Stake, 2006). Utilizing descriptive exploratory qualitative methodology, professional experiences, and its expression in language will assist in the future evaluation of person-centered individual service plans as a possible appropriate planning tool to empowering individuals with intellectual disabilities to meet social-sexual goals.

## **Participants and Sample**

Convenience sampling was used to recruit participants for this research study. Purposeful convenience sampling is utilized to add credibility and not for generalization purposes (Houghton et al., 2013; Nastasi, 1998). For this reason, eight service and support administrators, employed with the CCBDD for ten years were selected to participate in this study. Service and support administrators who had a consumer(s) on their current caseload that expressed a desire to develop intimate relationships or a consumer whom they think would be interested in receiving social-sexual services were eligible to participate in this study. Intimate relationships could involve dating, getting married, engaging in intercourse, or having a more active social life.

Participants selected were formally trained in person-centered planning or ELP techniques through continuing education courses often offered by the CCBDD. Purposefully selecting participants in this position who possess employment history allows for a wide range of experiences and perspectives (Rubin & Rubin, 2012; Yin, 2012). Wolcott (2008a) stated that having a small sample size is justified because information gathered should provide ample opportunity to identify themes of a case. Although purposeful and convenience sampling was used, further narrowing of possible participants occurred by selecting eight of the service and support administrators who responded to research participation letter met participation criteria, appeared to have extensive knowledge of person-centered planning, and a willingness to openly discuss and plan for sexuality services for individuals with intellectual disabilities. A written



explanation of the study was provided to the participants, and informed consent for participation was collected.

Another criterion considered important to this research study was the intellectual functioning level of individuals being discussed. This study is not inclusive to individuals who have a behavioral, predatory, criminal, or victimization(s) diagnosis. The service and support administrators were asked to consider individuals on their caseload who can benefit from social-sexual training/classes and expressed a desire to receive services. Individuals must have a diagnosis of intellectual disability, as defined by the AAIDD (2016), individuals with intellectual disabilities are those individuals who have an intelligence quotient score between 70-75.

### **Setting**

Interviews were scheduled at the convenience of the participants. Data collection occurred in a private, secure meeting room at Cuyahoga County Public Library on the Eastside and Westside of Cleveland, Ohio. To ensure confidentiality and reduce threats to validity, the meeting rooms provided privacy during the interview process and for the participants from co-workers or other CCBDD staff. Arrangements were made to meet with the service and support administrators during non-working hours for approximately 1-2 hours to conduct interviews (Nastasi, 1998).

### **Data Collection Techniques**

Once IRB approval was received, data collection began with an email requesting volunteers for the research study. This request was initially sent to CCBDDs Human Resource Director, and the Community Medicaid Services manager for approval to

conduct this research with county staff . Upon approval from CCBDDs human resource department, the request for study participants was sent out to the service and support administration department, requesting volunteers for this exploratory research study involving individuals receiving services in Cuyahoga County, Ohio (see Appendix A).

Distribution of the initial email request for participants occurred in early June 2017, with a 2-week submission request. The two weeks went by with only two submissions. The request for participants was sent back out to the service and support administration department in mid-July 2017, and 16 potential participants responded. Upon reflection on the small sample size of this study, there appeared to be two reasons for the lack of response: (a) The request for participants went out to staff during staff summer vacations, and times when the agency shut down, and (b) there were very few staff members who have been service and support administrators 10 consecutive years. Many workers were promoted, left the agency, or were in the process of retiring from CCDBB during the study period. I reviewed each submission verified that potential participants met study requirements, and selected every other submission for study participation until she identified eight study participants.

Data collected for this study consisted of three qualitative data collection types: Interviews, document review, and computerized materials. I developed four semi-structured, open-ended questions and conducted face-to-face interviews with the participants (see Appendix B). Interviews were necessary to obtain in-depth answers, views, and experiences from the service and support administrator professionals regarding the phenomenon under study. Information received from The National Core

Indicators 2013-2014 report discussing consumer satisfaction with services and supports received by individuals with intellectual disabilities around the area of romantic relationships and self-advocacy were also reviewed. A review of a current computerized individual service plan occurred to determine current options for social-sexual supports for individuals with intellectual disabilities.

### **Role of the Researcher**

My role as the researcher was to design this case study and initially establish the direction of the study (Rubin & Rubin, 2012). Creating the overall study design, research findings, gaining IRB approval, selecting study participants, data collection, analysis and reporting the final-result report were also my responsibilities. As the researcher, I was the primary data collection instrument, and had to account for personal bias during the development of the study design. I was very familiar with the current roles and responsibilities of service and support administrators, including but not limited to, plan writing, serving as single points of contact, and coordinating services with the CCBDD, after 15 years of employment (CCBDD, 2016). Although many services and support administrator were acquainted with the researcher, none of them were daily coworkers or served under my supervision. Due to this extensive knowledge of service and support administration, personal biases could have arisen throughout this study about the topic of research, participants, or research site must be considered (George & Bennett 2005; Starman, 2013). To address unforeseen bias, I reminded participants' that all answers would become part of the study, and the researcher did not share any personal

experiences with participants. All measures were taken to limit any researcher bias including the use of peer debriefing to review to ensure objectivity and credibility.

### **Procedures**

A written agreement of cooperation between the researcher and CCBDD was obtained. Gaining approval from Walden University's IRB to recruit participants and conduct the study was the next step. I composed an email, and approval by the CCBDD human resources department. The email went out to the Support Administration department requesting volunteers for this exploratory research study involving individuals receiving services in Cuyahoga County, OH (see Appendix A). I reviewed the participants' submissions, then, contacted potential participants to verify they met the inclusion criteria. From the approved list, eight service and support administrators were selected to participate in this study. Once participants identification occurred, each participant received notification, and a formal informational meeting was scheduled with each participant. At the meeting, I explained the nature and purpose of the study, participant expectations, and allowed participants' time to pose study related question. The next step included the review and collection of a written informed study participant consent form from each study participant. After obtaining informed consent forms from the study participants', they were each assigned code names or pseudonyms to protect their privacy.

### **Data Collection**

In qualitative case study designs, the researcher served as the primary data collection instrument (Merriam, 2009). Therefore, I collected all data for this study. Eight

service and support administrators were interviewed about their experiences and perception of PCP as an effective tool when developing individual service plans that address the social-sexual needs of individuals with intellectual disabilities. Open-ended interviews provide richer and more extensive data, and the possibility for a lengthy conversation (Yin, 2012). No individuals were directly involved with this research study, although anecdotal stories may be told by the interviewees, without disclosing identifiable information about the individual. I digitally recorded all interviews and study related conversations with each participant.

### **Data Management and Analysis Techniques**

#### **Data Management**

All information, transcriptions, and research notes were stored in a locked, fire-proof storage cabinet in my home office. For additional protection of data collected, a password-protected file was created on the researcher's personal computer. In addition, an encrypted USB drive was used to store all research data electronically. The informed consent form was the first document stored for each participant's study file which contained all notes, transcriptions, and documentation related to the study. To ensure participant confidentiality, no identifying information was included in the individual files and participants were reminded throughout the interviewing process that research notes and recordings would be used in the study. Each participant was assigned a code name for identification purposes. Per Kaiser (2009), code names are pseudonyms designed to

have no conceptual inference to the individual's real name. The assigned names used by me and participants for the duration of the study.

### **Data Interpretation and Analysis**

Data analysis is the process of moving from raw interviews, artifact reviews, and observations, to evidence-based interpretations (Rubin & Rubin, 2012). Data without analysis is meaningless (McMillan & Schumacher, 2014). I ensured accuracy, honesty, and transparency by accurately representing and transcribing exact words as spoken by the interviewee and performed member checking. Member checking improves the credibility and accuracy of the transcription (Merriam & Tisdell, 2016). This system of review also allowed the study participants' the opportunity to discuss and clarify interpretations, as well as, add new or additional thoughts (Krefting, 1991).

Analyzing narrative data is different from data that is analyzed using an algorithm method (Yin, 2012). Case study analysis began with the systematic organization of narrative data into matrices (Yin, 2012). Code development followed the steps laid out by Rubin and Rubin (2012): (a) finding concepts and themes, (b) assigning labels to data, (c) determine and define key concepts and themes for coding purposes, and (d) put key concepts and themes together to show how data answer the research question and discuss broader social implications.

### **Code Development**

#### **Identifying Themes**

My first step in identifying themes was to take the coded data and group information. I grouped coded data into clusters. For example, terms like *behaviors*, *asexual*, or *deviant* described sexuality and individuals with intellectual disabilities, all words with common meanings. I then grouped coded data and reflected on what the coded data collectively implied.

### **Review and Reflection**

Label development involved taking the concepts identified during the review of interview data, academic literature, and computerized information used for individual service planning with the CCBDD.

### **Coding**

Each interview was reviewed again, to mark data that referred to the same subject matter. I am a visual person, so during the review process, I used multicolored highlighters to represent various subjects, words or phrases from each interview. From this information, a code table was developed, listing themes that re-occurred during the interviews, appeared relevant, or emphasized in the previous literature.

### **Verification of Trustworthiness and Authenticity**

In this study, accuracy was substantiated by digitally recording all interviews and study related conversations with each participant. I transcribed and printed audio recordings, as well as, performed member checking as a means of ensuring the accuracy of data collected. Interview transcriptions were saved on a password-protected file on my

personal computer. Identifying information were removed from the original transcripts for analysis purposes.

I selected professionals who worked in the developmental disabilities field at the time of the study, which added credibility to the research, because of their extensive knowledge of the phenomenon under examination. The participants were selected purposely for that reason, in addition to, the training and experience they possess in regards to individual service plan development and plan writing (Nastasi, 1998; Rubin & Rubin, 2012). In an attempt to collect accurate, truthful experiences and perceptions, I developed unbiased, open-ended interview questions. Good interview questions are free of bias and promote the free exchange of ideas (Baxter & Jack, 2008).

An additional strategy used for this research study was the triangulation of data. Triangulation is the use of multiple research methods and data sources, combined, to investigate a phenomenon while gaining an understanding of the phenomenon. Triangulation is also used to ensure the qualitative data collected is rich and well developed by comparing data from different sources. Triangulation increases study credibility and understanding, therefore written, verbal, and recorded responses were reviewed and compared for consistency in responses. The use of reflection notes and peer review feedback was also used to limit any researcher bias and ensure the validity and reliability of data collected (Baxter & Jack, 2008; Yin, 2003).

### **Additional Ethical Consideration**

All measures to ensure participants rights, in accordance with the steps outlined by Walden University and the Institutional Review Board were upheld. An informed



consent form for participation in this research was developed and given to each participant. The assurance of confidentiality was highlighted by assigning code names to all participants', to assure interview responses would be expressed freely and held in confidence. If any identifiable information appeared on the consent form, the information was omitted to ensure participant confidentiality. If a participant's identity became identifiable through experiences or verbiage, a case composite of their responses took the place of reporting experiences. Participants were given the opportunity to review their transcribed interview before submission to ensure the accuracy of their responses.

I developed the study informed consent form for research study participation, and each research participant received both a verbal and written form. The consent form specified that participation in the research was voluntary, withdrawal from participation could take place at any time during the data collection process, and privacy protected. The informed consent form also provided participants with details about the nature of the research, benefits the research may have for individuals with intellectual disabilities and included a section where they could pose additional questions if needed. I secured a letter of cooperation from the CCBDD to conduct interviews with service and support administrators currently employed by the agency (see Appendix A). This permission was necessary as I am a current employee of the CCBDD.

### **Potential Participant Risks and Benefits**

There was no physical, emotional, or financial risk to the participants or to the refusal to participate in this research. Researchers have shown that with PCP, a circle of support and appropriate services, individuals with intellectual disabilities can lead

successful lives (Esmail et al., 2010, Joseph & Murphy, 2013; Martin & Ouellette-Kuntz, 2014). Since referrals for all services are the responsibility of the service and support administrator, their perceptions and experiences about this area of planning are important. Participating in this research allowed service and support administrators input into the future direction of social-sexual planning techniques for individuals with intellectual disabilities. Depending on the participant's personal beliefs or bias, they may become better advocates of sexuality services for individuals with disabilities receiving service by the CCBDD. Service and support administrators can advocate for sexuality services that include topics from abstinence to family planning. Obtaining information from the service and support administrators may benefit the CCBDD as an agency because it can prove helpful in the future development of human sexuality services and supports.

### **Summary**

There is a need for the education of caregivers, providers, family members, educators, and professionals working with individuals with intellectual disabilities regarding discussing the development of relationships and sexuality at a societal and policy level (McGuire & Bayley 2011). Gardiner and Braddon (2009) believed that it was vital to facilitate a relationship and sexuality program for adults with intellectual disabilities and their parents to aid in the planning and support process.

This study intended to examine the perception and experiences of service and support administrators in Cuyahoga County, Ohio, about the usefulness of the individual service plans as a standardized tool in addressing the social-sexual needs of individuals with intellectual disabilities. After a review of the literature, I was unable to find a

standardized assessment or planning tool available to professionals in the human services field to address the social-sexual needs of individuals with intellectual disabilities.

Therefore, using an exploratory method was considered most acceptable to gather descriptive information about what happens as a result of program activities (Patton, 2002). Chapter 4 highlights the results of this study.

## Chapter 4: Results

### **Introduction**

In this study I examined the perceptions and experiences of service and support administrators in utilizing the person-centered approach when developing individual service plans addressing social-sexual needs of individuals with intellectual disabilities. An individual service plan is a tool used by human service professionals when setting goals and outcomes for individuals. Through a series of questions about the individual, service and support administrators can assess the individual's likes and dislikes, daily routines, and support systems required to keep them healthy and safe. The data gathered provides the information required to develop the person's service plan based on aspirations and goals identified by the individuals and their planning team members.

Person-centered planning (PCP) for the development of individual service plans is a valuable technique (Joseph & Murphy, 2013; Travers et al., 2014). Researchers have shown that a lack of planning for their sexual needs, places individuals with intellectual disabilities at risk of abuse, unsafe sex, and unplanned pregnancies (Brodwin & Frederick, 2010; Gregory, 2015; Joseph & Murphy, 2013; Travers et al., 2014). Person-centered planning is a discovery process that uses interviews, observations, and assessments to identify the talents and interests of an individual (Glicksman et al., 2017). In Cuyahoga County, Ohio, service and support administrators employed by the CCBDD, are primarily responsible for all plan development. Therefore, I explored the experiences of service and support administrators utilizing PCP when discussing the social-sexual

needs and desires of the individuals with an intellectual disability they serve. I was also interested in how study participants included information gained into their service plan.

In this chapter, I described the study including the setting of the interviews and participants' demographic backgrounds. It also includes a comprehensive explanation of how data from the interviews were collected, categorized and analyzed. There is also a synopsis of interview answers obtained from the participants that addressed the research question.

### **The setting of the Interviews**

The Cuyahoga County Public Library provides meeting spaces in its branches where groups can gather for cultural, civic, intellectual and informal educational engagement. Interviews took place in a private, secure meeting room at the public library, in Cuyahoga County, Ohio, to ensure participants' confidentiality. The rooms provided privacy during the interview process, low noise levels for recording, and confidentiality for the participant. I scheduled interview meeting dates and times at the convenience of the participants during September and October 2017.

### **Location of the Study**

#### **Disability Services in Cuyahoga County, Ohio**

The Cuyahoga County Board of Mental Retardation established in 1967, as a result of strong lobbying efforts by parents whose local school districts refused to enroll their children (CCBDD, 2016). In the early 1980s, the legislature added the term 'developmental disabilities' to the name and responsibilities, and in 2009 Legislature

removed the term 'mental retardation' from the name and the agency became known as the CCBDD (CCBDD, 2016). Cuyahoga County is the second largest of 88 counties in Ohio with 1,249,362 residents (Ohio Development Services Agency, 2017). The CCBDD offers a full range of services to over 10,000 men, women, and children of Cuyahoga County. Services include in-home early intervention programs, leisure programs for seniors, specialized therapies, psychological services, support administration, family resources, respite care, supported living, vocational training, community employment, rehabilitation engineering and crisis intervention (CCBDD, 2016). Operational funding for services and supports provided by the CCBDD derives from three sources: countywide property tax, state and federal funding (CCBDD, 2016). The CCBDD is composed of a seven-member, unpaid board, who oversees the overall operation of the agency. The Cuyahoga County Executive appoints five members, and the presiding Judge of Probate Court appoints two members, with at least three of appointed board members being either parent of or immediate family an enrollee (CCBDD, 2016). Each board member serves a year term with the possibility of two additional appointments for a maximum of 12 years of service (CCBDD, 2016). The mission of the CCBDD is to support and empower people with developmental disabilities to live, learn, work and play in the community (CCBDD, 2016).

Service and support administrators employed by the CCBDD utilizes person-centered planning tools like the ELP to assist in the development of individual service plans. These individual service plans address six domains of an individual's life: transportation, mealtime, communication, health and safety, employment, and

community involvement (CCBDD, 2016). After a review of an individual service plan, based on PCP, there did not appear to be an area in the plan that specifically addressed the development of or the maintenance of social and intimate relationships for individuals with intellectual disabilities receiving service from the County Board. Although the community involvement section addresses social activity participation, there is no discussion about intimate relationships or dating. Human sexuality services provided by CCBDD include social skills information and training. Consultation, assessments, and recommendations are available by referral from the service and support administrator. Human sexuality services can benefit planning team members like advocates, social service professionals, educators, other community stakeholders like medical professionals and law enforcement agents.

Most importantly, the individual and their family members/caregivers need services and supports that support and maximize the individual's ability to live, learn, work and play in the community (CCBDD, 2016). Human sexuality staff members employed by the CCBDD have at least ten years of social services experience with a wide variety of backgrounds including professional experience in adult residential services, working with adults in vocational training, and even those with challenging behaviors (CCBDD, 2016). However, participants included in this study agreed that referrals to human sexuality are mainly submitted for individuals with inappropriate sexual behaviors, not for someone looking for sexuality programming.

Developing a person-centered service plan that routinely includes conversations addressing the social-sexual needs of consumers receiving services is important.

Researchers have shown that collaborating as a team, ensuring the individual's health and safety while working towards wanted outcomes is the ultimate goal to successful planning (Callicott, 2003; Fanstone, 2010; Gardiner, 2009; Gougeon, 2009; Tavares & Gavidia-Payne, 2012; Trainor, 2007).

### **Participants**

Interviewees who are professionally knowledgeable, possess the first-hand experience, and whose combined views present a balanced perspective on a topic are considered appropriate candidates and can add credibility to research (Rubin & Rubin, 2012). Therefore, a purposive sampling of service and support administrators employed by the CCBDD was used for their expertise and not for generalization purposes (Houghton et al., 2013). There are 123 service and support administrators employed by the CCBDD (CCBDD, 2016). In Cuyahoga County, the primary responsibilities of service and support administrators include establishing an individual's eligibility to receive services from the CCBDD, individual service plan development, and the provision of services and supports that ensure the person's health and safety. The support administrator also facilitates the development of a self-directed, person-centered plan for individuals with disabilities that promote self-determination (CCBDD, 2016).

Support administrators develop and authorize personal budgets based upon the outcomes identified in a person's plan. They assist individuals and their families in exploring and obtaining services and supports while ensuring the health and safety of individuals through shared work with families, technical support staff and the community (CCBDD, 2016). They also promote community presence and participation in ways that



are age-appropriate and valued by society. Service and support administrators assist and collaborate with communities to develop the capacity to support individuals with developmental and physical disabilities, addressing issues of social barriers (CCBDD, 2016). The individual service plans, based on person-centered planning and developed by support administrators, are instrumental in breaking down barriers in an individual's environment that prevent the person from participating in what is considered 'normal' everyday activities enjoyed by their non-disabled peers. Service and support administrators revise plans as needed based on individual concerns by monitoring these concerns and completing quality assurance reviews. It is the responsibility of the support administrator to implement an ongoing system of monitoring, assisting individuals and families in identifying issues, concerns, and outcomes that are important to them. Service and support administrators ensure the delivery of supports according to each plan and the achievement of desired results. Support administrators coordinate further assessment of services as necessary and assist individuals in selecting providers of services (CCBDD, 2016).

Eight support administrators out of the 16 who responded were selected to participate in this research study. I selected every other response received for study participation until I acquired eight study participants. Criteria set forth for participation in this research study included the following: (a) employment with the CCBDD as a Service and Support Administrator for a minimum of 10 years, (b) currently have a consumer on their caseload that expressed a desire to develop intimate relationships, and (c) formal training in PCP or ELP techniques. Once selected, each participant received a written

explanation of the study, and each participant signed an informed consent form before the start of the interview session. Seven of the eight study participants were female, and one was male. Six of the participants had bachelor's degrees while two possessed a master's degree. The median years of service and support administration experience among the eight participants were 16.8 years. After the initial meeting, I assigned code names for each participant using colors with numbers starting at 00 with four-digit intervals, except for the first one (see Table 1).

Table 1

*Participants Demographic Information*

Participants	Code Name	Age/Sex	Ethnic Background	Educational Level	Years As SA
Participant 1	Grey 00	60/F	AA	BA	18.5
Participant 2	Red 02	48/F	AA	BA	15
Participant 3	Brown 06	45/F	AA	BA	15
Participant 4	Black 10	54/M	AA	BA	15
Participant 5	Silver 14	53/F	AA	BA	15
Participant 6	Purple 18	56/F	AA	BA	21
Participant 7	Yellow 22	47/F	AA	MBA	16.5
Participant 8	Pink 26	49/F	AA	MBA	14

*Note:* F-Female; M-Male; AA-African American; B.A.-Bachelor of Arts; MBA-Master Business Administration; SA-Service and Support Administrator

## **Data Collection**

The qualitative case study design permits the researcher to act as the primary data collection instrument (Merriam & Tisdell, 2016; Turner, 2010). Therefore, the researcher was responsible for all data collection. Data collected for this research study included:

### **Interviews**

I developed four, semi-structured, open-ended questions that participants were asked during the interviews (see Appendix B), and conducted face-to-face interviews to allow for in-depth answers, views, and opinions from the service and support administrators. All interviews were scheduled at the convenience of the participant and conducted during non-working hours. Interview meetings took place at the public library in Cuyahoga County, Ohio, in a meeting room that provided comfort and privacy. All interviews were digitally recorded, transcribed and reviewed to ensure credibility and for triangulation purposes. I took notes pertaining to the participant's answers and behavior while answering questions and notes on my reaction to interviewees for self-reflection.

### **Document Review**

To validate the need to discuss the social-sexual development of individuals served in Cuyahoga County, Ohio, I reviewed information received from The National Core Indicators 2013-2014 report, discussing consumer satisfaction with services and supports received by individuals with intellectual disabilities in Cuyahoga County, Ohio (Martin, 2014). The areas of home life, relationships and self-advocacy were reviewed to determine if there was a need to discuss social-sexual issues with individuals in

Cuyahoga County. Data from the survey showed that 57% of respondents felt home would be better if they had more privacy and autonomy. Forty-two percent of respondents felt lonely at least half of the time, while 46% of the respondents stated that having a romantic relationship would be nice. Only 1% of the respondents felt that they needed assistance with understanding relationships, and 34% indicated they would like to have more time with friends outside of work (Martin, 2014). This information showed that individuals receiving services want to incorporate sexuality and relationship development into the individual service planning tool utilized by the CCBDD.

### **Digital Recording and Document Review**

I digitally recorded and reviewed all interviews to ensure the accuracy of transcriptions. I reviewed documents and short videos associated with PCP techniques utilized by service and support administrators, and the format for the individual service plan document that develops from PCP, to determine where in the document dating and social-sexual activities were discussed. During the research period, CCBDD decided to update and revise the format of the individual service plan. Since a new individual plan is being investigated, I also examined the revised individual service plan. From the review, I could not identify an area of the individual service plan document that specifically addressed the social-sexual needs or desires of the individual receiving supports. However, the service and support administrator could approach this sensitive subject with the individual receiving services, within some of the other areas of the document, such as the home life or the community integration area.

## **Data Analysis Findings**

Open-ended interview questions provided extensive data that allowed for the possibility of more lengthy conversations if needed. Interviewees had the opportunity to discuss and clarify interpretations, as well as add new or additional thoughts. This approach allowed me to explore the experiences of service and support administrators involved in the study. I ensured accuracy, honesty, and transparency by accurately representing and transcribing participants answers to the research questions verbatim, with interviewees reviewing the final transcript for accuracy.

### **Interview Question 1**

All eight support administrators agreed that PCP is used in Cuyahoga County to promote social autonomy for individuals receiving services; however, the tool is not routinely used to discuss typical dating or sexual concerns like dating or appropriate relationship behavior. Two of the study participants admitted to not discussing sexual relationships with individuals during the planning process unless the consumer started the conversation. The two themes that were identified from data collected for Interview Question 1 was misconceptions and lack of empowerment. Yellow 22 stated

Unless a person brings up sex or dating, in the typical way I don't bring it up.

Cuyahoga County Board of Developmental Disabilities is a voluntary agency that provides supports based on person-centered planning, but the plan we use does not prompt me to discuss dating or intimate relationships, so we don't talk about it...I mean if a consumer or their family are not requesting specific services, like

sexuality training and the person-centered questions do not lead me down that path, what am I supposed to do? Where does that leave me if I am not comfortable discovering their relationship likes and dislikes?

Black 10 agreed with Yellow 22 stating, “if there is not a sexual behavior problem to address, I usually don’t talk about relationships, positive or negative ones.” Six out of eight interviewees felt there were no outlets, prompts, or guidelines during the planning process that specifically addressed the social and sexual needs of the individuals during the planning process. Gray 00 stated

Well, the tool really isn’t designed to address the sexual autonomy of individuals. The subject can be highlighted more in the template, to promote sexual autonomy by discussing their interest in participating in the community and developing intimate relationships, in whatever shape, form, or fashion that might be. There's maybe only one section I can think of called the “personal profile section” where you are asked to identify someone’s immediate circle, and that's where you could identify a boyfriend, girlfriend, spouse or what have you, but there's no specified area.

Six of the eight interviewees discussed the inability for individuals with intellectual disabilities to be seen as sexual beings or have sexual autonomy. Brown 06 stated

I don’t think our individual service plan based on person-centered planning addresses sexual autonomy, although consumers are told that they have a right to have a boyfriend or girlfriend relationship, relationships are not usually planned

for. Well, I guess the tool address that they have the that right, but I can't say people actually try to facilitate or to assist them with that and it may be because of some folks maybe not feeling comfortable with dealing with sexual activities because the individual is disabled.

Silver 14 stated:

There is nowhere in the tool where dating and relationships are discussed. I suppose I could be creative and find a section in the plan, but even in the section about community relationships, there's nothing in community relationship that says, "does this person have a significant other," or "does this person initiate any physical touch.

After I reviewed the individual service plan utilized by service and support administrators during the research study period, sections, where the social-sexual aspect of an individual's life could be inserted, appeared to be limited, and the service and support administrator would have to discuss social-sexual activities with the consumer to include the information in plan development.

**Misconceptions.** Most of the time, according to Silver 14, "there is no need to bring up issues about dating or sex unless the person is exhibiting behaviors, society does not see our consumers as naturally being sexual." Brown 06 stated, "...people have prejudices and misconceptions...they look at the person as a 'baby' or as a 'child,' who shouldn't be engaging in that type of activity, so the topic is not planned for."

Throughout the interview process the theme of societal misconceptions played a significant role in how services and supports occur. Two interviewees shared they did not discuss the subject unless the individual initiates the conversation. Pink 26 stated

The consumer may share they like someone or are interested, I try to work with them, however, people in their circle may be against relationships because they feel the person don't understand the emotions of dating and can make providing assistance to the individual difficult.

Black 10 felt, "the problem is our definition of a relationship, may be very different from what the person thinks a relationship is. Maybe everyone needs to work from the same relationship definition to squash misconceptions and falsehoods."

**Lack of empowerment.** Red 02 stated, "I can't say people actually try to facilitate or to assist consumers develop relationships. It may be because some folks may not feel comfortable with dealing with sexual activities, because of the individuals being disabled."

Another sentiment that echoed throughout the interviews concerned the belief that individuals with intellectual disabilities are not considered capable of making informed decisions about their sexual development. Purple 18 stated, "Most team members involved seem to think that due to the fact our individuals have intellectual disabilities, they should not make informed choices and decisions about their sexuality because they don't understand...can't understand."



## Interview Question 2

This question examined what techniques and tools are presently being used to support individuals to express themselves sexually. A lack of resources was a major theme that emerged from this question. Six of the eight study participants said they would make a referral to the human sexuality staff member for assistance. According to Gray 00

Little assistance is really given, I must admit unless you are having some major behavior difficulties, it's difficult to get assistance because they deal with 'high risk' individuals the human sexuality staff may talk about sexually transmitted diseases, and sexually explicit words, for understanding purposes I guess. She talks about the 'outside' experience of sex, not the intimacy part which is what a lot of our consumers are looking for and need. Once I know you are your own guardian, what we do next is all up to you. You (the individual) make your decision, and I as your Support Administrator will assist you achieve your goal. That's person-centered planning. Me empowering you and accepting decisions have consequences, good or bad. Red 02 concurred stating

They are just like us, they are not just looking for that overall sexual gratification, they are looking for the intimacy too. Consumers I have worked with have been higher functioning and find a way to meet their sexual needs without much help from me, and this is because they have freedom in the community and can often advocate for themselves and for what they want. When this occurs, I have that

open and realistic conversation I would have with a peer or that I would have with a friend, because I want them to have a healthy sexual experience.

While Black 10 professed, “The thing that is addressed with the County’s sexuality staff mostly is inappropriate sexual behavior. Not normal sexual exploration, mostly inappropriate behavior.” Nothing is readily available for those that just want to have a healthy relationship. I have talked with co-workers about situations to see if they knew of any supports. Brown 06 stated, “I would also look for maybe some support group that provide sex education and see if they would be willing to include our guys in their classes.” Pink 26 stated

I don’t normally talk about sex or dating unless it comes up, however, I worked with an individual that said they wanted to have a girlfriend, but the more we talked about what having a girlfriend meant, I quickly realized him having a girlfriend had some underlying sexual feelings and emotions that required our sexuality staff assistance. In that case, my first step in providing assistance to this young man was getting human sexuality involved.

Both Purple 18 and Silver 14 felt they would look to the community first. Purple 18 stated, “I wouldn’t even really turn to that person (human sexuality staff), for someone who just wanted some basic information. I do not think the human sexuality staff offers basic dating and sex education.” Silver 14 stated

CCBDDs human sexuality department does not offer basic sexuality training to our individuals, not as far as I know. So, I would not make a referral to that department first unless the need was for assistance with inappropriate sexual

behavior. Depending on what the person wants I would check with the support team and try to assist the person the best I can if that means arranging transportation or assist with purchasing tickets for a movie as long as the team is onboard.

**Lack of resources.** Grey 00 stated,

Once the conversation about dating or having intimate relationships is had, what's next? Where do we send our consumers to get assistance with developing intimate relationships? What agency has those type of special classes or education available specifically for individuals we serve?"

Yellow 22 declared, "the human sexuality staff could be more helpful by maybe offering monthly classes...or have a few peer support groups to offer individuals."

### **Interview Question 3**

This question was important because according to previous researchers, parental, professional, and social attitude towards sex, and the disabled, effect and influences the learning of new life skills, as well as the development of sexual behavior (Brown & Pirtle, 2008; Gardiner & Braddon, 2009; North Carolina Council on Developmental Disabilities, 2012). The theme identified here was lack of autonomy for individuals receiving service in Cuyahoga County. Purple 18 stated

We're all created as sexual beings and regardless of your intellectual disability, everyone has a desire to be loved and to be touched. I believe people are born sexual beings, but I am not totally comfortable bringing the subject up with our

population, if they or their guardians want to talk about finding services, of course we would talk, but there are so many things that must to be considered when dealing with our population and intimate relationships. I don't want to be responsible if something is overlooked or goes wrong. Yellow 22 stated: Sexuality and individuals with intellectual disabilities is a very touchy subject. I am not even sure what the Board's position is on individuals developing as sexual beings. I personally don't believe in sex before marriage (for anybody), then you throw having a disability into the mix, I am not sure. I worry about our individuals being taken advantage of, I worry about them emotionally and I worry they may put themselves in abusive relationships, but I feel this way about my children. I will plan accordingly, but personally, I am still on the fence.

Silver 14 stated, "I believe everyone is born sexual beings. Now how that emotion comes across is different around the world, and from person to person. Being born a sexual being means you have rights and responsibilities that go along with being inappropriate relationships." Red 02 stated, "If a person is able to express their desire to date or get married or have a baby, and they can do so safely, why not?" Brown 06 shared I had an eye-opening moment while she was talking with one of her consumers. A consumer asked me one day, "don't you have a husband?" and I had to say yes, and so she wanted to know this because she wants a boyfriend, maybe a husband if she loves him and he is nice. So, that right there made me take a step back and say, you know what? She is just as human as I am you know? She wants to have

that relationship for whatever it means to her. I have another individual who also talked to me about getting married and I don't know if he wanted to actually get married, or if it's the concept he sees, you know? You see a husband and wife, you see a relationship. These two individuals are high functioning enough to express their needs and seeking relationships.

Pink 26 stated:

With higher functioning consumers, I have no problem talking about relationships, and when I know they are interested in dating or meeting people, I try to find out the type of activities they like and help them plan appropriate dates. I just put the information under the narrative tab in the service plan.

**Autonomy.** Providing sexual education to individuals with intellectual disabilities is vital to ensuring that these individuals have the knowledge and capacity to make informed decisions about their sexuality (Danaher, 2013; Finlay, Rohleder, Taylor, & Culfear, 2015). Red 02 stated, "Higher functioning individuals who are able to access the community unsupervised, can advocate for themselves because they have more opportunity to exercise their right to experience intimacy and self-gratification because they have greater expression and social experiences."

#### **Interview Question 4**

This question provided information directly from the service providers regarding obstacles to planning. This question yielded two themes, societal misconceptions, and consent and capacity. Red 02 stated

I think that's a big barrier, other people's prejudices, or other people thinking what they feel is appropriate. You know, like I said some folks look at people with disabilities and they don't see this person as a person... they see this person as Charlie with autism, or they see that person as Charlie with down syndrome, so they don't see Charlie, the young man with sexual needs. Yellow 22 stated I would say the biggest barrier to us planning and having those types of plans to address people's human sexuality and autonomy would be the guardian at large. I have worked with individuals who are clearly interested in sexual activities. The individual expressed this to their guardian, however the guardian was against it. At that point, there was nothing else I could do.

Black 10 stated, "Typically, a lot of guardians don't feel like they shouldn't be able to date and have intimate relationships because everyone worries about procreation."

In agreement, Brown 06 shared

Guardians cause barriers because guardians tend to want to act like sex and dating is something their children shouldn't be doing. I talk directly with the individual, their family, guardian, support group or whoever they have in their life about dating. Especially if I know the person is curious. I do this to gauge how everybody is feeling. These are grown people who do grown people things you know? So, having the 'talk' is necessary, uncomfortable sometimes, but necessary.

When discussing consent and capacity of the individual receiving service, Red 02 stated

I think we need to meet them on the road where they are, because those who are their own guardian and able to say or able to express what they what, no matter what the expression is has the right to speak up. I had a person who was non-verbal and just wanted to go sit next to another person, and that was their relationship, so, I think you have to meet them where they are.

**Society.** The refusal of guardians or family members to acknowledge the social, sexual needs of individuals with intellectual disabilities can be a barrier. This denial or refusal to support the individual with choices can be very frustrating, according to service and support administrators interviewed for this research, when they are trying to provide social and sexual services while keeping individuals healthy and safe. According to Brodwin and Frederick (2010), attitudes and beliefs of society regarding the development of meaningful romantic relationships, among individuals with intellectual disabilities, affects how individuals with intellectual disabilities view themselves as sexual beings.

**Consent and capacity.** Capacity and competence are used interchangeably because both terms refer to a person's ability, and for this research, having the capacity to give informed consent to explore sexuality services and supports is important in achieving goals if there is opposition to the plan. Persons with developmental disabilities have their capacity to consent questioned more than most groups (Brown & Brown, 2009). Sexual consent capacity cannot be established as a generic capability (Lyden, 2007). According to Dukes and McGuire (2009), an individual may have limitations giving consent in one area of their lives and yet exhibit the ability to give consent to other areas of their lives. Providing information to individuals with intellectual disabilities is

important to ensure these individuals have the knowledge, information, and the capacity to make informed decisions about sexual activities. Once an individual receives sufficient training, education, counseling, and opportunity to socialize, individuals can gain experience and knowledge in which to base future decisions.

### **Summary**

All eight research participants agreed that PCP is a useful tool when gathering information about a person. However, they also agreed that individual service plan derived from the person-centered interview is not designed to address the sexual needs of individuals receiving services. The PCP technique is a tool that allows for discussion about social-sexual activities in the individual life by asking specific questions.

To gain knowledge or insight into the desires of the individual, discussions during the planning phase can include questions about who is important to the individual. What type of community social activities do they participate in (or would like to participate in)? These types of discussions only occur if the individual or the service and support administrator approach the topic. There is no specific section of the individual service plan, currently utilized by support administrators in Cuyahoga County, which organically prompt discussions about social-sexual issues. Misconceptions and social prejudices towards sexuality and individuals with intellectual disabilities, lack of resources, autonomy, consent, and capacity are topics identified by the eight study participants and emerged as themes from data collected during interview sessions.

Ultimately, each participant acknowledged the usefulness of the person-centered techniques in gaining information about an individual. However, the individual service



plan developed by services and support administrators, based on information gathered during the person-centered planning phase of plan development, does not have a specific section that addresses social-sexual activities. In chapter 5, there is a discussion about the interpretation and findings of this research study, limitations, the implication for social change, and recommendations for additional research.

## Chapter 5: Interpretations and Recommendations

### **Study Purpose and Methodology**

In this study I examined the perceptions and experiences of service and support administrators in Cuyahoga County regarding their use of the person-centered approach when developing individual service plans to address the social-sexual needs of individuals with intellectual disabilities. Person-centered techniques and individual service plans are useful tools that can empower and promote sexual autonomy for individuals with intellectual disabilities (Joseph & Murphy, 2013; Martin & Ouellette-Kuntz, 2014). A qualitative descriptive exploratory case study was conducted. This research approach was used to explore support administrator experiences. The use of a descriptive case study allowed for the exploration of person-centered individual service planning as a phenomenon in the real-life context, to address the social-sexual needs of individuals with intellectual disabilities (Yin, 2012).

### **Summary of the Findings**

The person-centered individual service plan is a tool that can empower and promote social-sexual autonomy for individuals with intellectual disabilities. Four interview questions related to the experiences and perceptions of service and support administrators employed by the CCBDD regarding their use of the person-centered approach to developing individual service plans for individuals with intellectual disabilities guided this research study. Individuals with intellectual disabilities have frequently been marginalized, oppressed and left out of discussions of sexuality. Researchers have shown when others acknowledge people with disabilities have the

capacity for choice and have sexual rights; they convey a sense of mutual respect (Friedman, Arnold, Owen, & Sandman, 2014). To examine how service and support administrators in Cuyahoga County, Ohio, assist individuals with intellectual disabilities, regarding services and supports needed to meet their social-sexual needs, service and support administrators were asked specific questions during the interviews that pertained to the phenomenon studied (see Appendix B).

The four interview questions from this research study yielded six themes:

1. **Misconceptions:** Five of the eight interviewees stated in one way or another that misconceptions about individuals with intellectual disabilities and their sexuality hinder their ability to plan appropriately.

2. **Lack of Empowerment:** All eight of the service and support administrators' interviewees communicated that there was no real discussion about planning for the sexual needs of the individuals on their caseloads using person-centered planning to develop individual service plans.

3. **Resources:** Six of the eight interviewees felt there was very little they could directly do to assist individuals receiving services because they felt sexuality type services did not exist for the population they serve.

4. **Autonomy:** All eight service and support administrators interviewed felt it was a person's right to live, and love regardless of the individual's disability, however, there is lack of opportunity for consumers to exercise sexual autonomy. None of the participants felt they are encouraged to empower individuals to express themselves as sexual beings during the planning process.

5. Society: Six out of eight of the service and support administrators agreed that the barriers to assisting individuals with intellectual disabilities in sexually expressing themselves included misconceptions of society, believing these individuals are not able to develop intimate relationships or are even sexually curious. The refusal of society to accept and support individuals with intellectual disabilities as they become sexual beings is a barrier to safe and appropriate social-sexual planning.

6. Consent and Capacity: All eight service and support administrators agreed individuals with intellectual disabilities they have assisted are not typically viewed as sexual beings with sexual feelings. Therefore, planning for typical adult social-sexual activities is never addressed. Even if the individual has the ability to give consent, there is still many legal and moral concerns related to safeguards for those individuals in a protected-populations.

The consensus among participants was that PCP is a great tool to gain knowledge about a person that spans across various domains of their lives. Intimate relationships and dating are not areas currently addressed when developing individual service plans. Pownall et al. (2012) found that the lack of planned social interaction makes individuals with disabilities ashamed or embarrassed about their romantic feelings. Service and support administrators in Cuyahoga County, Ohio, act as the single point of contact for all assessments and referrals made within the county and are primarily responsible for the development of individual service plans.

During the interview process, there appeared to be a common opinion among the interviewees, that person-centered planning could be a useful tool when assisting

individuals with intellectual disabilities plan for their future sexual development. The individual service plan currently being utilized in Cuyahoga County does not have a section in the document that specifically addresses the social-sexual development of the individual. The topic of sexuality could occur when developing the individual service plan, at the discretion of the service and support administrator working with the individual. There is no mandate to discuss any area of sexuality with individuals or family members. Therefore, the topic is usually omitted, unless there are issues of inappropriate sexual behavior or sexual concerns, per interviewees.

### **Limitations of the Study**

There are three apparent limitations to this study: location, sampling technique, and sample size. Purposive sampling and documents reviewed for this study were limited to service and support administrators employed by the CCBDD, and current PCP techniques and individual service plans specifically utilized by this agency. Expectations for employment and documents develop from person-centered planning may differ in different counties, affecting the outcome of future studies. The geographical location is considered a limitation, because of the lack of transferability. Meaning future research in another location may render different results. The sampling method and size were selected because the researcher wanted to gain a better understanding of how to use person-centered techniques to develop individual service plans in Cuyahoga County. Service and support administrators are primarily responsible for all service plan development in Cuyahoga County. Therefore, research was specific to this employment

position. This group of professionals also had the best information about the usage of the person-centered tool within the organization.

This qualitative research study focused on the experience of service and support administrators using person-centered techniques to develop individual service plans that identify and address the social-sexual desires of individuals with intellectual disabilities. The decision to limit participation to eight participants allowed for a more in-depth look at the experience and perceptions of staff using the tool.

### **Implications for Social Change**

The routine omission of discussions surrounding the social-sexual activities of individuals with intellectual disabilities continues to be a barrier to planning according to participants. Some human service professionals, educators, family members, and advocates have misconceptions about a person's interest or ability to develop and maintain an intimate relationship. Attitudes and beliefs of society regarding the development of meaningful romantic relationships among individuals with intellectual disabilities affect how the individuals view themselves as sexual beings (Brodwin & Frederick, 2010; Keshav & Huberman, 2006), but developmental, structural, and environmental barriers circumvent the desires of sexuality for individuals with intellectual disabilities (Olen-Kramers, 2017). Previous researchers indicated that parental, professional, and social attitude towards sex and the disabled, effect and influence the learning of new life skills, as well as, the development of sexual behavior (Brown & Pirtle, 2008; Gardiner & Braddon, 2009; North Carolina Council on Developmental Disabilities, 2012).

This study showed service and support administrators felt social misconceptions prevent routine discussions concerning individuals with intellectual disabilities and social-sexual activities like dating or sexual interest during the person-centered discovery portion of plan development in Cuyahoga County. Social misconceptions may also explain why there is no specific area in the individual service plan that addresses intimate relationships. Findings indicated that there are limited opportunities to discuss an individual's intimate relationship issues during plan development. Sexual expression among people with intellectual disabilities creates challenges on the individual and policy levels for many service providers. A person's capacity may be questioned to ensure the individual is making informed decisions. It is important for any agency and plan writer to determine an individual's ability to make informed decisions and give consent, whether it refers to medical care, sex, marriage, or even a rental agreement.

According to Danaher (2013), sexual autonomy is the right and capacity of individuals to decide and makes choices about with whom, when, and how they express themselves sexually, regardless to a person's ability. Capacity is not static. Per Dukes & McGuire (2009), capacity to complete a task or learn a new skill can increase or decrease throughout a person's lifetime, depending on the person, supports received, the disability and many other factors. Capacity occurs on a continuum and varies over time (Hillman, 2017; Lyden, 2007). Researchers have shown that it is important professionals, caregivers, and family members to assist individuals with intellectual disabilities and support their desire to develop sexually (Esmail, Darry, Walter, & Knupp, 2010). Helping individuals with intellectual disabilities advocate for themselves and their sexual

exploration plays an important role in determining program availability and how the human sexuality curriculum is discussed from childhood through the transition into adulthood (Esmail et al., 2010). Although research into sexuality and individuals with disabilities has increased over the past few decades, the topic remains highly sensitive and frequently neglected in disability services.

A collaborative approach to promoting sexual autonomy for individuals with intellectual disabilities utilizing person-centered planning may provide human service professionals, caregivers, and family members insight into how they feel, as well as, what is important for a successful plan outcome regarding sexual and relationship development. Support administrators can educate family members, educators, and community agencies about sexual development and individuals with intellectual disabilities. Support administrators can debunk myths, fears, or stereotypes that society has about the sexual development of this vulnerable population. Researchers have shown that with PCP techniques, a circle of support, and appropriate services, it is possible for individuals with intellectual disabilities to have successful, fulfilled lives (Brodwin, 2010; Gilmore & Brooke, 2010; McGuire & Bayley, 2011).

Depending on the personal beliefs or bias of the service and support administrator, they can become better advocates of sexuality services for individuals receiving services from the CCBDD. Ways to assist service and support administrators become better advocates include basic training on interviewing techniques when discussing sexuality issues with individuals with intellectual disabilities. Acquiring interview skills could assist staff when having difficult conversations about sexuality



with their clients. The CCBDD could provide in-house professional development or allow time off from normal duties to attend training that specifically addresses human sexuality and individuals with intellectual disabilities concerns. Advocacy may include services surrounding abstinence education to services regarding family planning. Agencies should create mission statements and policy that provide for a commitment to empower the individual and support their choices while keeping them healthy and safe. Increasing supports while providing an opportunity to make informed choices can increase the social-sexual autonomy for an individual with intellectual disabilities.

### **Recommendations for Further Study**

According to Gregory (2015), social perceptions, legal concerns surrounding informed consent, ethical, and moral considerations maybe reasons sexuality for individuals with intellectual disabilities need to be explored further. Existing literature suggested that the person-centered technique is useful and could increase sexual autonomy for individuals with intellectual disabilities (Travers et al., 2014). However, Travers et al. (2014) also acknowledged additional research is needed into sexuality and individuals with intellectual disabilities that focuses on legal, ethical and moral considerations agencies and social service organizations may face.

The demand for needed services drives the supply of such services. Therefore, additional research into PCP as a tool that specifically addresses the social-sexual supports required to assist individuals with intellectual disabilities in developing and maintaining intimate relationships should continue. Research should include sex education programming, prevention, and sexuality support services. This study has

shown that whether or not sexuality or developing intimate relationships are discussed during the person-centered planning process, the discussion is at the discretion of support administrators. There are no agency mandates within the CCBDD, or mandated assessments conducted by its service and support administrators, which specifically address the sexuality of individuals with intellectual disabilities other than where it concerns inappropriate behavior. Once agencies know their limitations and responsibilities as social service providers, sexuality and relationship development can become a standard requirement of the person-centered plan. Under legal research, future research conducted should focus on issues surrounding the individual's ability to give consent or assent.

The establishment of clear legal/ethical standards and guidelines may allow social service organizations the ability to provide additional support for the social-sexual development of individuals with intellectual disabilities. Finally, individuals with intellectual disabilities are but one group of individuals living with a disability who could benefit from routine human sexuality training, planning, and supports. Future research should be conducted to assess how utilizing PCP techniques could benefit individuals on the autism disorder spectrum, individuals with physical disabilities, and individuals that have social anxiety issues, regarding their sexual development and autonomy.

### **Conclusion**

This qualitative research study was designed to explore the perceptions and experiences of service and support administrators in Cuyahoga County regarding their use of the person-centered approach when developing individual service plans for

individuals receiving services. Participants' did not oppose discussing intimate relationships or maintaining intimate relationships as part of the planning process for individuals with intellectual disabilities. In each interview, the interviewees shared that there was no explicit area in the individual service plan that specifically discussed intimate relationships. Discussions about intimate relationships are at the discretion of the support administrator and may not occur organically.

Three of the interviewees shared how discussions regarding significant others in their client's life have taken place on several occasions. Information gathered during the PCP process about significant others is placed into the individual service plan as a narrative. Usually, there are no identifiable outcomes or goals associated with this information to plan around. The significant others information is just information contained in the plan, and that information is only gathered if the service and support administrator explore intimate relationships the individual.

This research explored the perceptions and experiences of eight service and support administrators who utilize person-centered techniques to develop individual service plans that specifically address the social-sexual needs of individuals with intellectual disabilities. Themes of social misconceptions, lack of resources, and issues of consent were identified in this study. Participants' believed that person-centered techniques were most useful in gaining information about individuals receiving services. However, the individual service plan currently being used is not designed to address the sexual needs of individuals with intellectual disabilities. Exploring the area of sexuality during the planning process is not mandated by the CCBDD, and is therefore up to the

individual, family, or guardian to broach the subject. Otherwise, it left to the discretion of the support administrator planning with the individual to start the conversation.

Through the interview and review of the data process, I recognized the issue of empowering individuals with intellectual disabilities in becoming sexually autonomous is not with the unwillingness of staff to discuss sexual topics. It seems that since there is no mandate or emphasis placed on discussing intimate relationships, service and support administrators may or may not introduce the subject with individuals. Researchers have shown that individualized planning can be used as a tool to impact transitions positively when discussing realistic expectations (Kaehne & Beyer, 2014; Travers et al., 2014). Travers et al. (2014) showed in their research how specializing services could increase sexual autonomy for individuals with intellectual disabilities while supporting sexual development, but also recognized more research was needed to develop policies and individualized plans for sexual development. For future studies, it may be helpful to insert a section about intimate relationships in plan development. Adding this section may compel support administrators to discuss things like meeting people, socializing, dating, sexual activities, marriage, and parenthood. Information gained would dictate if the individual requires additional services and supports to participate in a social or sexual activity safely. If services and supports are mandated, the support administrator and planning team members could assist their disabled clients with planning for a successful outcome.

## References

- Adnanes, M., Ose., & Kalseth. (2015). Individual plan-helpful or not for mental health service users? *International Journal of Integrated Care*, 15, 1-2.  
doi:10.5334/ijic.2034
- Advocates for Youth. (2016). Retrieved from: <http://advocatesforyouth.org>.
- Amado, A., Stancliffe, R. L., McCarron, M., & McCallion, P. (2013). Social inclusion and community participation of individuals with intellectual/developmental disabilities *Intellectual and Developmental Disabilities*, 51(5), 360-375.  
doi:10.1352/1934-9556-51.5.360
- American Association on Intellectual and Developmental Disabilities. (2016). *Sexuality*. Retrieved from <https://aaidd.org/news-policy/policy/position-statements/sexuality>
- Anastas, J. W. (1999). *Research design for social workers and the human services*. New York, NY: Columbia University Press. Retrieved from <https://questia.com/library/journal/1G1-252289585/a-social-constructionist-approach-to-disability-implications>
- Anastasiou, D., & Kauffman, J. (2011). A social constructionist approach to disability: Implications for special education. *Exceptional Children*, 77, 367-384.
- Barclay, L. (2011). Justice and Disability: What kind of theorizing is needed? *Journal of Social Philosophy*, 42(3), 273-287. Retrieved from <https://doi.org/10.1111/j.1467-9833.2011.01533.x>
- Barnes, C. (2012). The Social Model of Disability: Valuable or irrelevant? In N

- Watson, A. Roulstone, & C. Thomas, *Routledge Handbook of Disability Studies*, 12-29. London, England: Routledge
- Baxter, P., & Jack, S. (2008). Qualitative cases study methodology: Study design and implementation for novice researchers. *Qualitative Report*, 13(4),544-559.  
Retrieved from <https://doi.org/10.1111/j.1467-9833.2011.01533.x>
- Bernert, D. J., (2011). Sexuality and disability in the lives of women with intellectual disabilities. *Sexual Disability*, 29(2), 129-141. doi: 10.1007/s11195-010-9190-4
- Bernert, D. J., & Ogletree, R. J. (2003). Women with intellectual disabilities talk about their perception of sex. *Journal of Intellectual Disability Research*, 57(3), 240-249. doi.org/10.1111/j.1365-2788.2011. 01529.x
- Braddon, E. & Gardiner, T. (2009). A right to know. Facilitating a relationship and sexuality programme for adults with intellectual disabilities in Donegal. *British Journal of Learning Disabilities*, 37(4), 327-329. doi.org/10.1111/j.1468-3156.2009. 00591.x
- Brault, M. (2012). *Current population reports*. United State Census Bureau. Retrieved from <https://doi.org/10.1111/j.1468-3156.2009.00591.x>
- Brodwin, M. G., & Frederick, P. C. (2010). Sexuality and Social beliefs regarding persons living with disabilities. *Journal of Rehabilitation*, 76(4), 37. Retrieved from <https://www.questia.com/library/journal/1G1-240913502/sexuality-and-societal-beliefs-regarding-persons-living>
- Bronfenbrenner, U. (1979). *The ecology of human development: Experiments by nature and design*. Cambridge, MA: Harvard University Press.

- Brown, I., & Brown, R. (2009). Choice as an aspect of quality of life for people with intellectual disabilities. *Journal of Policy and Practice in Intellectual Disabilities*, 11-18. doi.org/10.1111/j.1741-1130.2008.00198.x
- Brown, R., & Pirtle, T. (2008). Beliefs of professional and family caregivers about the sexuality of individuals with intellectual disabilities: Examining beliefs using a Q-methodology approach. *Sex Education*, 8(1), 59-75. doi: 10.1080/14681810701811829
- Buntinx, W. H., & Schalock, R. (2010). Models of disability, quality of life, and individualized supports: Implications for professional practice in intellectual disability. *Journal of Policy and Practice in Intellectual Disabilities*, 7(4), 283-94. Retrieved from [http://www.buntinx.org/yahoo\\_site\\_admin/assets/docs/Models\\_of\\_Disability\\_-\\_Buntinx\\_\\_Schalock\\_2010\\_JPPID.144132950.pdf](http://www.buntinx.org/yahoo_site_admin/assets/docs/Models_of_Disability_-_Buntinx__Schalock_2010_JPPID.144132950.pdf)
- Callicott, K. J. (2003). Culturally sensitive collaboration within person-centered planning: *Autism and Other Developmental Disabilities*, 18, 60-68. Retrieved from <http://www.worksupport.com/documents/culturallySensative.pdf>
- Cleary, M., Horsfall, J., & Hayter, M. (2014). Data collection and sampling in qualitative research: Does size matter? *Journal of Advanced Nursing*, 70(3), 473-475. doi.org/10.1111/jan.12163
- Connelly, L. M. (2016). Understanding research: Trustworthiness in qualitative research. *MEDSURG Nursing*, 25(6), 435-436. Retrieved from <http://www.medsurnursing.net/archives/16nov/435.pdf>

- Convention on The Rights of Persons with Disabilities. (2006). Retrieved from Division for Social Policy and Developmental Disabilities. Retrieved from [www.un.org/disabilities/convention](http://www.un.org/disabilities/convention).
- Cooper, H. M. (1984). *The integrative research review: A systematic approach*. Beverly Hills, CA: Sage.
- Cuskelly, M., & Gilmore, L. (2007). Attitudes to sexuality questionnaire Individuals with an intellectual disability: Scale development and community norms. *Journal of Intellectual & Disability*, 32(3), 214-221.  
[doi.org/10.1080/13668250701549450](https://doi.org/10.1080/13668250701549450)
- Cuskelly, M., & Bryde, R. (2004). Attitudes towards the sexuality of adults with an intellectual disability: Parents support staff, and a community sample. *Journal of Intellectual & Developmental Disability*, 29(3), 255-264. Retrieved from <https://doi.org/10.1080/13668250412331285136>
- Cuyahoga County Board of Developmental Disabilities. (2016). Retrieved from <http://www.cuyahogabdd.org/aboutus.asp>.
- Danaher, J. (2013). *Philosophical Disquisitions*. Retrieved from Philosophical Disquisitions: <http://www.philosophicaldisquisitions.blogspot.com/2013>.
- Department of Developmental Disabilities. (2016, July). Retrieved from [www.dodd.ohio.gov](http://www.dodd.ohio.gov).
- Devi, N. (2013). Supported decision-making and personal autonomy for persons with intellectual disabilities: Article 12 of the UN convention on the rights of persons with disabilities. *Journal of Law, Medicine & Ethics*, 41(4), 792-806.



doi.org/10.1111/jlme.12090

- Di Giulio, G. (2003). Sexuality and people living with physical or developmental disabilities: A review of key issues. *Canadian Journal of Human Sexuality*, 12(1), 53-68. Retrieved from <https://www.thefreelibrary.com/Sexuality+and+people+living+with+physical+or+developmental...-a0112167281>
- Disability Action in Islington. Retrieved from Social Model of Disability, [http://www.dali.org/about/social\\_of\\_disability](http://www.dali.org/about/social_of_disability)
- Division for social policy and developmental disabilities. (2016). *Convention on the Rights of Persons with Disabilities: Preamble*. Retrieved from [www.http://un.org/disabilities/convention](http://www.un.org/disabilities/convention).
- Doyle, J. (2008). Improving sexual health education for young people with learning disabilities, *Pediatric Nursing*, 20(4), 26-29. doi:10.7748/2008.05.20.4.26.CB251.
- Dukes, E., & McGuire, B. E. (2009). Enhancing capacity to make sexually related decisions in people with intellectual disabilities. *Journal of Intellectual Disability Research*, 53(8), 727-734. doi:10.1111/j1365-2788.2009.01186x.
- Dworkin, S. (2012). Sample size policy for qualitative studies using in-depth interviews. *Archives of Sexual Behavior*, 41(6), 1319-1320. doi.org/10.1007/s10508-012-0016-6
- Eastgate, G. (2011). Sex and intellectual disability. Dealing with sexual health issues. *Australian Family Physician*, 40(4), 188-191. Retrieved from

<https://www.ncbi.nlm.nih.gov/pubmed/21597526>

Esmail, S., Darry, K., Walter A., & Knupp, H. (2010). Attitudes and perceptions towards disability and sexuality. *Disability and Rehabilitation*, 32(14), 1148-1155.

[doi.org/10.3109/09638280903419277](https://doi.org/10.3109/09638280903419277)

Fantone, C. (2010). *People with learning disabilities, sex, and the law*. Brighton, United Kingdom: Pavilion Publishing.

Finlay, W. M., Bohleder, P., Taylor, N., & Culfear, H. (2015). Understanding as a practical issue in sexual health education for people with intellectual disabilities: A study using two qualitative methods. *Health Psychology*, 34(4), 328-338.

[doi:10.1037/hea0000128](https://doi.org/10.1037/hea0000128)

Flyvbjerg, B. (2006). Five misunderstandings about case-study research. *Qualitative Inquiry*, 12(2), 219-245. [doi.org/10.1177/1077800405284363](https://doi.org/10.1177/1077800405284363)

Forest, M., Pearpoint, J., & Snow, J. (1992). *MAPS: Action planning*. In *The inclusion papers: Strategies to make inclusion work*. Toronto: Inclusion Press, 52-56.

Franco, D. G., Cardoso, J., & Neto, I. (2012). Attitudes towards affectivity and sexuality of people with intellectual disability. *Sex disability*, 30(3), 261-287.

[doi.org/10.1007/s11195-012-9260-x](https://doi.org/10.1007/s11195-012-9260-x)

Futcher, S. (2011). Attitudes to sexuality of patients with learning disabilities: A review. *British Journal of Nursing*, 20(1), 8-14. Retrieved from

<https://www.ncbi.nlm.nih.gov/pubmed/21240133>.

Gardiner, T, & Braddon, E. (2009). A right to know: Facilitating a relationship and sexual

- programme for adults with intellectual disabilities in Donegal. *British Journal of Learning Disabilities*, 37, 327-329. doi.org/10.1111/j.1468-3156.2009.00591.x
- George, A. L. & Bennett, A. (2005). Case studies and theory development in the social sciences. Cambridge: MT Press.
- Gerowitz, A. (2007). *Social support systems for quality service delivery: A historical view*. In L. Walker-Hirsch, *The facts of life...and more: Sexuality and intimacy for people with intellectual disabilities*. Baltimore, MD: Paul H. Brookes.
- Gilmore, L., & Brooke, C. (2010). Intellectual disabilities and sexuality: Attitudes of disability support staff & leisure industry employees. *Journal of Intellectual and Developmental Disability*, 35(1), 22-28.  
doi: 10.3109/13668250903496344
- Glicksman, S, Goldberg, C., Hamel, C., Shore, R., Wein, A., Wood, D & Zummo, J. (2017). Rights-based and person-centered approach to supporting people with intellectual disability: A dialectical model. *Intellectual Developmental Disability*, 55(3) 181-191. doi: 10.1352/1934-9556-55.3 181.
- Gomez, M. T. (2012). The S words: Sexuality, sensuality, sexual expression and people with intellectual disability. *Sex and Disability*, 30(2) 237-245.  
doi:10.1007/s11195-011-9250-.
- Gougeon, N. (2009). Sexuality education for students with intellectual disabilities, a critical pedagogical approach: Outing the ignored curriculum. *Sex Education*, 9(3), 277-291. https://doi.org/10.1080/14681810903059094

- Graneheim, U.H., & Lundman, B. (2004). Qualitative content analysis in nursing research: Concepts, procedures, and measures to achieve trustworthiness. *Nurse Education Today*, 24(2), 105-112. doi: 10.1016/j.nedt.2003.10.001
- Gregory, M. (2015, Feb). There's no need to laugh. Isn't this a normal subject? People with learning disabilities talking about sex and relationships. *The Learning Disabilities Elf*, retrieved from:  
<http://www.thelearningdisabilitieself.net/?s=sexuality>.
- Grieve, A., McLaren, S., & Lindsay, W. R. (2007). An evaluation of research and training resources for the sex education of people with moderate to severe learning disabilities. *British Journal of Learning Disabilities*, 35(1), 30-37. doi.org/10.1111/j.1468-3156.2006.00401.x
- Hatch, J. A. (2002). *Doing qualitative research in education settings*. Ithaca, NY: State University of New York Press.
- Hayshi, M., Arakids, M., & Ohashi, K. (2011). The effectiveness of a sex education program facilitating social skills for people with intellectual disability in Japan. *Journal of Intellectual and Developmental Disability*, 36(1), 11-19. doi: 10.3109/13668250.2010.549463
- Healy, E., McGuire B. E., Evans, D. S., & Carley, S. N. (2009). Sexuality and personal relationships for people with an intellectual disability. Part 1: Service-user perspectives. *Journal of intellectual Disability Research*, 905-912. doi: 10.1111/j.1365-2788.2009.01203.x

- Hillman, J. (2017). Sexual consent capacity: Ethical issues and challenges in long-term care. *Clinical Gerontologist*, 40(1), 43-50. doi: 10.1111/j.1365-2788.2009.01203.x
- Houghton, C., Casey, D., Shaw, D., & Murphy, K. (2013). Rigour in qualitative case-study research. *Nurse Researcher*, 20(4), 12-17. Retrieved from: <http://journals.lww.com/nursingresearchonline/pages/default.aspx>.
- Hussein, A. (2015). The use of triangulation in social sciences research: Can qualitative and quantitative methods be combined? *Journal of Comparative Social Work*, 4. Retrieved from <http://journal.uia.no/index.php/JCSW/article/view/212/147>.
- Individuals with Disabilities Education Act (2016). About *IDEA*. Retrieved from <https://sites.ed.gov/idea/about-idea/>.
- Jahoda & Pownall. (2013). Sexual understanding, sources of information and social work: The reports of young people with intellectual disabilities and their non-disabled peers. *Journal of Intellectual Disability Research*, 58(5), 430-441. doi.org/10.1111/jir.12040
- Joseph, S., & Murphy, D. (2013). Person-centered approach, positive psychology, and relational helping builds bridges. *Journal of Humanistic Psychology*, 53(1), 26-51. doi.org/10.1177/0022167812436426
- Kaehne, A., & Beyer, S. (2014, July). Person-centered reviews as a mechanism for planning the post-school transition of young people with intellectual disability. *Journal of Intellectual Disability Research*, 58(7), 603-613. doi.org/10.1111/jir.12058

- Kaiser, K. (2009). Protecting respondent confidentiality in qualitative research. *Qualitative Health Research*, 19(11), 1632-1641.  
doi.org/10.1177/1049732309350879
- Keshav, D., & Huberman, B. (2006, Apr). *Sex education for physically, emotionally, and mentally challenged youth*. Retrieved from  
<http://www.advocatesforyouth.org/storage/advfy/documents/challengedyouth.pdf>.
- Kijak, R. J., (2011). A desire for love: Considerations on sexuality and sexual education of People with intellectual disability in Poland. *Sexuality and Disability*, 29(1), 65-74. doi:10.1007/s11195-010-9184-2
- Krefting, L. (1991). Rigor in qualitative research: The assessment of trustworthiness. *American Journal of Occupational Therapy*, 45(3), 214-222. Retrieved from  
<https://pdfs.semanticscholar.org/643c/6521f1e78e395313cbe3cdbc285b3e16c9fa.pdf>.
- Lafferty, A., McConkey, R., & Simpson, A. (2012). Reducing the barriers to relationships and sexuality education for persons with intellectual disabilities. *Journal of Intellectual Disabilities*, 16(1), 29-43.  
doi.org/10.1177/1744629512438034
- Langtree, I. (2015, Oct. 26). *Definitions of the model of disability*. Retrieved from  
<http://www.disabled-world.com>.
- Larrick, D., Schmidley, R., Kell., & Kelly, S. (2017, July). *Ohio County Indicators*. Ohio Research Office. Retrieved from  
<https://development.ohio.gov/files/research/C1091.pdf>.

- Lew-Starowicz, Z., & Dlugolecka, A. (2006). *Sexual education*. Warszawa: World Books.
- Luckasson, R., Coulter, D. L., Polloway, E. A., Reese, S., Schalock, R. L., Snell, M. E., & Stark, J. A. (1992). *Mental Retardation: Definition, classification & systems of supports. Application for clinicians, educators, disability program managers & policy makers. (10<sup>th</sup> ed)*. Washington, D. C.: American Association on Mental Retardation.
- Lumley, V. A., & Scotti, J. R. (2001). Supporting the sexuality of adults with mental retardation: Status and future directions. *Journal of Positive Behavior Interventions*, 3(2), 109-111. <https://doi.org/10.1177/109830070100300208>
- Lyden, M. (2007). Assessment of sexual consent capacity. *Sexuality and Disability*, 25, 3-20. doi:10.1007/s11195-006-
- Mackelprang, R. W. & Salsgiver. (2009). *Disability: A diversity model approach in human service practice. (2<sup>nd</sup> ed.)*. Oxford University Press.
- Mansell, J., & Beadle-Brown J. (2004). Person-centered planning or person-centered action? Policy and practice in intellectual disability services. *Journal of Applied Research in Intellectual Disabilities* 17(1), 1-9.  
doi.org/10.1111/j.1468-3148.2004.00175.x
- Marshall, C., & Rossman, G. B. (2006). *Designing qualitative research. (4<sup>th</sup> ed)*. London: Sage Publishing.
- Martin, A. M., & Carey, E. (2009). Person-centered plans: Empowering or controlling? *Learning Disability Practice*, 12(1) 32-27. Retrieved from ‘

<https://search.proquest.com/openview/c0b8272e23ea75649847725e9f33389e/1?pq-origsite=gscholar&cbl=44392>.

Martin, J. L. (2014). *Strategic Planning Leadership Group*. Synergy Conference.

Retrieved from <http://www.synergyohio.org/>.

Martin, L., & Ouellette-Kuntz H. (2014). Perspectives of team members on person-directed planning. *Journal on Developmental Disabilities*, 20(2), 67-77.

Retrieved from [http://oadd.org/wp-content/uploads/2014/12/41018\\_JoDD\\_20-2\\_v10f\\_67-77\\_martin\\_\\_ouellette-kuntz.pdf](http://oadd.org/wp-content/uploads/2014/12/41018_JoDD_20-2_v10f_67-77_martin__ouellette-kuntz.pdf).

McGuire, B. E., & Bayley, A. A. (2011). Relationships, sexuality and decision-making capacity in people-directed planning. *Current Opinion Psychiatry*, 5, 398-402.

doi: 10.1097/YCO.0b013e328349bbcb

McMillan, J., & Schumacher, S. (2014). *Research in education: Evidence-based inquiry*.

Edinburgh Gate Harlow, Essex: Pearson.

McRuer, R., & Mollow, A. (2012). *Sex and disability*. Durham, NC: Duke University Press.

Merriam, S. (2009). *Qualitative research guide to design & implementation*. San

Francisco, CA: Jossey-Bass.

Merriam, S., & Tisdell, E. J. (2016). *Qualitative research: A guide to design and*

*implementation* (4<sup>th</sup> ed). San Francisco, CA: Jossey-Bass.

Moein, D., Rivard, M., Crocker, A. G., Boursier, C. P., & Caron, J. (2013). Public

attitudes towards intellectual disability: A multidimensional perspective. *Journal of Intellectual Disability Research*, 57(3), 279-292.



<https://doi.org/10.1111/jir.12008>

- Nastasi, B. (1998). Study notes: *Qualitative research: Sampling & sample size considerations*. Adapted from a presentation by Dr. Bonnie Nastasi, Director of School of Psychology Program.
- National Core Indicators. (2016, Jul). Ohio National Core Indicator. Retrieved from <https://www.nationalcoreindicators.org/states/OH/>.
- National Gateway to Self-Determination. (2012). *Research to practice in self-determination series*. Retrieved from [https://www.aucd.org/docs/publications/nti\\_selfd\\_issues/issue4\\_sm.pdf](https://www.aucd.org/docs/publications/nti_selfd_issues/issue4_sm.pdf).
- Obe, D. S. (2009). Making it happen for everyone: A reflection on changing services for adults with learning disabilities. *Mental Health Review Journal* 14(2), 14-19.
- Ohio Department of Education. (2016). Whose IDEA. Retrieved from: <http://www.education.ohio.gov/topics/special-education/whoseidea>.
- Olen-Kramers, A. (2017). Quantitative assessment of sexual knowledge and consent capacity in people with mild to moderate intellectual disability. *South African Journal of Psychology*, 47(3), 367-378. doi.org/10.1177/0081246317726457
- Parchomiuk, M. (2012). Specialist and sexuality of individuals with disability. *Sex Disability*, 30(4), 407-419. doi.org/10.1007/s11195-011-9249-x
- Parchomiuk, M. (2013). Model of intellectual disability and the relationship of attitudes towards the sexuality of persons with an intellectual disability. *Sexuality & Disability*, 31, 125-139. <https://doi.org/10.1007/s11195-012-9285-1>
- Parks, J. M., Murray, C., Haney, S. N., Cavano C., Feinn, W., McCurdy, S., Sheehan, B.

- (2015). *Cuyahoga County, OH 2014-2015 Budget Plan*. Retrieved from Cuyahoga County Fiscal Office: <https://www.fiscalofficer.cuyahogacounty.us>.
- Patton, M. (2002). *Qualitative research & evaluation methods*. (3rd ed). Thousand Oaks, CA: Sage Publications, Inc.
- Pearpoint, J., O'Brien, J., & Forrest, M. (1991). *PATH: A workbook for planning positive possible futures*. Toronto: Inclusion Press.
- Pownall, Jahoda A., Hasting, R., & Richard, P. (2012). Sexuality and sex education of adolescents with intellectual disability. *Intellectual and Developmental Disabilities*, 50(2), 140-54. doi.org/10.1352/1934-9556-50.2.140
- Randolph, J. (2009). A guide to writing the dissertation literature review. *Practical Assessment Research and Evaluation*, 14(13), 1-13. Retrieved from <http://pareonline.net/getvn.asp?v=14&n=13>.
- Rembis, M. (2010, Mar). Beyond the binary: Rethinking the social model of disabled sexuality. *Sexuality & Disability*, 28(1). doi: 10.1007/s11195-009-9133-0
- Richards, D., Miodrag, N., & Watson, S. (2006). Sexuality and developmental disability: Obstacles to healthy sexuality throughout the lifespan. *Developmental Disability Bulletin*, 34(12), 137-155. Retrieved from <https://files.eric.ed.gov/fulltext/EJ815715.pdf>
- Robertson, J., Emerson, E., Hatton, C., Elliott J., McIntosh, B., Swift, P., Joyce T. (2007). Person-centered planning: Factors associated with successful outcomes for people with intellectual disabilities. *Journal of Intellectual Disability Research*, 51(3), 232-243. <https://doi.org/10.1111/j.1365-2788.2006.00864.x>

Robertson, J., Emerson, E., Hatton, C., Elliott J., McIntosh, B., Swift, P., Joyce T.

(2007). Reported barriers to the implementation of person-centered planning for people with intellectual disabilities in the U. K. *Journal of Applied Research in Intellectual Disabilities*, 20(4), 297-307. <https://doi.org/10.1111/j.1468-3148.2006.00333.x>

Rogers, C. (1942). *Counseling & Psychotherapy: Newer concepts in practice*. Oxford England: Houghton Mufflin. Rogers, C. (1951). *Client-centered therapy: Its current practice, implications and therapy*. Oxford England: Houghton Mifflin

Rubin, H. J. & Rubin, K. S. (2012). *Qualitative interviewing* (3<sup>rd</sup> ed). Los Angeles, CA: Sage Publishing, Inc.

Rudestam, K., & Newton R. (2007). *Surviving your dissertation. A comprehensive guide to content and process*. Thousand Oaks, CA: Sage Publishing.

Rueda, H. A., Linton, K. F. & Williams, L. R. (2014). School social workers' needs in supporting adolescents with disabilities towards dating and sexual health: qualitative study. *Children & Schools*, 36(2), 79-90. <https://doi.org/10.1093/cs/cdu006>

Scullion, P. A. (2010, Mar). Models of disability: their influence in nursing and potential role in challenging discrimination. *Journal of advanced nursing*, 66(3), 697-707. doi: 111/j.1365-2648.2009.05211

Sex Education for physically, emotionally and mentally challenged youth. (2016).

Retrieved from Advocates for Youth: <http://www.advocatesforyouth.org>.

- Shakespeare, T. (2000). Disabled sexuality: Towards rights and recognition. *Sexuality & Disability*, 18(3), 159-166. <https://doi.org/10.1023/A:1026409613684>
- Shurack, N. Y., & Roling, C. (2014). Incorporating the concept of quality of life in individual support plans. *International Public Health Journal*, 6(4), 387-402.  
Retrieved from  
<https://search.proquest.com/openview/20b5790f05c90598ae645277c9184ff5/1?pq-origsite=gscholar&cbl=2034853>
- Simpson, A., Lafferty, A., & McConkey, R. (2006). Out of the shadows: A report on the sexual health & wellbeing of people with learning disabilities. Northern Ireland, London England: Family Planning Association.
- Smull, M., Sanderson, H., Sweeney, C., Skelhorn, L., George, A., Bourne, M., & Steinbruck, M. (2009). *Essential lifestyle planning for everyone*. Annapolis, MD. The Learning Center. Retrieved from  
[https://www.researchgate.net/profile/Helen\\_Sanderson2/publication/265179859\\_Essenti\\_Lifestyle\\_](https://www.researchgate.net/profile/Helen_Sanderson2/publication/265179859_Essenti_Lifestyle_)
- Stake, R. (2006). *Multiple case study analysis*. Guilford Press.
- Starman, A. B. (2013). The case study as a type of qualitative research. *Journal of Contemporary Educational Studies*, 64(1) 28-43. Retrieved from  
[https://www.researchgate.net/profile/Biba\\_Rebolj/publication/265682891\\_The\\_case\\_y\\_as\\_a\\_type\\_of\\_qualitative\\_research/links/54183f560cf25ebee988104c/The-case-study-as-a-type-of-qualitative-research.pdf](https://www.researchgate.net/profile/Biba_Rebolj/publication/265682891_The_case_y_as_a_type_of_qualitative_research/links/54183f560cf25ebee988104c/The-case-study-as-a-type-of-qualitative-research.pdf)
- Stevens, B. (2011). Politicizing sexual pleasure, oppression and disability: Recognizing

and undoing the impacts of ableism on sexual and reproductive health. Center for Women Policy Studies.

- Stewart, D. S. (2009). Making it happen for everyone. A reflection on changing services for adults with learning disabilities. *Mental Health Review Journal*, 14(2), 14-19. doi: 10.1108/13619322200900009
- Swango-Wilson, A. (2008). Caregiver perception and implications for sex education for individuals with intellectual and developmental disabilities. *Sexuality & Disability*, 26, 167. <https://doi.org/10.1007/s11195-008-9081-0>
- Swango-Wilson, A. (2010). Systems theory and the development of sexual identity for individuals with intellectual/developmental disability. *Sexuality & Disability*, 28(3), 157-164. doi.org/10.1007/s11195-010-9167-3
- Swango-Wilson, A. (2010, Sept). Systems theory and the development of sexual identity for individuals with intellectual/developmental disability. *Sexuality & Disability*, 28(3), 157-164. doi: 10.1007/s11195-010-9167-3
- Swango-Wilson, A. (2011). Meaningful sex education programs for individuals with intellectual disabilities. *Sexuality and Disability*, 29(2), 113-118. doi.org/10.1007/s11195-010-9168-2
- Szollos, A., & McCabe, M. (1995). The sexuality of people with mild intellectual disabilities: Perceptions of clients and caregivers. *Journal of Intellectual and Developmental Disabilities*, 20(3), 205-222. doi: 10.1080/07263869500035561

- Tavares-Meaney, R., & Payne-Gavidia, S. (2012). Staff characteristics and attitudes towards the sexuality of people with intellectual disability. *Journal of Intellectual & Developmental Disability*, 37(3), 269-273. Retrieved from <https://doi.org/10.3109/13668250.2012.701005>.
- Taylor, H. (2014). Helping people with learning disabilities exercise their right to autonomy. *Learning Disability Practice*, 17(7), 32-37. doi: 10.7748/ldp.17.7.32.e1567
- Terzi, L. (2004). The social model of disability: A philosophical critique. *Journal of Applied Philosophy*, 21(2), 141-157. <https://doi.org/10.1111/j.0264-3758.2004.00269.x>
- Test, D. W., Fowler, C. H., Wood, W. M., Brewer, D. M., & Eddy, S. (2005). A conceptual framework of self-advocacy for students with disabilities. *Remedial and Special Education*, 26, 43-54. <https://doi.org/10.1177/07419325050260010601>
- Thompson, D. (2011). Decisions about sex for people with learning disabilities. *Nursing Times*, 107.
- Thompson J. & Cobb, J. (2004). Person-centered health action planning. *Learning Disability*, 7(5), 12-15.
- Trainor, A. (2007). Person-centered planning in two culturally distinct communities: Responding to divergent needs and preferences. *Career Development for Exceptional Individuals*, 30(2), 92-103. doi.org/10.1177/08857288070300020601

- Travers, J., Tincani, M., Whitby, P. S., & Boutot, E. (2014). Alignment of sexuality education with self-determination for people with significant disabilities: A review of research and future directions. *Education and Training in Autism and Developmental Disabilities*, 49(2), 232-247. Retrieved from <http://www.jstor.org/stable/23880607>.
- United States Census. (2012). Retrieved from: <https://www.census.gov>.
- United Nations. (2006). *Convention on the rights of persons with disabilities*. New York, United Nations.
- Walker-Hirsch, L. (2012, Sept). Healthy relationships, sexuality, and self-determination. *Research to Practice in Self-Determination*, 3, 20-22. Retrieved from <http://www.nqsd.org>.
- Ward, K., Atkinson, J., Smith, C., & Windsor, R. (2013). A friendship and dating program for adults with intellectual and developmental disabilities: A formative evaluation. *Intellectual and Developmental Disabilities*, 51(1), 22-32. <https://doi.org/10.1352/1934-9556-51.01.022>
- Winges-Yanez, N. (2014). Why all the talk about sex? An autoethnography identifying the troubling discourse of sexuality and intellectual disability. *Sex Disability*, 32(1), 107-116. [doi.org/10.1007/s11195-013-9331-7](https://doi.org/10.1007/s11195-013-9331-7)
- Wolcott, H. F. (2008a). *Ethnography: A way of seeing* (2<sup>nd</sup> ed.). Walnut Creek, CA: Sage Publishing.
- Yin, R. K. (2003). *Case study research: Design and methods*. Thousand Oaks, CA: Sage Publication.

Yin, R. K. (2009). *Case study research: Design and method* (4th ed). Thousand Oaks, CA: Sage.

Yin, R. K. (2012). A very brief refresher on the case study method. In *Application of case study research* (pp. 4-23). Thousand Oaks, CA: Sage Publication, Inc.



### Appendix A: Study Participation Request

Hi. My name is Earlie S. Brown-Hall, and I am a doctoral candidate at Walden University, conducting a research study, examining the use of person-centered planning and the development of individual service plans to address the social sexual needs of individuals with intellectual disabilities. I am seeking participants for my dissertation study. I am in need of input from Service and Support Administrator, employed by Cuyahoga County Board of Developmental to discuss your experience using person-centered planning to develop individual service plans for individuals on your caseload who have a diagnosis of intellectual disability(ies).

- Have you been employed by Cuyahoga County Board of Developmental Disabilities as a Support and Service Administrator for at least 10 years?
- Have you been formally trained in the person-centered planning techniques, which include Essential Lifestyle planning techniques?
- Do You have an individual(s) on your current caseload who have expressed an interest in social sexual services?

If so, I need your input on a 4 question semi-structured interview for my research study about the person-centered planning process, in the use of developing individual service plans for individuals with intellectual disability(ies). Your participation in this study is voluntary, therefore there is no financial compensation for your participation and you will receive a copy of this consent for your records. There will be at least two face-to-face interview sessions, that may last up to two hours each.

I will work with you to schedule these interview sessions at a mutually agreeable non-work time, location, and date. As the study researcher, I can be reached via email at [earlie.hall@waldenu.edu](mailto:earlie.hall@waldenu.edu). If you interested in participating in this research study, please respond to me via by Friday, June 16th at 4:30 pm.

Thank you to everyone, in advance, for your interest in this research study.

Sincerely,

Earlie S. Brown-Hall, Doctoral Candidate

Walden University

### Appendix B: Interview Questions

1. What are your perception(s), as a Service and Support Administrator, regarding the utilization of the person-centered planning tool to promote sexual and social autonomy for individuals being served by Cuyahoga County Board of Developmental Disabilities?
2. How do you, as a Service and Support Administrator, currently assist individuals with intellectual disabilities address their desire to develop and maintain intimate relationships?
3. How do you, as Service and Support Administrator, view sexuality and individuals with intellectual disabilities?
4. What barrier(s) do you, as a Service and Support Administrator, believe prevent discussion and management of sexuality goals for individuals with intellectual disabilities? If any barrier(s) exist?