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Mental health counseling for individuals with intellectual disabilities: A phenomenological study of client perspectives.

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MENTAL HEALTH COUNSELING FOR INDIVIDUALS WITH INTELLECTUAL

DISABILITIES: A PHENOMENOLOGICAL STUDY OF CLIENT PERSPECTIVES

By

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DEDICATION

This dissertation is dedicated to the many people who loved and supported me

through this long academic journey. Thank you, Mini and Pips, my supportive parents,

for providing me with love, guidance, and a healthy environment in which I could

flourish. Because of you, I believed in my capability to attain any academic achievement

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ABSTRACT

MENTAL HEALTH COUNSELING FOR INDIVIDUALS WITH INTELLECTUAL

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Mental illness is three to four times as prevalent among individuals with intellectual disabilities compared to those without intellectual disabilities (Munir, 2016). There is a body of research supporting the efficacy of mental health counseling to decrease symptoms and behaviors in individuals with intellectual disabilities, but scarce research exists which describes the experiences of these individuals. This interpretive phenomenological analysis was designed to gather information about how individuals with mild intellectual disabilities experience the four common components of psychotherapy that contribute to change (from Lambert, 1992; Thomas, 2006) – client and extra therapeutic factors, relationships factors, expectancy, and model / techniques – and counseling outcomes. Individuals with mild intellectual disabilities between the ages of 18 and 40, who have had experience with mental health counseling, were interviewed. Interview data from 11 participants were used in this interpretive phenomenological analysis. It was found that the study participants highlighted the power of hope and expectation, as well as the importance of therapeutic alliance. Participants spoke about their family and other caregivers being helpful while they worked to make changes.

Many participants also identified strengths within themselves that they drew on. The findings from this study led to several recommendations for mental health counselors and counselor educators. For example, the study highlighted the need for counselors to be aware of the problems for which their clients are at-risk, assess whether their client's basic needs are being assessed, and be prepared to refer clients for additional support as needed. Counselor educators can provide education, training, and supervision on the needs of individuals with intellectual disabilities to counselors-in-training. Counselor educators can also continue researching best practices for serving individuals with intellectual disabilities. Future research will allow for a fuller understanding of how the field of counseling can best serve this population.

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CHAPTER I: INTRODUCTION

In 2018, there were over 7 million individuals with intellectual and / or developmental disabilities (abbreviated as I/DD) living in the United States (Larson, et al., 2021). According to the 5th Edition of the *Diagnostic & Statistical Manual of Mental Disorders* (DSM-5; American Psychiatric Association, 2013), intellectual disability involves impairments in the conceptual (e.g., language, math and reading), social (e.g., empathy and communication) and practical (e.g., hygiene, money management and scheduling) domains; these impairments begin in childhood. The Intelligence Quotient (IQ) of a person with an intellectual disability is generally under 70, which is two standard deviations below the mean.

Intellectual disability can be caused by a variety of conditions. According to Boat and Wu (2015), the following conditions are those generally associated with the etiology of intellectual disabilities: genetic conditions (e.g., Down Syndrome and Fragile X Syndrome), environmental conditions (e.g., exposure to toxins), nutritional conditions (e.g., prenatal iodine deficiency), and brain-related conditions (e.g., brain radiation, childhood brain infections, traumatic brain injury, and pre- and post- natal complications). Many of these conditions occur before birth, such as in genetic conditions and prenatal environmental exposures, or in early childhood through severe injuries, infections, or other medical problems during early development (Boat & Wu, 2015).

"By definitional criteria, intellectual disability must be identified during developmental years" (Patel et al., 2018, p. 1). Assessment of intellectual disability occurs sometime during childhood when a doctor, teacher, or other caregiver notices impairment and refers the child for professional assessment (Patel et al., 2018). Historically, formal IQ assessments have been the most common way of diagnosing intellectual disability (Boat & Wu, 2015). Qualified practitioners administered standardized assessments - such as the Stanford-Binet Intelligence Scale and the Woodcock-Johnson Test of Cognitive Abilities – which yield numeric scores. The mean score is 100 and individuals with scores two standard deviations under this (70 or under) were considered to have an intellectual disability. These standardized IQ tests are still used today, but in correlation with other clinical assessments of functioning. The most recent version of American Psychiatric Association's (APA) diagnostic manual – called the DSM-5 (APA, 2013) – guides practitioners to assess a client's ability to complete daily skills / tasks (Boat & Wu, 2015).

"Intellectual disability (intellectual developmental disorder) is a disorder with onset during the developmental period that includes both intellectual and adaptive functioning deficits in conceptual, social, and practical domains. The following three criteria must be met: (A) Deficits in intellectual functions, such as reasoning, problem solving, planning, abstract thinking, judgment, academic learning, and learning from experience, confirmed by both clinical assessment and individualized, standardized intelligence testing. (B) Deficits in adaptive functioning that result in failure to meet developmental and sociocultural standards for personal independence and social responsibility. Without ongoing support, the adaptive deficits limit functioning in one or more activities of daily

life, such as communication, social participation, and independent living, across

multiple environments, such as home, school, work, and community. (C) Onset of

intellectual and adaptive deficits during the developmental period" (APA, 2013,

p. 13).

The DSM-5 (APA, 2013) also states that the severity of the intellectual disability - mild,

moderate, severe, or profound - should be diagnosed based on level of adaptive

functioning.

Intellectual disabilities are generally considered to be nonprogressive and stable

(APA, 2013). However, there are some exceptions to this. For example, early

intervention can trigger significant improvement in adaptive functioning, leading to the

removal of an intellectual disability diagnosis (APA, 2013). There are also cases wherein

the severity of the intellectual disability changes; for example, a person's intellectual

disability may move from mild to moderate if a seizure disorder causes progressive

cognitive damage (APA, 2013).

Individuals with intellectual disabilities are more likely to have other diagnosable

conditions than those without intellectual disabilities (Cooper et al., 2015). Researchers

have identified conditions occurring comorbidly with intellectual disabilities (Matson &

Cervantes, 2013). Physical health conditions identified as comorbid with intellectual

disability include asthma, cancer, constipation, diabetes, epilepsy, gastrointestinal

problems, obesity, thyroid problems, and more (Matson & Cervantes, 2013).

Psychopathological conditions found to occur comorbidly with intellectual disability

include autism, ADHD, schizophrenia, depression, personality disorders, anxiety, OCD,

general mental health problems, and more (Matson & Cervantes, 2013). Comorbid

behavioral challenges include aggression, hand-mouthing, pica, self-injurious behavior,

and stereotyped movements (Matson & Cervantes, 2013). In summary, researchers have identified many conditions comorbid with intellectual disabilities including physical, mental, and behavioral conditions (Matson & Cervantes, 2013).

Mental illness is three to four times as prevalent among individuals with intellectual disabilities compared to those without intellectual disabilities (Munir, 2016). In a systematic review of research on comorbidity of these conditions, Einfeld et al. (2011) found that mental disorders occurred in 30 to 50% of those with intellectual disabilities as compared to 8 to 18% of the comparison groups. "Dual diagnosis" is a term that can be used to describe the presence of both an intellectual disability and a diagnosed mental illness in an individual. The increased prevalence of mental illness (in those with intellectual disabilities as compared to the rest of the population) is pervasive throughout the lifespan (Cooper et al., 2015).

Due to the increased risk of mental illness for individuals with intellectual disabilities, it is important that mental health supports are available to those with dual diagnoses. Mental health counselors are trained to provide these mental health supports. Mental health counselors work to improve the well-being of their clients, including those with dual diagnoses (American Mental Health Counselors Association [AMHCA], 2019). Mental health counselors serve individuals with dual diagnoses in both inpatient and outpatient settings (Hassiotis, 2002).

Mental health counselors are required to receive graduate-level education, practicum and internship experience, supervision, and licensure. Through this graduate-level education and training, mental health counselors learn how to implement preventative interventions, assess for the presence of diagnosable conditions, and design and implement treatment plans for clients with various needs and abilities. In accordance

with the AMHCA (2019), counselors must be able to choose assessments and interventions appropriate for special populations, including individuals with intellectual disabilities. Prevention, assessment, and treatment are the three main components of practice that a mental health counselor must be trained to conduct; these are described below.

There are three types of prevention interventions that individuals with intellectual disabilities could receive from a mental health counselor (Miller, 2014). *Primary prevention* in counseling involves minimizing risk factors and maximizing protective factors. An example of primary prevention is a program promoting increased connectedness and decreased bullying to prevent mental health issues. *Secondary prevention* involves screening, early identification, and brief treatment with the goal of slowing or stopping the progression of a mental illness. An example of secondary prevention is screening a group for anxiety symptoms and placing those with mild symptoms in a brief group intervention. The group intervention would be designed to prevent those group members from developing a diagnosable anxiety disorder. In *tertiary prevention*, a counselee learns how to better cope with a mental illness, decrease the impact of the mental illness on domains of life, and improve overall life functioning. Tertiary prevention can involve planning for managing symptoms, building insight, decreasing stressors, and more.

In addition to prevention interventions, individuals with intellectual disabilities can receive mental illness diagnoses from mental health counselors. When mental health counselors diagnose mental health conditions, they use clinical interviews, observations, and various research-based assessments (American Counseling Association [ACA], 2014). A diagnosis can help an individual with an intellectual disability understand the

symptoms that they are experiencing. For example, an individual experiencing racing

heartbeat, dizziness, and feelings that he or she is losing control might be comforted to

know these are common symptoms in panic disorder which is treatable..

In addition to prevention and assessment, individuals with intellectual disabilities

can receive treatment for mental health conditions in mental health counseling.

Individuals with dual diagnoses can receive evidence-based treatment methods for

improving mental health (Whitehall et al., 2006). Evidence-based techniques for use with

individuals with intellectual disabilities include social skills training, parent-implemented

interventions, visual supports, and technology / video modeling (NC Department of

Health and Human Services, n.d.). When evidence-based techniques and treatment

methods are used, mental health counseling can lead to decreases in both mental illness

symptoms and problematic behaviors in individuals with intellectual disabilities

(Armstrong et al., 2015; Brown et al., 2013; Florez & Bethay, 2017; Hartley et al., 2015;

Newlands & Benuto, 2021; Swan & Ray, 2014).

Statement of the Problem

While there is a body of research supporting the efficacy of mental health

counseling to decrease symptoms and behaviors in individuals with intellectual

disabilities (as mentioned above), scarce research exists which describes the experiences

of these individuals. In the systematic review included later in this dissertation, only 16

studies were identified that included a qualitative investigation of the experiences of

individuals with intellectual disabilities in mental health counseling. Of these studies,

only 25% were conducted outside of the United Kingdom.

It is a problem that qualitative research on mental health counseling for

individuals with intellectual disabilities is limited. The perspectives of so many

individuals with intellectual disabilities who have received mental health counseling are absent from the body of counseling literature. There is a need for research that aims to "privilege the perspective of clients with disabilities, and how well their needs and presenting counseling issues are met" (Rivas & Hill, 2018, p. 130). The lived experiences of individuals with intellectual disabilities should be explored to inform the practice of mental health counseling (MacMahon et al., 2015).

When qualitative methods are used to conduct research on mental health counseling in individuals with intellectual disabilities, this is advantageous for several reasons, including the following three (Palinkas, 2014). Firstly, participants can provide data using their own voices; their answers are not limited by categories / choices (Palinkas, 2014). This is particularly valuable when a research area is still in its infancy and there is much to explore about the topic. Secondly, qualitative research can yield a "thick description" of a phenomenon as the research allows the topic to be explored deeply (Geertz, 1970). Thirdly, qualitative methods can yield insight as to *how* counseling leads to outcomes for individuals with intellectual disabilities (such as in process evaluation research) (Palinkas, 2014).

If researchers neglect to conduct qualitative studies on the experiences of individuals with intellectual disabilities in counseling, the field of counseling will be negatively affected. The voices of an already marginalized group (individuals with intellectual disabilities) will be missing from the literature (Lloyd, Gatherer & Kalsy, 2006). Research on mental health counseling for individuals with intellectual disabilities will be lacking the depth that is possible when using a qualitative approach. The counseling field of research will lack information about "the processes that participants [with intellectual disabilities] perceive as most salient to their experiences" in counseling

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(McMahon, 2015, p. 343). Reciprocally, the field will cause harm to individuals with disabilities by failing to elevate the voices of these individuals. This study has been designed to contribute to the small body of literature about how individuals with intellectual disabilities have experienced mental health counseling.

Purpose of the Study & Research Questions

The purpose of this qualitative research study is to describe the experience of mental health counseling for individuals with mild intellectual disabilities. This interpretive phenomenological analysis is designed to gather information about how individuals with mild intellectual disabilities experience (a) the four common components of psychotherapy that contribute to change and (b) counseling outcomes. The four common factors of change include client and extra therapeutic factors, relationship factors, expectancy, and model / techniques (Lambert, 1992; Thomas, 2006). The research questions guiding the study are:

1. How do individuals with intellectual disabilities perceive the characteristics of themselves and their environment which contribute to change (such as personal strengths, support from others, access to transportation and paid work, and/or other personal and environmental factors)?

2. How do individuals with intellectual disabilities perceive the relationship between themselves and their counselors?

3. How do individuals with intellectual disabilities perceive the ability of counseling to help them make meaningful life changes?

4. How do individuals with intellectual disabilities perceive the process of counseling such as goal setting, interventions / activities completed in-session and homework?

5. How do individuals with intellectual disabilities perceive their outcomes from mental health counseling?

Significance of the Study

Readers of this Interpretive Phenomenological Analysis (IPA) study will learn about individuals with mild intellectual disabilities in relation to their counseling experiences. The study findings will benefit the work of counselors and counselor educators. Counselors and educators may gain understanding of what components of therapy are considered beneficial and detrimental to clients with intellectual disabilities.

This study will promote diversity and social justice which are core values identified by many counseling associations including AMHCA (2019) and ACA (2021). Individuals with disabilities are part of a marginalized group and may face ableism, which is prejudice and maltreatment based on disability. It is important for counselors to be open to understanding how ableism affects their clients with disabilities (Smith et al., 2008). This phenomenological analysis will promote understanding of diversity and disability for counselors and will encourage readers to consider how they approach this marginalized group.

Summary

In this chapter, the etiology, diagnosis, and prognosis of intellectual disabilities were introduced. Common comorbidities of intellectual disabilities were listed, including mental health conditions. Since individuals with intellectual disabilities are at risk for mental health problems, mental health counseling was offered as an effective intervention. Prevention, diagnosis, and treatment methods in counseling were discussed; evidence was provided for their effective use in individuals with intellectual disabilities. Unfortunately, there is a lack of research about the experience of the individuals

themselves in counseling. A phenomenological study was introduced, and research

questions were proposed.

CHAPTER II: LITERATURE REVIEW

In the introduction, a phenomenological study of the experience of individuals with intellectual disabilities in mental health counseling was proposed. The current chapter is a review of literature relative to this study. First, three key concepts are explored: American policies affecting individuals with intellectual disabilities, mental health conditions in individuals with intellectual disabilities, and counselors working with individuals with intellectual disabilities. For each of these concepts, key terms are reviewed, and historical contexts are provided when appropriate.

After reviewing the three concepts, a systematic review is conducted. Qualitative studies of mental health counseling for individuals with intellectual disabilities are identified and summarized. The findings are synthesized, and gaps in the research are identified. After the systematic review, the theoretical underpinnings of the study are described. A feminist disability lens is defined, and the way it is used in this study is described.

American Policies Affecting Individuals with Intellectual Disabilities

As described in the introduction, an intellectual disability diagnosis requires three conditions which includes deficits in cognitive functioning, deficits in adaptive functioning, and onset before age 22 (APA, 2013). Mental health professionals use assessments, interviews, and observations to diagnose intellectual disabilities. These

professionals also determine the degree of intellectual disability – mild, moderate, severe, or profound – through assessment of adaptive functioning.

Individuals with intellectual disabilities have not been treated humanely throughout the history of the United States. Before the mid-19th century, individuals with intellectual disabilities were considered uneducable and never able to participate in society; accordingly, many were institutionalized (Conrad, 2020). By the end of the 19th century, public opinion about the potential of individuals with intellectual disabilities began to change, and many schools and programs for the disabled were built (Conrad, 2020).

Also toward the end of the 19th century, Francis Galton began developing the concepts of normality and eugenics through composite portraits (Stephens & Cryle, 2017). These composite portraits were images made up of the images of others, with the most common features more defined than less defined features; these portraits "were representative of the complex network of institutions and discourses in which the theory of eugenics emerged and this time, and demonstrate how these came to shape the medical and legal treatment of people now understood to be disabled" (Stephens & Cryle, 2017, p. 367). Galston argued that normality could be quantified; the concept of normal distribution was developed as "the statistic basis for eugenic theory" (Stephens & Cryle, 2017, p. 368). Galston also promoted the idea that intelligence was racially inherited (Stephens & Cryle, 2017). As standardized intelligence tests were developed in the early 1900's, they were used to determine whether immigrants were smart enough to stay in the country (Katz, 2022). So, standardized intelligence tests were originally conceived out of racism, xenophobia, and ableism.

Also in the beginning of the 20th century, institution size grew; overcrowding and low funding led to poor conditions in many of these facilities (Smith et al., 2013). During the same time, the popularity of eugenics led to many individuals with intellectual disabilities being involuntary sterilized (Conrad, 2020). By the mid-20th century, many institutions for individuals with intellectual disabilities shifted from an educational focus to neglect and maltreatment wherein residents' cognitive and psychological abilities degraded (Conrad, 2020; Smith et al., 2013).

During the Civil Rights movement of the 1960s, awareness was built about the needs of individuals with disabilities; accordingly, many institutions made improvements (Conrad, 2020). In 1973, Section 504 of the Rehabilitation Act was passed which prohibits "discrimination on the basic of disability in programs, services and activities receiving federal financial assistance" (U.S. Department of Education, Office for Civil Rights, 2015, p. 6). The Education of All Handicapped Children Act followed in 1975; this made it so that a free and appropriate public education was available to all children, regardless of disability (Meldon, 2019). In the 1980s, the Reagan administration pushed for the closing of long-term facilities including those serving individuals with intellectual disabilities. Over the next twenty years, most institutions that housed individuals with disabilities for long-term care closed. Former patients of these facilities moved into the community. To help individuals with disabilities be successful outside of an institution, the Medicaid Home and Community-Based Services (HCBS) program began in 1981 (Conrad, 2020).

The Medicaid HCBS program still exists at the time of this writing. This program funds services that help individuals with intellectual and/or developmental disabilities live successfully outside of institutions. Funded services include adult day programs,

behavior therapy, music therapy, wellness nursing, residential staff, staff to accompany the client into the community, staff to help the client work in the community and more. In Indiana, the HCBS waivers are currently called the Family Support Waiver (FSW) and the Community Integration and Habilitation Waiver (CIH). The FSW is generally awarded to individuals who have families involved in their care, while the CIH is generally awarded to individuals who do not have assistance from family members who can provide care and supervision. The same services are available under both waivers; the dollar amount is what varies. Again, the overarching goal is allowing individuals with disabilities to live full lives in the community.

Less than a decade after the development of the HCBS program, another large milestone happened; in 1990 the Americans with Disabilities Act (ADA) was passed. This law made it so that individuals with disabilities cannot legally be discriminated against in public life. Americans with disabilities were guaranteed equal access to employment, transportation, telecommunication, and public places overall (Mid-Atlantic ADA Center, 2017). Agencies involved in the enforcement of ADA policies include the U.S. Department of Labor, the U.S. Equal Employment Opportunity Commission, the U.S. Department of Transportation, the Federal Communications Commission, the U.S. Department of Justice, the U.S. Department of Education, the U.S. Department of Health and Human Services, the Architectural and Transportation Barriers Compliance Board, the Office of Federal Contract Compliance Programs, and the Civil Rights Center (U.S. Department of Labor, n.d.).

While 1990's ADA was designed to provide individuals with disabilities equal access to all aspects of public life, the act was not without its faults. Title 1 is the component of the ADA requires that employers not discriminate against qualified

individuals with disabilities. Legal controversy surrounded who fits the definition of a person with a disability who would be protected by this act (Buonocore-Porter, 2019). In 2008, the ADA Amendments Act (ADAAA) provided an expanded definition of disability, a clarification of who is protected by Title 1; this led to a decrease in related appellate cases (Buonocore-Porter, 2019). Despite clarification with Title 1, parameters of the ADA and accompanying amendments will continue to be challenged in the American court systems (Buonocore-Porter, 2019).

In summary, lives of Americans with intellectual disabilities have changed dramatically since the origin of the country. Psychological and educational researchers have developed interventions to help individuals with intellectual disabilities learn new information and skills. Legislation has led to individuals with intellectual disabilities being considered equal, with the same opportunities (to education, employment, housing, transportation, and more) as those without intellectual disabilities (U.S. Department of Labor, n.d.). However, these policies have not consistently led to individuals with disabilities actually obtaining equal access and opportunity. Individuals with disabilities still experience several problems disproportionately, including poverty and victimization. In the section below, such problems are discussed further.

Mental Health Conditions in Individuals with Disabilities

As reviewed in the section above, American legislation and policy currently calls for a wide range of equal opportunities for individuals with intellectual disabilities. However, these policies have not always ensured equality for the intended. Ableism and the oppression of individuals with intellectual disabilities persist and disparities in mental illness remain. Approximately one-third of Americans with intellectual and/or developmental disabilities are estimated to also have a mental illness (Fletcher et al.,

2007). Comparatively, approximately one-fifth of the whole American population is estimated to have a mental illness (Substance Abuse and Mental Health Services Administration, 2019).

Cree, et al. (2020) highlighted the disproportionate mental health problems among individuals with intellectual disabilities (as compared to those without intellectual disabilities). Cree et al. (2020) reported findings from a 2018 nationwide telephone study called the BRFSS (Behavioral Risk Factor Surveillance System, mentioned previously). The 430,949 participants were found using randomized dialing to cell phone and landlines. There was a median response rate of 49.9% yielding a sample of 430,949 participants (Cree et al., 2020). Participants were asked about their disabilities as well as whether they had experienced mentally unhealthy days for 14 or more days in the past 30 days; this was called "frequent mental distress" (Cree et al., 2020, p. 1238). Among participants with a cognitive disability and no other disabilities, 51.6% reported experiencing mental distress (Cree et al., 2020). Among participants with a cognitive disability and a mobility disability, 55.6% reported experiencing mental distress (Cree et al., 2020). These percentages are much higher than the number of individuals without a cognitive or mobility disability and reporting mental distress: 22.5% (Cree et al., 2020). These findings – which highlight that individuals with intellectual disabilities are at risk for developing mental health problems – suggest that mental health services may be helpful for many individuals with intellectual disabilities. Researchers have proposed reasons for the higher prevalence of mental health problems in those with intellectual disabilities; these proposed reasons include income, social issues (including victimization and isolation/exclusion), biology, and diagnostic masking and overshadowing (Rojahn & Meier, 2009). These issues are explored further below.

Income

  Depending on the level of intellectual disability and comorbid conditions, some

individuals with intellectual disabilities are unable to earn enough money to support

themselves. According to the U.S. Department of Labor (2021), 21.6% of individuals

with disabilities ages 16 and up are employed; this is compared to 67.3% of Americans

(also ages 16 and up) without disabilities who are employed. According to the United

States Census Bureau, when compared to other workers, individuals with disabilities are

more likely to work part-time or seasonally, as opposed to full-time (Day & Taylor,

2019). Also, despite American law against such discrimination, "individuals with

disabilities continue to confront employment discrimination" (Van Wieren et al., 2012, p.

159). Research suggests that workplace discrimination is the main factor contributing to

individuals with intellectual disabilities not reaching their full career potential (Van

Wieren et al., 2012). Americans with disabilities are overrepresented in the group of

those living in poverty (DeNavas-Walt & Proctor, 2015). In 2022, the poverty threshold

for one adult is an annual income of $13,590[1].

  Americans with intellectual disabilities can apply for programs such as

Supplemental Security Income and/or Social Security Disability Insurance but these are

often low monthly payments leaving people under or around the poverty level (Livermore

et al., 2017). For individuals with intellectual disabilities with low incomes, financial

stressors can include finding affordable housing and paying for transportation, utility

bills, groceries, medical and dental care, and other expenses. According to the Anxiety &

Depression Association of America (n.d.), financial stressors are linked to mental health

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[1] The poverty threshold was originally calculated in 1963; it involved multiplying the cost
of a minimum amount of food by three (U.S. Census Bureau, 2017). Since then, the
threshold has been updated by adjusting for current prices (U.S. Census Bureau, 2017).

problems. So, the prevalence of financial problems in individuals with intellectual disabilities is potentially one of the causes of higher levels of mental health problems in this population.

The American Psychological Association (2019) suggested that a number of variables may contribute to the relationship between income and mental health: health disparities, treatment issues, and employment. First, health disparities may contribute to the relationship between low income and poor mental health; these issues include elevated acute and chronic stress, exposure to unhealthy environmental factors, limited access to healthy foods and exercise spaces, and limited exposure to programs for the prevention of poor health outcomes (American Psychological Association, 2019). Second, treatment issues may also contribute to poor mental health such as practitioner bias (assumptions about the patient's understanding, investment in their health, and other important aspects of a patient's health) and barriers to care such as transportation (American Psychological Association, 2019). Finally, career concerns and unemployment also contribute to the relationship between low income and poor mental health. Research shows that socioeconomic status is correlated with academic success, career aspirations, and career development (American Psychological Association, 2019).

Social Issues: Victimization & Isolation/Exclusion

In addition to the high rates of poverty and low incomes among individuals with intellectual disabilities, there are other potential contributors to the higher rates of mental health conditions among individuals with intellectual disabilities. Despite the rules and policies surrounding fair treatment of individuals with disabilities, people with disabilities experience victimization at a higher rate than non-disabled peers (The Arc's National Center on Criminal Justice and Disability, 2015). Types of victimization / abuse

incurred by many people with disabilities include emotional, physical, sexual, and financial abuse, as well as isolation and exclusion, neglect and exploitation; these problems can happen throughout the lifespan (Thornberry & Olson, 2005).

One form of victimization incurred by many young people is bullying. According to the official United States website stopbullying.gov (2020), bullying is "unwanted aggressive behavior among school aged children that involves a real or perceived power imbalance. The behavior is repeated, or has the potential to be repeated, over time." Bullying can include emotionally and/or physically abusive behavior. According to the National Bullying Prevention Center (n.d.), individuals with intellectual and/or developmental disabilities are 2 – 3 times more likely to be bullied than their non-disabled peers. The National Bullying Prevention Center (n.d.) also reported the troubling outcomes correlated with being bullied at school which included both decreases in concentration, grades, and interest in school and increases in school absences and dropout rates.

While a large amount of bullying occurs among school-aged children, financial exploitation is a form of victimization that can occur anytime that an individual is receiving money (from a job, government disability check, inheritance, or something else). Individuals with intellectual disabilities may have help with managing money. For example, recipients of funds from the Social Security administration can elect a "Representative Payee" to receive their money and pay bills accordingly (Gray, 2019). If these funds are purposefully misused, this is financial abuse or financial exploitation. Mismanagement of money is often done by someone the individual knows, but strangers sometimes financially abuse individuals with intellectual disabilities as well. "Phishing" scams are when a perpetrator uses emails and/or calls / texts to manipulate a victim into

giving them money and/or personal information. Victims of financial abuse may have

their credit scores ruined, lose assets, and more.

Physical and sexual violence are other troubling forms of victimization

experienced by individuals with intellectual disabilities. Funded by the World Health

Organization's Department of Violence and Injury Prevention and Disability, Jones et al.

(2012) conducted a systematic review of studies about violence against children. As a

result of the systematic review, it was determined that children with intellectual and

mental health disabilities experience all types of violence at a higher rate than their peers

(Jones et al., 2012).

Sexual violence occurs more frequently for adults with disabilities compared to

those without disabilities as well (Mitra et al., 2016). Mitra et al. (2016) analyzed data

from the Behavioral Risk Factor Surveillance System's (BRFSS) Sexual Violence

Module. The BRFSS was a large health survey completed via telephone using a random

digit dialing system. While Mitra et al. (2016) did not report the sample composition, the

Center for Disease Control and Prevention (n.d.-a) reported that hundreds of thousands of

participants are involved each year. Mitra et al. (2016) found that lifetime sexual violence

victimization occurred in 8.8% of men with disabilities compared to 6.0% of men without

disabilities and in 25.6% of women with disabilities compared to 14.7% of women

without disabilities.

Individuals with intellectual disabilities may be targeted for physical and sexual

abuse because perpetrators may find this population easier to manipulate and/or less

likely to be believed if they report the crime (RAINN, n.d). Individuals with intellectual

disabilities may also be more dependent on caregivers (increased vulnerability) and may

have difficulty communicating to others about the abuse they are suffering (Palusci et al.,

2015). The experience of being abused is traumatic and can lead to mental health problems such as post-traumatic stress, anxiety, depression, low self-esteem, and more (Basile & Smith, 2011).

Social isolation and exclusion also disproportionately affect individuals with intellectual disabilities. Social exclusion is faced by many with intellectual disabilities (Wilson, et al., 2017). Research shows that people with intellectual disabilities typically have fewer friendships than those without intellectual disabilities (Wilson et al., 2017). In an analysis of survey data, Emerson et al. (2021) found that "people with disability experienced loneliness, low perceived social support and social isolation at significantly higher rates that people without disability… Loneliness was a particularly significant driver of poor wellbeing amount people with disability" (p. 1).

In summary, individuals with intellectual disabilities are at-risk for several types of social problems. For those who experience victimization, social isolation, or both, mental health problems may arise. So, problems in the domain of interpersonal dynamics are one of the proposed reasons for the elevated prevalence of mental health conditions in individuals with intellectual disabilities (as compared to the whole population).

Biology

In addition to issues of low income and victimization, biological makeup of individuals is another potential cause for the high incidence of mental health conditions among individuals with intellectual disabilities. Rojahn and Meier (2009) conducted a literature review on the origin of mental health conditions in individuals with intellectual disabilities. They found that "psychopathology in ID [intellectual disability], as in the general population, is a function of complex interactions of often still poorly understood factors that include neurobiological substrates, personal characteristics, and

socioeconomic circumstances" (Rojahn & Meier, 2009, p. 239). Certain chromosomal

conditions can lead to both mental health problems and intellectual disability. While

these connections are still being researched, it seems that shared biological conditions are

one reason for the comorbidity of intellectual disability and mental illness.

Diagnostic Masking and Overshadowing

Income disparities, victimization, and biology are all potential causes of mental

health conditions in individuals with intellectual disabilities. Diagnostic masking and

diagnostic overshadowing are concepts that could explain why individuals do not receive

treatment in a timely manner (preventing worsening of mental health problems / relief

from these conditions). Diagnostic masking occurs when an individual's intellectual

disability keeps symptoms of psychopathology from being observable to a clinician

(Manohar et al., 2016). Diagnostic overshadowing occurs when a clinician does not

assess an individual fully and attributes symptoms to the intellectual disability as opposed

to a mental health condition (Manohar et al., 2016).

The example of diagnostic masking and overshadowing provided by Manohar, et

al. (2016) involves a young lady who was often late for school and irritable with family

members. She stayed in the bathroom for long periods of time and became aggressive

when given feedback / redirections from her parents. Initially, the clinician identified

irritability as the main problem; risperidone was prescribed to decrease that symptom.

The client's symptoms worsened as she took the risperidone. Further diagnostic

assessment (MINI-KID parent version) allowed the clinician to see that the client was

experiencing obsessive compulsive disorder (OCD). The client was washing her hands

for long periods of time which was leading her to be tardy. She became irritable when

asked not to engage in the ritual handwashing triggered by her OCD. Once the

appropriate diagnosis was uncovered, the client was able to receive appropriate medication (serotonin reuptake inhibitors) and psychosocial interventions. The parents received psychoeducation and training on how to better assist their daughter as well. The clinician realized that the irritability that he often sees with intellectual disability masked the OCD, and that diagnostic overshadowing occurred when he failed to perform the assessments needed to uncover an accurate diagnosis for the client.

In response to the identification of diagnostic overshadowing, the *Diagnostic Manual – Intellectual Disability (DM – ID): A Textbook of Diagnosis of Mental Disorders in Persons with Intellectual Disabilities* (Fletcher et al., 2007) was created. Ten years later, the second edition of this text was published (Fletcher et al., 2017). The purpose of this text is to help practitioners more accurately identify symptoms of mental illness in the population of individuals with intellectual disabilities. Ideally, the use of this text leads to early identification of mental health problems in individuals with intellectual disabilities. Early identification and treatment of mental health conditions "can change life trajectories and save lives" (Bostic & Cullins, 2017). Unfortunately, it seems unlikely that many counselors-in-training are taught to use this manual; research suggests that disability-related content is not consistently included in graduate training programs' curriculum (Feather & Carlson, 2019). Therefore, diagnostic masking and overshadowing continues for many individuals with intellectual disability and mental health problems.

Counselors Serving Individuals with Intellectual Disabilities

Individuals with intellectual disabilities and mental health problems can benefit from receiving evidence-based treatment/interventions. These interventions – along with prevention and assessment - can be provided by mental health counselors. In this section,

the role of the mental health counselor is explored. Emphasis is placed on the mental health counselors' role in helping individuals with intellectual disabilities. First, a brief history of the mental health counseling field is provided.

Mental Health Counseling History

The modern field of mental health counseling originated in the middle of the 20th century. During World War II, many American soldiers were discharged due to mental health problems (Pols & Oak, 2007). According to Pols and Oak (2007), low morale, discrimination, and other factors contributed to soldiers' mental health problems. After being discharged from the military, some of these soldiers with mental illness struggled to acclimate into their communities. Accordingly, mental health professionals were needed to assist these people as they transitioned from active duty to civilian life (Pols & Oak, 2007). The Veteran's Administration provided funding for counselor education in response to the need for counselors (Smith, 2012).

Shortly after the end of WWII, the National Mental Health Act (of 1945) was enacted (National Institutes of Health, 2021). With this act, the National Institute of Mental Health (NIMH) was established (National Institutes of Health, 2021). The NIMH works to conduct "high-quality, impactful research and promote translation of such research into clinical practice, services delivery, and policy" (National Institutes of Health, 2021, para. 3). This led to an increase in publications on evidence-based treatment of mental illness.

In the 1950's, two major events occurred which contributed to the understanding and treatment of mental illness. In 1952, the first *Diagnostic and Statistical Manual of Mental Disorders* was published (Smith, 2012). This manual provided definitions and diagnostic criteria for mental illnesses as defined by the American Psychiatric

Association. Also, several psychiatric medications became available for prescription (Smith, 2012). While these advances in mental illness conceptualization and treatment occurred, some mental health professionals were alternatively wanting their practices to focus on healthy human development and prevention of – rather than treatment of – mental illness (Smith, 2012). This led to the beginning of the Counseling Psychology division of the American Psychological Association; this division focused on mental health and collaboration between client and mental health professional, as opposed to a model wherein a professional provides a treatment (Smith, 2012).

In the 1960s, many Americans pushed for the rights of marginalized groups. "The Civil Rights Movement, the Vietnam War, and the Women's Movement drew attention to the need for theories and professional services that addressed the whole of the community" (Smith, 2012, p. 4). There was a growing awareness of mental health and substance abuse problems American communities. In response, the Community Mental Health Act of 1963 was passed. This act provided funding for community-based mental health services throughout the United States (Pistole, 2001). With community mental health services in place and psychiatric medications available to individuals with serious mental illness, many individuals left inpatient psychiatric facilities and moved into the community (Smith, 2012). Mental health clinicians were needed for these community-based services.

In the 1960's and 1970's, some mental health clinicians were working in these community – based mental health centers but did not have a professional identity as they were not licensed social workers or psychologists (Pristole, 2001). These practitioners were often graduates of departments of education and were trained in psychology, behavioral health, education, and more. To develop a professional organization and

identity, some of these clinicians formed the American Mental Health Counselors Association (AMHCA) in 1978 (Pistole, 2001).

Since the inception of the AMHCA, the field of mental health counseling has grown. Mental health counseling has developed a professional identity of its own, separate from other related professions. This identity involves a "…focus on a wellness, holistic mental health philosophy, regardless of whether the clients' issues are more reflective of developmental struggles or more reflective of clinical pathology" (Pistole, 2001, para. 6).

The tasks of a mental health counselor include the following: observation and assessment of the client and their environment (and understanding how the environment affects the client); identification of client strengths; diagnosis / identification of areas for change; evidence-based treatment planning; collaboration and consultation with stakeholders; and more. While completing these tasks, mental health counselors provide support and positive regard and work to build healthy therapeutic relationships with clients. "Based in the knowledge of the behavior sciences and trained to focus on strengths, development, and the holistic, multifaceted aspects of on-going mental health, mental health counselors use scientific processes to strengthen or restore client's mental health" (Pistole, 2001, para. 5).

Mental Health Counseling with Individuals with Intellectual Disabilities

Mental health counselors serve individuals of all ages, races, ethnicities, gender identities, abilities, and other social categories. Counselors should embrace five core professional values as defined by the ACA (2014). These values are:

"1. Enhancing human development throughout the life span;

2. honoring diversity and embracing a multicultural approach in support of the

worth, dignity, potential, and uniqueness of people within their social and cultural

contexts;

3. promoting social justice;

4. safeguarding the integrity of the counselor–client relationship; and

5. practicing in a competence and ethical manner" (ACA, 2014, p. 3).

Core value number 2 refers to multicultural competencies, multicultural orientation and

cultural humility in counseling. The concept of multicultural competencies involves self-

awareness of one's cultural background, belief, and values, knowledge about diverse

cultures, and the use of culturally appropriate interventions (Hook et al., 2016). While

multicultural competencies generally refer to the way that therapeutic tasks are done,

multicultural orientation refers to a "way of being" (Hook et al., 2016 p. 151). Hook et al.

(2016) suggested that "cultural humility" – a term first coined by Tervalon,and Murray-

Garcia (1998) – is an appropriate way to adapt a multicultural orientation. "…The

culturally humble therapist strives to cultivate a growing awareness that one is inevitably

limited in knowledge and understanding of client's cultural backgrounds" (Hook et al.,

2016, p. 152).

Culturally humble counselors recognize and respect clients' backgrounds, values,

customs, and life experiences. Culturally humble counselors also work to uncover and

combat their own subconscious prejudices so that they can treat clients with fairness and

understanding. Developing these skills (for being a culturally humble counselor) allows a

counselor to better understand the many dimensions of their client's identities (Smith et

al., 2008).

Mental health counselors are expected to "demonstrate sensitivity and responsiveness to… [client's] family culture, age, gender, ethnicity, disabilities, socioeconomic background, religious beliefs, and sexual orientation" (AMHCA, 2021, p. 34). One dimension of a client of which a counselor needs to be aware is the client's needs and abilities. Mental health counselors need to understand the needs of individuals with disabilities and be prepared to serve them. The American Mental Health Association's Standards for the Practice of Clinical Mental Health Counseling demands that mental health counselors be competent in serving individuals with disabilities. Mental health counselors are expected to know how to obtain appropriate, research-based assessment instruments for special populations, including people with intellectual disabilities (AMHCA, 2021).

Mental health professionals should use multiple methods for assessment; examples of assessment methods include observations, interviews of client and stakeholders (such as family, teachers, other people important to the client), examination of collateral data (such as educational and medical records), and tests of cognition, personality, and behavior (APA, 2022). For standardized assessment instrument and interventions / treatment manuals to be considered acceptable for use with clients with individuals with intellectual disabilities, those assessments should be normed on that population (Chapin et al., 2018, p. 7). Additionally, appropriate accommodations should be provided when assessing individuals with intellectual disabilities; these are modifications to the environment / situation that do not affect the assessment results like extra time, large print, and questions read aloud, among others (APA, 2002).

Counselors are not required to choose a specific counseling theory / treatment method for individuals with intellectual disabilities (APA). This is because, for all types of psychotherapy / counseling theory:

> "…psychotherapy, regardless of the client, is shaped by the psychological concerns, the client's strengths and goals, negotiated with the [mental health professional], and meaningful, reasonably expected therapeutic outcomes based on available practice evidence… Potential therapeutic outcomes will depend on the therapeutic relationship and a realistic intervention plan within which to address goals and the [mental health professional]'s ability to understand the client's life circumstances (i.e., relevance to daily life), which may be more complex for people with disabilities" (APA, 2022, p. 38).

So, a mental health counselor should base their treatment approach on the client's mental health needs and goals; this should be done with all clients, not just those with intellectual disabilities (APA, 2022).

Unfortunately, many counselors are not well prepared to serve individuals with disabilities (Oksüz & Brubak, 2020). Three studies of counselor preparation for working with individuals with disabilities are briefly summarized below. Rivas and Hill (2018) studied counselors-in-training; Strike et al. (2004) studied counselors with varying levels of experience (from 1 – 36 years); and Feather and Carlson (2019) surveyed counselor educators.

Counselors-in-training were interviewed for Rivas and Hill's (2018) qualitative study. This was a phenomenological study of the experiences of counselors-in-training working with individuals with disabilities. The participants were enrolled in an internship at the end of a CACREP-accredited master's program. Overall, the participants reported

feeling inadequately prepared to provide counseling to individuals with disabilities. The participants reported that their graduate coursework had not covered disability at all, or only in isolation, and that their training experiences with individuals with disabilities was inconsistent. Rivas and Hill (2018) cited other studies of counseling students and argued that the lack of preparation (for counseling individuals with disabilities) is a common problem among counselors-in-training.

Mental health professionals with experience from 1 to 36 years were the participants of study in Strike et al.'s (2004) research. Strike's Counseling Clients with Disabilities Survey (2001) was utilized which measures three main constructs related to disability competence in counseling: perceived awareness, perceived knowledge, and perceived skills. This 67-item questionnaire included a list of statements about disability awareness, knowledge and skills and participants were asked to rate themselves on a Likert scale from strongly agree to strongly disagree. Scores from all items were added to compute level of disability competence. While all participants reported having experiences with disability, "the participants reported significant limitations in their disability competence (Strike et al., 2004, p. 326). When looking at all the participant data, Strike et al. (2004) found that the most competence was in awareness, followed by knowledge, and then skills. When comparing a group of experienced professionals to a group of newer professionals, the more highly experienced group had higher average scores for all three constructs. Strike et al. (2004) used their results to argue that mental health professionals could benefit from professional development on competence in counseling individuals with disabilities.

Counselor educators and graduate training programs were the focus of Feather and Carlson's (2019) study. These researchers surveyed 141 instructors from accredited

programs and administered three assessments: the School Counselor Education

Questionnaire, the Disabilities Questionnaire, and the Counseling Clients with

Disabilities Survey. Some of Feather and Carlson's (2019) key findings follow. Twenty-

one percent of instructors indicated that disability courses are required in their counseling

program; 18.8% of instructors answered that all students had experience with individuals

with disabilities in practicum and /or internship. When asked if their program addressed

counseling with adults with disabilities effectively, 36% admitted that they are

ineffective. Feather and Carlson (2019) also found correlation between both (a) inclusion

of disability content in curriculum and (b) disability-related experiences (both clinical

and personal) and perceived skills and competence in working with individuals with

disabilities. Feather and Carlson (2019) argued that there is evidence that it is beneficial

to include disability content into counseling curriculum and internship / practicum, yet

many counseling programs are not infusing disability content throughout their programs.

For post-graduate mental health counselors who want / need more training in

counseling for individuals with intellectual disabilities, there is a certification available

through the AMHCA. To become a Clinical Mental Health Counseling Specialist in

Developmental Disability Counseling, a counselor engages in 90 professional

development hours regarding disability counseling and engages in 100 hours of disability

counseling (AMHCA, n.d.). Such professional development would help counselors reach

proficiency in serving individuals with intellectual disabilities.

Systematic Review: Reports of How Individuals with Intellectual Disabilities

Experience Metal Health Counseling

A review of current literature reporting on the experience of individuals with

intellectual disabilities in mental health counseling was conducted. Reports on best

practice in literature reviews were consulted. According to recommendations laid out by

Harari et al. (2020), three search databases were used including both subject-area specific

databases (PsycInfo and PubMed) and large, more inclusive database (EBSCO

Academic). Relevant studies from all time periods were searched, but relevant studies

were found with the publication years from 2006 to more recent.

Figure 1 outlines the search strategy used for this review. The Preferred Reporting

Items for Systematic Reviews and Meta-Analyses (PRISMA) statement (Page et al.,

2020) was referenced when completing the flow chart in Figure 1.

Figure 1

Systematic Review Flow Chart (Page et al., 2020)
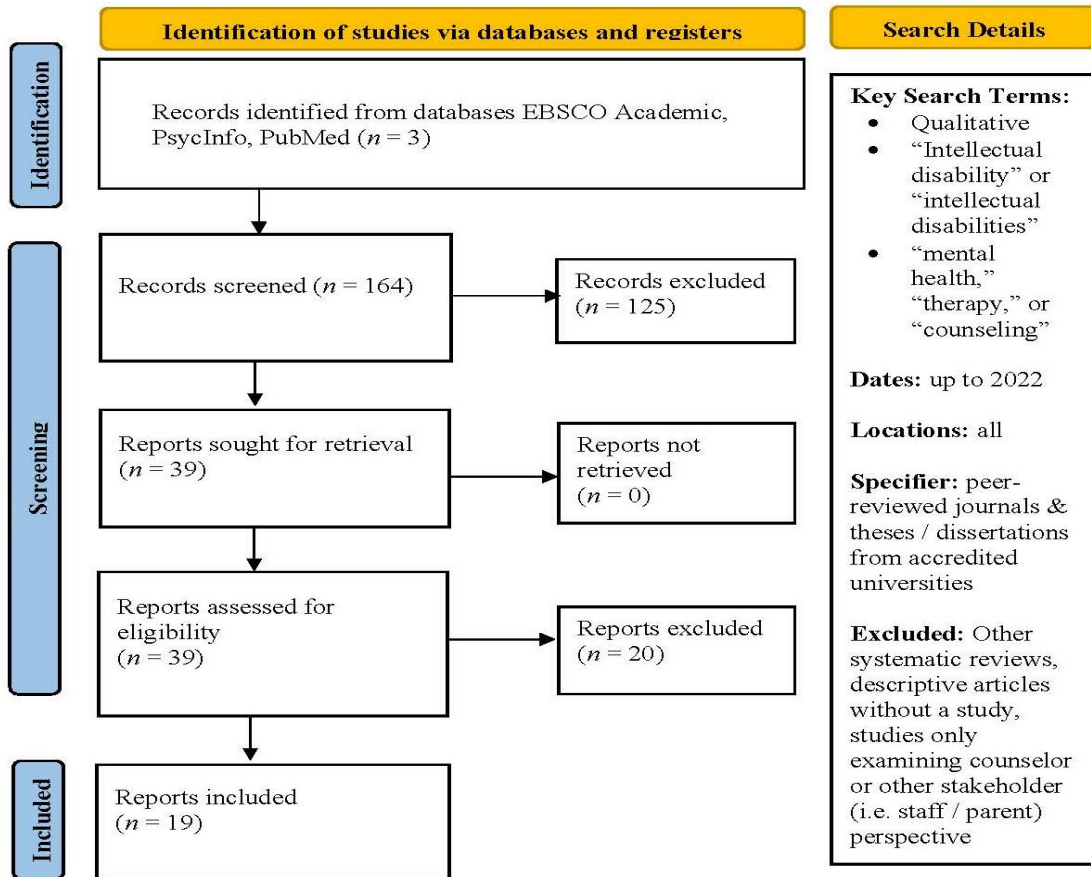
Using the search parameters outlined above, 19 studies were identified for inclusion in the systematic review. Table 1 includes basic information about these studies including authors, year of publication, location of study, research design, participant information, and relevant findings. Findings considered relevant were reported experiences of individuals with intellectual disabilities in mental health counseling. The studies are briefly described below the table.

Table 1

Summary of Studies in Systematic Review

Author(s) Year of Publication -- Location	Intervention	Research Design	Participants -- Age Range -- Level of Disability	Main Finding(s)
Cameron et al. (2020) -- UK	Psychodynamic, CBT, CAT, systemic	Qualitative (interviews) Thematic analysis of therapeutic alliance and content analysis of therapy bond, tasks, goals	6 clients + therapists -- 38 – 46 years -- Mild	•Bordin's model for therapeutic alliance (client and therapist bond and agreement on goals and tasks) is applicable to this population.
Crossland et al. (2022) -- UK	DBT group	Mixed method: •One group pre- and post-test •Thematic analysis of interviews	4 clients -- 24 – 48 -- Mild	•Psychological functioning improved; distress increased while well-being increased (quant). •Interview data revealed 6 themes: interpersonal relationships, group boundaries, making theory-practice links, our new skills, generalizing our skills out of group, suggestions for improvement. Overall, participants spoke highly of the DBT group.
Dowling et al. (2006) -- UK	Traditional bereavement counseling vs. bereavement support from usual caregivers	Mixed method: •Two matched groups •Semi-structured interviews – grounded theory	56 clients + caregivers and family members -- Adults, mostly between 30 – 50 years -- Mild, moderate, and severe	•Counseling led to significant changes in behavior while the other intervention did not (quant). •Participants reported that counselor-led treatment led to decreases in problems related to their grief, such as being angry, isolated, and withdrawn.

Hardiman et al. (2018) -- UK	CFT (compassion focused therapy)	Mixed methods: •One group pre-test and post-test •Interviews analyzed with IPA	3 clients -- 31 – 48 years -- Mild - moderate	•Anxiety decreased and self-compassionate attitudes increased for all 3 participants from before the intervention to immediately after. In later follow-up, anxiety was still significantly lower but changes in compassion varied. •Interviews revealed mostly positive thoughts that the clients had about the therapy which were grouped into subthemes: concealment vs joining the world, what helped, experiencing compassion, and understanding change.
Hassiotis et al. (2013) -- UK	Manualized Individual Cognitive Behavior Treatment (M-iCBT) + Treatment as Usual (TAU) vs TAU only	Mixed Methods: •True experiment •Semi-structured interviews	Quant: 32 clients, Qual: 13 clients -- 20 – 67 years -- Mild - moderate	•M-iCBT can be modified for use with individuals with mild – moderate intellectual disabilities. •In those participants with measurable depression at the beginning of the study, depression had a clinically significant reduction by the end of the study. •Thirteen participants agreed to be interviewed as a follow-up to the study. Interview data yielded 7 themes: (1) Participants' view of CBT, (2) Positive changes, (3) Challenges of therapy, (4) Therapist-participant relationship, (5) Role of the support worker, (6) CBT material and homework, (7) Further suggestions. Participants understood the treatment and reported that they would agree to participate in it in the future.
Hays et al. (2007) -- Australia	CBT group for sex offending (yearlong)	Qualitative (interviews)	16 clients -- 20 – 61 years -- Mild	•Participants appreciated relating to other participants and talking about their problems. Participants had varied issues about which they were dissatisfied, but, overall, most participants wanted to attend the group.
Jones et al. (2021) -- Canada	Adapted DBT groups	Mixed Methods: •True experiment •Semi-structured interviews – thematic analysis	20 clients + 20 caregivers -- 22 – 52 years -- Mild - moderate	•No statistically significant findings between control and treatment groups were found, possibly because of the low number of participants that completed all parts of the study. •For many participants, curriculum and core concepts made the therapy experience positive. Conflict with others, homework, and logistics (such as location) were described as negatively affecting the participants' experience with the intervention. Despite some negative components to the treatment, participants overall expressed satisfaction with the adapted DBT.

Kouimtsidis et al. (2017) -- UK	Adapted EBI (extended brief intervention) for drinking	Mixed methods: True experiment + semi-structured interviews	Quant: 30 clients, Qual: 7 clients -- 18 – 65 years -- Mild – moderate	•Alcohol consumption decreased after both 8 and 12 weeks of the intervention. •In interviews, participants reported mixed feelings about homework assignments, but participants generally evaluated their EBI experience positively.
Lundrigan (2007) -- New Jersey	Interactive behavioral therapy for loss	Mixed Methods: Descriptive statistics from a questionnaire + 5 case study interviews	Quant: 40 clients, Qual: 5 clients -- 39 – 55 years -- Mild – moderate	•85% of participants believed that their IBT group was helpful to them. •Six themes were identified from the interview data. (1) After losing family members, participants struggled with grief for years. (2) Participants felt that the groups helped them cope with issues in their lives. (3) Participants believe they provide support to the others in the group. (4) Participants were willing to talk to the researcher in order to help the researcher. (5) Participants who had a negative opinion of their IBT group had an interpersonal problem with a group member. (6) Participants with paranoia may be better served by individual therapy, as opposed to IBT group.
McMahon et al. (2015) -- UK	CBT group	Semi-structured interviews - IPA	11 clients -- 22 – 44 years -- Mild	•Three main themes and 10 subthemes were identified. (1) What it was like to take part: (a) the fun of the group, (b) the challenges of participation, (c) the importance of relationships, (d) talking and listening. (2) The difference the group made to my life: (a) A new me, (b) New knowledge and new skills, (c) New and improved relationships, (d) what the group didn't change. (3) Presenting a positive self: (a) attributing responsibility for anger to the actions of others and (b) an expert in anger management: demonstrating new skills and knowledge. Researchers determined that the participants found the group "effective and enjoyable" (MacMahon, et al., 2015, p. 342).
Oliver (2019) -- UK	Acceptance and Commitment Therapy	Case studies / semi-structured interviews	2 clients -- 28 and 39 years -- Mild	•Distress relief occurred quickly for both participants.

Pert et al. (2013) -- UK	CBT	Semi-structured interviews - IPA	15 clients -- 26 – 52 years -- Mild	•Themes and subthemes: (1) talking in therapy (talking is helpful, talking in private, talking can be difficult at first), (2) feeling valued and validated (being treated as an equal, my problems are taken seriously, feeling cared for and understood), (3) therapy and change (therapeutic goals, change in therapy, change is fragile). The authors found that "participants valued the opportunity to talk about problems with their therapist and benefited from therapeutic relationships characterised by warmth, empathy, and validation" (Pert, et al., 2013, p. 359). Participants identified changes in themselves but also wondered if these changes could only be temporary.
Ramsden et al. (2016) -- UK	Mental health counseling of various forms	Semi-structured interviews – thematic analysis	6 clients + psychologists and caregivers -- 19 – 43 years -- Mild	•The researchers sought to identify elements of therapy that promote and hinder positive change in individuals with intellectual disabilities. They found that the therapists were able to overcome many barriers. For example, therapists appropriately paced sessions to encourage client understanding. Despite overcoming barriers, many clients were found to be referred to mental health services repeatedly, like a revolving door. The authors suggested that therapist coordination with clients' wider support networks is a strong facilitator for positive change.
Trustam et al. (2021) -- UK	Recovery approach to mental health services	Semi-structured interviews IPA	9 clients -- 20 – 54 years -- Mild – moderate	•Two themes were identified; these were what led the participants to treatment and what contributed to their recovery. "Subthemes for entry to service included unfair treatment, valuing information and managing expectations. The recovery experience subthemes were therapeutic alliance, self-management, emotional development, autonomy, connectedness, positive identity and a belief in recovery." (Trustam, et al., 2021, p. 252). •The authors found that social difficulties led to mental health problems for many participants. Helping individuals build interpersonal connections can be beneficial in improving their mental health. The authors also recommended helping the clients understand intellectual disability and accept that intellectual disability is not the condition from which they are trying to recover in the sessions.
Whittle et al. (2019)	Overall mental health services	Semi-structured interviews	7 clients + caregivers and providers	•Interview data yielded barriers and enablers for four domains of access. Issues relating to both the clients themselves and their environments were included. The

-- Australia		and focus groups	-- Not disclosed -- Not disclosed	authors concluded that Australia's mental health care system is in need of an overhaul.
Wills, S. N. (2019) -- UK	Psychotherapy	Semi-structured interviews - IPA	4 dyads of therapist and client -- Over age 18 -- Mild – moderate	•Five super-ordinate themes were identified that related to the research questions. The first four themes described the process leading up to and surrounding the significant therapy events, comprising of: 1) The Uniqueness of the Therapeutic Relationship; 2) Using Adaptations to Express Emotions; 3) Client Behavior/Therapist Behavior; and 4) Hope and Paternalism. The final theme: 5) Meaning Making, depicted how clients and therapists made sense of the identified significant therapy event" (Wills, 2019, pp. 1 – 2). •Wills (2019) concluded that counseling with individuals with disabilities includes significant events, and that therapists need to facilitate these. The researcher suggested that when a therapist facilitates these significant events, the therapeutic relationship is strengthened. The strong therapeutic alliance allows the client to make positive change.

Cameron et al. (2020)

Cameron et al. (2020) investigated the use of Bordin's model for understanding

therapeutic alliances. In Bordin's model, the strength of the therapeutic alliance is found

in agreement between client and therapist on goals, tasks assigned (responsibilities given

to both client and therapist), and bond developed. To determine the applicability of this

model to individuals with intellectual disabilities, six dyads of therapists and clients with

intellectual disabilities were interviewed about therapeutic alliance. Thematic analysis

was used to organize the answers given by the dyads. The comments of the clients and

therapists closely aligned for therapeutic bond and tasks assigned. Regarding alignment

in goal identification, therapists identified some goals not listed by the clients, but

therapist and client often agreed on other goals. Researchers determined that Bordin's model is applicable for this population.

Crossland et al. (2022)

Crossland et al. (2002) used a mixed methods approach to examine the use of Dialectical Behavior Therapy (DBT) for individuals with intellectual disabilities. Four people participated in the DBT group. Pre-test and post-test psychological functioning test results were compared in the quantitative assessment; participants showed improvement from the first assessment to the next. The qualitative assessment involved interviews with participants and support staff regarding their experience receiving DBT. Client interviews yielded six themes. The first theme was interpersonal relationships. Clients noted their relationships with other group members growing throughout the intervention. The second theme involved group boundaries. Group policies led to clients feeling secure in sharing their confidential information. The third theme was making theory-practice links. Participants struggled with certain components of the intervention, such as the abstract content. The fourth theme involved new skills. Group members reported that while some group material was difficult to understand, their support workers helped them understand after the group. The fifth theme involved skill generalization. Participants varied in their self-reported use of newly acquired skills outside of group sessions. Suggestions for improvement was the final theme. Participants suggested various changes including weekly group introductions and changes to the number of sessions.

Dowling et al. (2006)

Dowling et al. (2006) also used mixed methods to examine the usefulness of two types of grief interventions for grieving individuals with intellectual disabilities. One

intervention was led by bereavement counselors and the other intervention was led by support staff. Based on pre- and post- intervention quantitative data, the intervention led by counselors was overall effective in decreasing symptoms of grief while the interventions led by support staff were ineffective. Semi-structured interviews were also conducted before and after the intervention period. Participants reported that counselor-led treatment led to decreases in problems related to their grief, such as being angry, isolated, and withdrawn.

Hardiman et al. (2018)

As with the studies above, Hardiman et al. (2018) employed a mixed methods approach to study psychotherapy provided to three individuals with intellectual disabilities. Compassion-focused therapy (CFT) was the intervention of study. Before and after the intervention, anxiety and self-compassion were measured via questionnaire. After the intervention, participants were interviewed about their perception of the therapeutic experience. Interpretive phenomenological analysis (IPA) was used to analyze the interview data and four themes were identified. One theme was called "concealment vs joining the world." Participants reported believing that they should keep feelings private before they received CFT. Participants began sharing their feelings as a result of the intervention. Another theme was "what helped." Participants said that their therapist and mindfulness techniques helped them make changes. "Experiencing compassion" was another theme. Despite the emphasis on compassion in CFT, compassion was not frequently described in the interviews. The final theme was "understanding change." Participants described feeling stuck with symptoms / distress before the intervention. They attributed CFT to releasing them from unhelpful thoughts and feelings.

Hassiotis et al. (2013)

Hassiotis et al. (2013) used quantitative and qualitative methods to explore the use of a manualized Cognitive Behavior Therapy (CBT) protocol for individuals with intellectual disabilities. Thirty-two participants were split into two groups: treatment as usual only or treatment and usual plus manualized CBT. Anxiety and depression were measured before and after the intervention. Changes in psychopathology symptoms were mixed based on existence of anxiety-symptoms before the intervention, but the study still showed evidence that "it is feasible to carry out a pragmatic randomized controlled trial of M-iCBT for people with mild to moderate intellectual disability" (Hassiotis 2013, p. 186). Thirteen of the participants agreed to be interviewed about their experiences in the intervention. Interview data analysis led to seven themes being identified. One theme was participants' view of CBT. Participants could identify key parts of the therapy such as content of sessions. Positive change was the next theme. Participants generally reported that CBT led them to positive change. The third theme was challenges in therapy. Participants mentioned some concerns including discomfort after sessions and difficulty generalizing skills to the real world. The fourth theme was therapist-participant relationship. Over half of the participants mentioned feeling positively about their therapist. Role of the support worker was the fifth theme. Overall, participants enjoyed the involvement of the support worker. The sixth theme was CBT material and homework. Participants found tasks easy to complete but did not like the idea of being assigned work. The seventh theme was further suggestions. Over half of the participants would recommend the intervention to others.

Hays et al. (2007)

In their qualitative study, Hayes et al. (2007) interviewed 16 males regarding a Cognitive Behavioral Therapy (CBT) group for sex offenders with intellectual disabilities. Participants were interviewed two months after completing the year-long treatment program. The researchers used The Service User Interview protocol to guide interviews; this protocol included questions about group content and participant opinions about the CBT group. The results indicated that most participants wanted to attend the group. "Having support, the knowledge that they had the same problems as other group members, and talking through problems, were appreciated as some of the 'best things' about the group, while the 'worst things' were generally person-specific" (Hayes et al., 2007, p. 106). Many participants found it emotionally challenging to talk about the sexual crimes they committed; however, many also found doing so beneficial.

Jones et al. (2021)

Another mixed methods study was conducted by Jones et al. (2021). Twenty clients and their caregivers were split into treatment and control groups. The treatment group participated in Dialectical Behavior Therapy (DBT) adapted for individuals with intellectual disabilities. Mental health, anger, and emotion regulation were variables used for quantitative analysis. The authors did not find a significant difference between treatment and control groups but speculated that this may be because of a low number of participants who completed all parts of the study. However, the authors also completed semi-structured interviews. Thematic analysis was completed, and key findings included the following. For many participants, curriculum and core concepts made the therapy experience positive. Conflict with others, homework, and logistics (such as location) were described as negatively affecting the participants' experience with the intervention.

Despite some negative components to the treatment, participants overall expressed satisfaction with the adapted DBT.

Kouimtsidis et al. (2017)

Kouimtsidis et al. (2017) studied the effect of the adapted EBI (extended brief intervention) for 30 participants with intellectual disabilities and alcohol problems. Researchers measured changes in alcohol intake during the intervention and conducted semi-structured interviews regarding participant experience. Alcohol consumption decreased after both 8 and 12 weeks of the intervention. In interviews, participants reported mixed feelings about homework assignments, but participants generally evaluated their EBI experience positively.

Lundrigan (2007)

Lundrigan (2007) wrote a dissertation about Interactive Behavioral Therapy (IBT) for bereavement in individuals with intellectual disabilities. Forty participants completed questionnaires about their perceptions of their well-being and interviews followed with five participants. Lundrigan (2007) found that 85% of participants believed that their IBT group was helpful to them. The researcher interviewed participants who both had positive and negative opinions about the groups. Six themes were identified from the interview data. Firstly, after losing family members, participants struggled with grief for years. Secondly, participants felt that the groups helped them cope with issues in their lives. Thirdly, participants believed they provided support to the others in the group. Fourthly, participants were willing to be interviewed to help the researcher. Fifthly, participants who had a negative opinion of their IBT group had an interpersonal problem with a group member. Lastly, participants with paranoia may be better served by individual therapy, as opposed to IBT group.

McMahon et al. (2015)

McMahon et al. (2015) conducted a qualitative analysis of participants'

perspectives of a CBT group for anger management. This CBT group was designed for

individuals with disabilities; staff led the group meetings using a manual. Post-

intervention, researchers conducted semi-structured interviews with 11 participants with

intellectual disabilities. Interview data was analyzed using Interpretative

Phenomenological Analysis (IPA). Three main themes and 10 subthemes were identified.

A main theme was what it was like to take part. Accompanying subthemes were the fun

of the group, the challenges of participation, the importance of relationships, and talking

and listening. The next main theme was the difference the group made to participants'

lives. Accompanying subthemes were "a new me," new knowledge and new skills, new

and improved relationships, and what the group didn't change. The third main theme was

presenting a positive self. Accompanying subthemes included attributing responsibility

for anger to the actions of others and an expert in anger management: demonstrating new

skills and knowledge. Researchers determined that, overall, the participants found the

group "effective and enjoyable" (MacMahon et al., 2015, p. 342).

Oliver (2019)

Oliver (2019) reported the experiences of two individuals with intellectual

disabilities having received Acceptance and Commitment Therapy (ACT). In this case

study, the therapist interviewed the participants about 2 months after treatment ended.

The self-report of both participants was that the treatment led to a decrease in

psychological distress. In fact, both participants shared that they experienced a decrease

in distressing thoughts after the first session. During qualitative analysis, the author found

that the comments made by the interviewee could be "mapped onto some of the ACT

processes, some of which were directly targeted, others more emergent" (Oliver, 2019, p. 261). These included defusion, present moment awareness, values and committed action.

Pert et al. (2013)

Pert et al. (2013) conducted a qualitative study about participant experiences in Cognitive Behavior Therapy. Fifteen individuals with borderline or mild intellectual disabilities and struggles depression, anxiety, and/or anger problems participated in this study. Participants received CBT from six different therapists and were interviewed after the first session and between sessions four and nine. Using IPA, the author identified three major themes, each with its own three subthemes. One major theme was talking in therapy. Accompanying subthemes included talking is helpful, talking in private, and talking can be difficult. The second major theme was feeling valued and validated. Accompanying subthemes included being treated as an equal, "my problems are taken seriously," and feeling cared for and understood. The third theme was therapy and change with the subthemes of therapeutic goals, change in therapy, and change is fragile. The authors found that "participants valued the opportunity to talk about problems with their therapist and benefited from therapeutic relationships characterised by warmth, empathy, and validation" (Pert et al., 2013, p. 359). Participants identified changes in themselves but also wondered if these changes could only be temporary.

Ramsden et al. (2016)

In Ramsden et al.'s (2016) qualitative study, participants, caregivers, and psychologists were all interviewed regarding therapy for individuals with intellectual disabilities. The researchers sought to uncover "barriers and facilitators to positive therapeutic change for people with intellectual disabilities" (Ramsden et al., 2016, p. 249). Participants were 3 psychologists, 3 caregivers, and 6 clients. Thematic analysis

yielded five superordinate themes; these had accompanying subthemes. The first superordinate theme listed was that which the client brings; subthemes were intellectual disability and level of engagement. The next superordinate theme listed was the wider system; subthemes were support networks and the influence of others. The third superordinate theme was therapy factors with the subthemes of therapeutic relationship and adaptations. The fourth superordinate theme was mental health general practitioner; accompanying subthemes were called coordinator and all needs met. The final superordinate theme was systemic dependency with subthemes called endings are difficult and function of the sick role. In addition to the superordinate and subordinate themes, Ramsden, et al. (2016) described the revolving door as the central theme; all participants described these individuals receiving mental health services as being re-referred to treatment. The authors concluded that this study provides cursory information on how to better tailor therapy for individuals with intellectual disabilities. They recommended that therapists address "wider health and social care needs of clients with disabilities" (Ramsden et al., 2016, p. 260).

Trustam et al. (2021)

Trustam et al. (2021) interviewed clients with intellectual disabilities regarding their experiences in recovery-based mental health services. IPA was used to analyze the interview data. Participants were nine adults with mild to moderate intellectual disabilities and a mental health condition. Two themes were identified; these were what led the participants to treatment and what contributed to their recovery. "Subthemes for entry to service included unfair treatment, valuing information and managing expectations. The recovery experience subthemes were therapeutic alliance, self-

management, emotional development, autonomy, connectedness, positive identity and a belief in recovery." (Trustam et al., 2021, p. 252).

Whittle et al. (2019)

Whittle et al. (2019) conducted a series of semi-structured interviews and focus groups with individuals with intellectual disabilities, caregivers, and service providers. Their goal was to identify barriers and enablers for individuals with intellectual disabilities to receive mental health services. Whittle, et al. (2019) drew on existing research to organize their findings into domains. In the service availability domain, participants mentioned both barriers and enablers. Some participants were located near multiple services, while some discussed the scarcity of services available to them. In the domain of utilization of services and barriers to access, participants mentioned various barriers including financial, personal, and organizational. In the domain of relevance, effectiveness, and access, participants discussed service providers and their quality, collaboration, language, and relationships. The participants noted that ineffective services are utilized at higher rates than helpful services. In the equity and access domain, participants noted the relationships between needs and opportunities in their communicates. For example, an indigenous participant described the way her son inappropriately treated based on clinician prejudice. The authors concluded Australia's mental health care system is in need of change.

Wills (2019)

Wills (2019) is a dissertation surrounding the process of therapy for individuals with intellectual disabilities. The author developed research questions about significant moments in the therapeutic process and how participants made sense of the process of therapy and these significant events. Participants were four therapy dyads; the clients in

these dyads were adults with mild or moderate intellectual disabilities. Data from semi-structured interviews of these dyads were analyzed using IPA. Wills (2019) found the following:

> "Five super-ordinate themes were identified that related to the research questions. The first four themes described the process leading up to and surrounding the significant therapy events, comprising of: 1) The Uniqueness of the Therapeutic Relationship; 2) Using Adaptations to Express Emotions; 3) Client Behaviour/Therapist Behaviour; and 4) Hope and Paternalism. The final theme: 5) Meaning Making, depicted how clients and therapists made sense of the identified significant therapy event" (pp. 1 – 2).

Wills (2019) concluded that counseling with individuals with disabilities includes significant events, and that therapists need to facilitate these. The researcher suggested that when a therapist facilitates these significant events, the therapeutic relationship is strengthened. A strong therapeutic alliance allows the client to make positive change.

Synthesis of Qualitative Studies

Sixteen studies qualified for this systematic review. The papers were published between 2006 and 2022. Of the 16 studies, nine were qualitative only and seven were mixed method. Twelve studies were conducted in the United Kingdom, two occurred in Australia, and the other two occurred in Canada and the United States. Within the studies, various therapies were employed including psychodynamic, behavioral, and more. Behavioral therapies – including CBT, DBT, and IBT – were the types of therapy most often used in these studies. Participants were between 18 and 67 years of age. In seven papers, the authors recorded all participants as having a mild intellectual disability. In seven other papers, the participants were all considered to have mild or moderate

intellectual disabilities. In one paper, participants were described as having mild, moderate, or severe intellectual disabilities. Finally, in one paper, the author did not disclose the level of intellectual functioning of the participants.

Despite the differences in the 16 studies (summarized above), common themes can be identified among participants' described experiences. From the interview data, the following can be summarized about the experiences of the recipients of counseling services with intellectual disabilities. Overall, participants experienced an improvement in psychological well-being while participant distress decreased. Some negative therapy experiences were shared by participants; these included locations of the counseling groups, conflict with other counseling group members, homework that the participants deemed unenjoyable. Participants reported some systemic concerns as well, such as a lack of coordination between their counselors and other providers. While interpersonal conflict in counseling group was reported by some, others reported feeling positively about their relationships with group members. Most participants reported that their therapeutic relationships were strong, that they felt positively about their experiences in therapy, and that they would return to therapy in the future.

Theoretical Framework

In this phenomenological study of the experiences of individuals with intellectual disabilities in mental health counseling, a feminist disability lens is being employed. In this section, feminist disability theory will be explained, including its underlying philosophical assumptions. Key points in the development of the philosophy of disability are then provided. Lastly there will be a rationale for the use of a feminist disability phenomenological approach in this study.

Feminist Disability Theory Defined

Within feminist disability theory, disability is conceptualized as a category of difference like sex, gender, sexual identity, ethnicity, nationality, and socio-economic status (SES). These categories are considered socially constructed "exclusionary and oppressive systems rather than as the natural and appropriate order of things" (Garland-Thomson, 2002, p. 6). This means that feminist disability theorists embrace a social model of disability (Hinton, 2021). In other words, individuals with physical, emotional, and/or cognitive impairments are disabled when oppressed by society (Crow, 1996; Morris, 2001). It is true that individuals with these impairments may experience real pain, fatigue, psychological symptoms, and other difficult experiences which require medical attention and/or accommodations. However, it is only through society that a conceptualization of a condition as something inferior, pathological, or something needing elimination is created. In an ableist society, people are expected to be able to function in a certain way. Individuals with physical, emotional, and/or cognitive impairments are considered imperfect or less than; those seen as different or abnormal are considered diseased and needing treatment (Hinton, 2021).

In this study, the antiquated, oppressive, ableist way of viewing the disabled as defective is rejected (Creswell & Poth, 2018; Siebers, 2008). Ability and disability are viewed as socially constructed categories of difference. A feminist disability lens is used in examining "the contingencies of human experience and consciousness and… understanding the pervasive influences of ideology, politics, language, and power structures as they construct and constrain the lived experiences of people" (Simms & Stawarska, 2013, p. 11).

Philosophical Assumptions. An important part of phenomenological, qualitative research is explaining the philosophical assumptions guiding the research (Mason, 2002). In fact, "...questions of validity involve ontological and conceptual clarity" (Mason, 2002, p. 188). Accordingly, the ontology, epistemology, axiology, and methodology underlying feminist disability theory are summarized in this section.

Ontological Beliefs. Ontology refers to the nature of reality. From the perspective of a qualitative researcher, "reality is based on power and identity struggles" (Creswell & Poth, 2018, p. 36). Power differentials exist in society based on people's various categories of difference. Privilege and oppression affect one's reality (Creswell & Poth 2018).

Epistemological Beliefs. Epistemology refers to the theory of knowledge. Many feminist disability theorists believe in standpoint theory; this is the idea that social position affects a person's access to knowledge (Stoetzler & Yuval-Davis, 2002). Knowledge is gathered through examination of oppression, power, control, and social structures (Creswell & Poth, 2018).

Axiological Beliefs. Axiology refers to how values are classified. Feminist disability theorists believe that the varying values of researchers and participants are important and should be explored in research (Creswell & Poth, 2018). A feminist disability researcher is to acknowledge her own values related to the research topic and share these with the reader (Ponterotto, 2005). Since feminist disability researchers accept that power is often maldistributed in society based on categories of difference, "a preset goal of the research is to empower participants to transform the status quo and emancipate themselves from ongoing oppression" (Ponterotto, 2005, p. 131).

Methodological Beliefs. Methodology refers to the process of research. Feminist disability theorists believe that a researcher should "start with assumptions of power and identity struggles, document them, and call for action and change" (Creswell, 2018, p. 36). Researchers should conduct meaningful social research, disseminate findings in ways accessible to many – not just other scholars – and advocate for findings to lead to real life change.

Feminist Disability Theory: History

To understand feminist disability theory, it is helpful to review some key developments in the history of philosophy and psychiatry. In 1961, Thomas Szasz released the seminal text, *The Myth of Mental Illness*. In this text, Szasz argued that doctors were mistakenly focused on physiochemistry when treating patients with disabilities and/or mental illness (Hogan, 2019). Szasz was initially an exclusionist which means that he rejected the "medical model," which was a term he coined (Hogan, 2019). Szasz's model was a social model; he argued that focusing treatment or the remediation of disability or mental illness was oppressive and inappropriate because this ignores the effect of societal problems on the patient (Hogan, 2019). Szasz – and others opposed to the medical model – believed that disability is a social construct created in a prejudiced society and that the medical model has led to "policies and services that… did not result in meaningful life improvements" (Richmond-Frank, 2015, p. 304).

While exclusionists wanted to prevent mental illness and disability from being treated medically, antireductionists pushed for medical reform (Hogan, 2019). Antireductionists acknowledged that certain parts of disability and mental illness are related to physiochemical factors and may require medical treatment, but the effects of society and

environment must be considered (Hogan, 2019). A popular proponent of the antireductionist approach was George Engel.

In 1977, Engel proposed a revision of the medical model called the biopsychosocial model. In the biopsychosocial model, the origins of disability and mental illness were conceptualized as being both within the patient and societal / environmental. Engel encouraged clinicians to consider "the interactions with genetic susceptibility, personality, stressful events, and, generally, with the patient's social context. Environmental factors "increase the probability of the clinical expression of amental disorder, play a role in the time of onset of an illness's manifestation, and they can also protect a vulnerable person from the disease" (Papadimitrou, 2017, p. 109).

In the 1990's, feminist disability theory was developed. This theory embraces a social model of disability, which means that disability is another social construction, like race, gender, ethnicity, and other categories of differences. In the social model, it is discrimination and exclusion which causes the suffering of those considered to be "different" or "the other."

Liz Crow (1996), a prominent feminist disability theorist, asserted that with disability, unlike other categories of difference such as gender or religion, issues of pain, fatigue, psychological problems, and other troubling symptoms can occur, regardless of societal influence. Therefore, Crow (1996) argued that impairment – including the objective concept of a person's limited bodily functions and an individual's subjective interpretation of their own experience in their body – can be acknowledged without calling a person's body inferior or labeling the experience of another as tragic. It is the wider social context of impairment, wherein discrimination and exclusion disable those with impairments – that is problematic (Crow, 1996). Therefore, feminist disability

scholars reject the medical model in that impairments lead to a person being considered defective or even unworthy of life. However, impairment is considered, which was not in a traditional social model.

Jenny Morris is another prominent feminist disability scholar. Morris (2001), like Crow (1996) argues for the use of a social model of disability with a recognition of impairment. Morris (2001) also argued for the acknowledgment of difference. She explained that all people have human rights, and for those with impairments, they may need certain accommodations or services to have their rights met (Morris, 2001). For example, all American children are entitled to a free and appropriate public education. For a child with a hearing impairment to receive education, an interpreter may be needed. In summary, there are many commonalities among people regardless of their bodily abilities; however, acknowledgement of differences can be necessary to determine what people need for their rights to be met.

Contemporary disability theorists have criticized early disability scholars for discussing a primarily white, Western, neurotypical, straight experience of disability. "As the field developed, scholars began to merge theories and methodologies used in Disability Studies with those popular in Queer and Feminist theory, demonstrating how ableism, or the preference for the able body, is imbricated in how we understand gender and sexuality as socio-historical constructions" (Hinton, 2021, p. 14). Intersectionality in disability studies continues to be explored. Topics explored include critical race (Schalk & Kim, 2020), international settings (Wiseman & Ferrie, 2020), domestic violence (Muster, 2021), neurodiversity (Johnson, 2021) and much more. Despite the varying topics of focus, feminist disability theory continues to be a lens through which scholars can analyze power differentials and promote social justice and change.

Feminist Disability Theory: Rationale for Use

Feminist disability theory was incorporated into this phenomenological study from the origin of the project. This theory / lens was chosen because the beliefs and values of feminist disability studies align with both the beliefs and values of the researcher and of the research project itself. Garland-Thomson's (2005) common components of feminist disability research will be discussed below as a rationale for the use of this theory.

Feminist disability scholars portray "disability as a social category of analysis" (Garland-Thomson, 2005, p. 1557). This is a primary assumption in the current study. The analysis is focused on the intersections of social constructs and how these are related to experiences of mental health counseling. Disability is seen as resulting from power dynamics (Garland-Thomson, 2005).

The field of feminist disability studies "understands disability as a system of exclusions that stigmatizes human differences" (Garland-Thomson, 2005, p. 1557). One can conceptualize an alternative universe wherein there are no intelligence quotients measured or labels placed on individuals based on assessment results. Society has defined intellectual disability and has conceptualized the condition as making one deficient. In this study, there is an underlying assumption that intellectual disability is a social construct. The antiquated way of viewing the disabled as defective is rejected (Creswell & Poth, 2018; Siebers, 2008).

The field of feminist disability studies also "reveals discriminatory attitudes and practices directed at those bodies" (Garland-Thomson, 2005, p. 1557). In this study, individuals with intellectual disabilities will be asked to share thoughts and feelings surrounding their experiences in mental health counseling. Any experiences of being

misunderstood or mistreated during counseling will be reported in the results and discussion sections.

In summary, feminist disability theory is appropriate for use in this phenomenological study because the underlying beliefs and goals are in sync. The researcher aims to help the voices of individuals with intellectual disabilities be heard. The experiences of individuals with intellectual disabilities in mental health counseling are important; these experiences should be heard by both researchers and practitioners.

CHAPTER III: METHODOLOGY

Clients' experiences are important to consider when evaluating the efficacy of psychotherapy (Macran et al., 1999). To be able to describe the essence of mental health counseling experiences for individuals with mild intellectual disabilities, a phenomenological, qualitative research design was chosen. Qualitative research involves gathering and analyzing information with the goal of constructing "rounded and contextual understanding on the basis of rich, nuanced and detailed data" (Mason, 2002, p. 3). Phenomenology is a type of qualitative research which is "descriptive and focuses on the structure of experience, the organizing principles that give form and meaning to the life world" (Laverty, 2003, p. 27). Phenomenology (Moustakas, 1994) involves the exploration of a person or group of people's experience of a topic; phenomenological researchers seek to describe the essence of that experience. Interpretive Phenomenological Analysis "seeks to explore how individuals make sense of their major life experiences and is committed to the detailed study of each particular case before moving to broader claims" (Charlick, et al., 2016). Descriptions include both "what" was experienced and "how" it was experienced (Creswell & Poth, 2018). In this chapter, the following components of this qualitative, phenomenological study will be explored: participants, researcher as a human instrument, study procedures, data analysis, and methods to ensure trustworthiness.

Participants

Participants in this study were gathered from a pool of Indiana Medicaid waiver recipients. In Indiana, individuals of all ages who were diagnosed with an intellectual and/or developmental disability by the age of 21 can apply for a Medicaid waiver - the Family Support Waiver and/or the Community Integration and Habilitation Waiver. The goal of these waivers is to:

> "provide access to meaningful and necessary home- and community- based services and supports…. [The Bureau of Developmental Disability Services] seeks to implement services and supports in a manner that respects the participant's personal beliefs and customs, ensures that services are cost-effective, facilitates the participant's involvement in the community where he/she lives and works, facilitates the participant's development of social relationships in his/her home and work communities, and facilitates the participant's independent living" (Indiana Family and Social Service Administration, 2020).

To answer the research questions, eligibility criteria included intellectual disability diagnosis, a history of mental health counseling treatment, and willingness to discuss experiences in counseling. Study population eligibility criteria also included being between ages 18 and 40 and mild intellectual disability diagnosis. Other diagnoses (such as developmental conditions like Cerebral Palsy) did not preclude participation so long as the participant is able to communicate with the researcher through speech or writing. "Psychological homogeneity" was the sampling goal; participants were "selected based on the possession of a particular trait or ability" (Robinson, 2014, p. 28). Also, both emancipated individuals and those with guardians were invited to participate; guardian approval was obtained when appropriate.

Interested participants learned about informed consent from the researcher. The researcher explained the purpose of the study, the time / date / setting for the interview, confidentiality which means that names and other identifying information are withheld from publication and that the data was marked with codes only known by the researcher, the voluntary nature of the study which means that participants could stop at any time without fault, contact information for mental health resources should study participation lead to any mental health concerns, and contact information for the researcher. Participants were encouraged to ask questions if they had any questions or concerns.

In a qualitative study, Ahern (2012) studied the efficacy of the informed consent process in conveying benefits and risks in qualitative research. Ahern (2012) completed telephone interviews with 9 obstetric health professionals regarding a study about distressing personal and professional issues in which they were participants. Participants were to share about their experiences with being research participants, the benefits / harms they perceived as occurring from participation, how worthwhile they found being a participant, how accurate their experiences were portrayed in the research results, and their thoughts about being a research participant again in the future (Ahern, 2012). Ahern (2012) used iterative thematic analysis via a computer program to identify themes. Some key findings included the following. Participants experienced some distress during the qualitative interview regarding personal and professional issues. Informed consent documents are often daunting, even for the highly educated participants in Ahern's (2012) study. Participants were given transcripts of their interview to review for accuracy during the original study, and some participants reported to Ahern (2012) that this experience was embarrassing. Overall, the participants found that the benefits of the

experience outweighed the temporary trepidation that they initially experienced (Ahern, 2012).

Ahern's (2012) findings and accompanying recommendations were considered in the design of this study's informed consent procedures. Effort was made to make the interview process less stressful for participants. This was done by explaining that the study is exploratory, that there are no consequences for the counselors or participants based on information revealed in the interview. The participants were also invited to choose a time and setting for the interview to increase comfort. The explanation of informed consent was described using simple language and questions for clarification were encouraged. Transcripts for the interview were not provided. Instead, at the end of each interview, the researcher reviewed the content of the discussion and invited the participant to clarify provided information, make changes, and/or add to the information provided. Each participant was also invited to contact the researcher after the interview with further information. (No participants have reached out to the researcher at the time of this writing.)

Researcher as a Human Instrument

In addition to obtaining consent, the researcher participated in "all stages of the study from defining a concept to design, interview, transcription, analysis, verification and reporting the concepts and themes" (Sanjari et. al., 2014, p. 2). In this qualitative study, the researcher served as a human instrument. This is because the "qualitative researcher is the primary instrument for data collection and analysis. Data are mediated through this human instrument, rather than through inventories, questionnaires, or machines" (Atieno, 2009, p. 14). Researchers are considered effective human instruments due to their ability to quickly synthesize data and provide follow-up during the data

collection process (Sanjari et al., 2014). The researcher led semi-structured interviews with participants. An interview protocol (Appendix B) was used to guide the interview process, but "it is through the researcher's facilitative interaction that a conversational space [was] created" (Pezalla et al., 2012, p. 167).

Since the researcher served as a human instrument in this qualitative study, it is important that this researcher make a personal statement of positionality (Holmes, 2020). According to Savin-Baden and Major (2013), when a researcher explores their positionality, they should consider doing the following:

> "Firstly locating themselves about the subject, i.e., acknowledging personal positions that have the potential to influence the research. Secondly, locating themselves about the participants, i.e., researchers individually considering how they view themselves, as well as how others view them, while at the same time acknowledging that as individuals they may not be fully aware of how they and others have constructed their identities, and recognizing that it may not be possible to do this without considered in-depth thought and critical analysis. Thirdly, locating themselves about the research context and process, i.e., acknowledging that research will necessarily be influenced by themselves and by the research context" (Holmes, 2020, p. 3).

These suggestions are used in exploring researcher positionality below.

The researcher is a feminist who advocates for the rights of those generally labeled as "other." The researcher approaches research projects with the hope of challenging power dynamics and promoting the needs of oppressed groups. This passion influenced the researcher to study a group known to experience victimization (individuals with intellectual disabilities). Because of her passion for investigating issues of power

and oppression, the researcher was aware of how issues of power and oppression operate but was still mindful to avoid looking / actively trying to find discrimination during the study. This is an exploratory study, and the researcher remained open to the results; otherwise, errors such as confirmation were at risk for tainting the findings. Methods for combating bias are reviewed below.

The researcher has over ten years of experience providing behavior services to individuals with intellectual disabilities. This experience has given the researcher some perspective on how she and potential participants may relate to one another. The researcher is white; this is the most common race in the area where the participant pool was gathered. The researcher has been a member of the middle-class throughout her life. As income is low for many individuals with intellectual disabilities (DeNavas-Walt & Proctor, 2015), it is possible that the SES of the participants and the researcher were different. The researcher has not had an intellectual disability but has participated in mental health counseling before. It is unlikely that participants in the study were aware of the researcher's diagnoses or treatment experiences. The researcher tried to convey openness and a lack of judgment to encourage the participants be open to share their experiences, regardless of whether they believed that the researcher has similar experiences.

Through bracketing, the researcher worked to be cognizant of potential biases and to put aside preconceived notions (Creswell & Poth, 2018, p. 314). The goal of bracketing is to "mitigate the potential deleterious effects of unacknowledged preconceptions related to the research and thereby to increase the rigor of the project" (Tufford & Newman, 2010, p. 81). As a part of this process, the researcher was careful about the way questions were asked during the interview; the interview protocol

(Appendix B) was followed. Attention was paid to nonverbal communication as well; attempts were made to appear interested, open, and nonjudgmental to participants. Notes were taken throughout the processes of data collection and analysis. Chan et al.'s (2013) guidelines, such as using a reflexivity journal, were employed. Efforts at increasing transparency and reducing the effects of researcher bias took place throughout the study.

To continue the process of reflexivity, the researcher's assumptions about the study will now be explored. The researcher's educational experiences in school psychology and clinical mental health counseling contribute some bias regarding the experience of individuals with intellectual disabilities in mental health counseling. The researcher felt that without her school psychology degree, she would have felt underprepared to serve individuals with intellectual and developmental disabilities. Therefore, the researcher expected that study participants would likely feel that at least some mental health counselors were underprepared for servicing their / their special needs. This expectation can lead to a bias in the way the interviewee's statements are interpreted. Accordingly, methods including peer review and debriefing – which are described more thoroughly in the methods section – were used to decrease the negative effects of bias.

Study Procedures

Participant Recruitment Plan

Participants were recruited from the pool of Indiana CIH and FSW waiver participants. The researcher is affiliated with a waiver-based service, and therefore has connections to case managers, behavior consultants, other therapists, and program managers who assisted in finding eligible participants. The researcher did not recruit from her own caseload. An IRB-approved recruitment email was sent to those service

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providers (Appendix A). Providers were provided a summary of the study and eligibility criteria for participants. Providers were asked to give the researcher's contact information to potential participants. After interviews are completed, participants were invited to refer other waiver-users who may be interested in taking part of the study.

A mixed sampling approach was used to gather participants (Creswell & Poth, 2018). Convenience sampling occurred first; the researcher contacted local professional contacts to help find eligible candidates. Criterion-based sampling then allowed the researcher to gather participants meeting certain requirements which were mild intellectual disability diagnosis, a history of being in mental health counseling, a willingness to discuss experiences in counseling, and being between ages 18 to 40. Snowball / chain sampling would have occurred if participants referred others to take part in the study; however, no participants did that.

When sampling procedures are done well, a qualitative study yields rich, detailed information about a phenomenon (Palinkas et al., 2016). The following seven qualities of strong sampling strategies for both qualitative and quantitative research were proposed by Kemper et al. (2003). The sampling strategy is chosen with the conceptual framework and research questions in mind. The sampling procedure will lead to a thorough description of the phenomenon. The study of the sample should lead to inferences being made from the data. The sampling procedure is ethical. The sampling procedure is feasible. The sampling procedure will lead to results generalizable to some. The sampling procedure is efficient.

Kemper et al.'s (2003) suggestions for strong sampling procedures were used in the development of the current study. Participants with varying categories of difference (e.g., sexes, races) were welcome to participate. The goal was made for 10 participants to

be identified, as this has number has been deemed appropriate by many

phenomenological researchers (Moser & Korstjens, 2018; Groenewald, 2004)[2]. When

determining the sampling strategy most appropriate for this study, qualitative sampling

strategies were employed. In *quantitative* studies, researchers generally seek out a large,

diverse sample to increase generalizability of results. However, in qualitative work,

> "statistical representativeness is not a prime requirement when the objective is to
>
> understand social processes… The purpose is not to establish a random or
>
> representative style from a population but rather to identify specific groups of
>
> people who either possess characteristics or live in circumstances relevant to the
>
> social phenomenon being studied" (Mayes & Pope, 1995, p. 110).

Therefore, participants will be gathered who are able to contribute information that will

yield a rich picture of the experience of mental health counseling for individuals with

mild intellectual

disabilities.

Developing Interview Questions

The interview protocol was designed by the researcher. Four main sources were

drawn upon when the protocol was created. These were Moustakas' (1994)

conceptualization of phenomenology, the study research questions, Trustam et al.'s

(2021) interview protocol format, feminist disability theorists' critical approach /

rejection of pathologizing and other assumptions based on the medical model, and

Hollomotz' (2018) suggestions for interviewing individuals with intellectual disability.

Moustakas (1994). Moustakas' (1994) conceptualization of phenomenology

inspired the types of questions asked. Phenomenology is an exploration of the essence of

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[2] More participants would have been welcome, but the researcher was unable to find
more participants after recruiting for approximately 7 months.

a topic experienced by participants. According to Moustakas (1994), participants should be asked about what they experienced and what affected their experiences. Accordingly, interview questions were designed to prompt participants to share the "'what' and 'how' of their lived experiences" related to counseling (Thai, 2018 p. 63).

Research Questions. This study's research questions guided the aims of the interview questions. In other words, the content of the interview questions was designed with the research questions in mind. These research questions focused on how individuals with intellectual disabilities perceive the characteristics of themselves and their environments which contribute to change (including, but not limited to, personal strengths, support from others, and access to transportation and paid work), the relationships between themselves and their counselors, their expectations of counseling and its ability to affect positive change, the process of counseling (including goal setting, interventions / activities completed in-session, and homework) and outcomes from counseling. As mentioned in chapter 1, the first four of these areas are based on Lambert's (1992) four factors for therapeutic change. The final research question is based on participant perceptions of the outcomes of counseling. Interview questions were designed to address each of the four factors and the outcomes of counseling. Interview questions / prompts can be seen in Table 2.

Trustam et al. (2021). Trustam et al. (2021) provided an interview protocol design that was used in this study. Trustam et al. (2021) conducted a phenomenological analysis of the experiences of individuals with intellectual disabilities in a recovery-based treatment program. The interview protocol for this study included the aim, the area of focus, and prompts for each topic.

Feminist Disability Theory. As previously described, feminist disability theorists reject the pathologization of disability and conceptualize disability as a socially constructed category (cf. Hinton, 2021). Accordingly, a critical lens was employed when designing the interview questions. The questions did not reference diagnoses, referenced environmental effects on mental health (instead of focusing only on participant), and rejected the assumption that mental health counseling would be beneficial for the participants (and instead asked the participants to share their thoughts about the helpfulness of the counseling).

Hollomotz (2018). Hollomotz's (2018) suggestions for improving interviews with individuals with intellectual disabilities were used when completing the interview protocol. To increase an interview's accessibility to the participants, Hollomotz (2018) suggested that interviewers of individuals with intellectual disabilities consider: getting to know interviewees' communication preferences, adjusting depth of questioning, providing a frame of reference, using less ambiguity in the questions, providing options for closed or open-ended answers, consulting with secondary sources (when appropriate) for verification of participant reports, and referring to field observations. The interview questions are shown in table 2. The full protocol can be viewed in Appendix B.

Table 2

Interview Questions

	Aim	Introduce area of focus	Example prompts
1	Expectations of counseling	I am interested in your thoughts about counseling when you began receiving it.	Did you expect that counseling would lead to meaningful changes in your life?

2	Personal and environmental contributions to change	Perhaps there were reasons why you thought you would / would not make meaningful change.	What was it about you or your environment that made you feel like you were (or were not) going to make meaningful change?
3	Therapeutic relationship	I'm also interested in the experiences you've had in your counseling relationship(s).	How would you describe the relationship you had with your counselor?
4	Counseling process	Please think about the activities you completed in sessions with your counselor (homework you were assigned, the information you were provided, etc.).	What did you think about the activities, assignments, education, etc. provided / led by your counselor?
5	Outcomes from counseling	Now, let's discuss what happened as a result of counseling.	How did counseling affect you, if it did? Did it live up to your expectations?

Recruitment, Interview Procedures, and Data Collection

After the dissertation proposal was approved by the dissertation committee, the research protocol (Appendix C) and other study information was submitted to the University of Louisville's Institutional Review Board. After getting IRB approval, the researcher began recruiting participants via email in the spring of 2023. This involved contacting 10 coworkers who also work with consumers of the Community Integration & Habilitation and Family Support Medicaid waivers with the IRB-approved recruitment email (Appendix A). The coworkers who were contacted included two other behavior consultants, three music therapists, two case managers, one day program manager, and two direct support staff members. These coworkers were asked if they had any consumers on their caseload who were between ages 18 and 40 and had a history of receiving mental health counseling. If so, they were asked to contact that consumer and ask if the researcher could interview them. Twelve potential participants were referred to the researcher.

For emancipated individuals, the next step involved reviewing informed consent. For individuals with guardians, the researcher first discussed informed consent with the guardian. Informed consent conversations and interviews took place virtually and in-person, depending on the preference of the participant (and guardian, when applicable). The interviewer explained that interview data will be coded, rather than named, to help with confidentiality. The researcher also explained that interview data, including quotes, may be used in the research paper, but that this will be done anonymously. Participants and guardians were informed that an audio recording was made for each interviewee, but these were destroyed after transcription. The researcher explained that it could be distressing to discuss counseling experiences; participants were encouraged to reach out

to mental health resources if they experienced any of this distress. These resources were given to the participants. Guardians signed informed consent documents while participants gave verbal consent (as per guidelines approved by the IRB). All 12 referred individuals agreed to participate and were interviewed.

Once participants and guardians understood informed consent, the researcher interviewed each participant. The IRB-approved interview protocol (Appendix B) was used to guide the interviews. The participants were thanked for taking their time to participate in the interview. An introduction to the study followed. The interviewer explained that the purpose of the study was to investigate the experiences of individuals with intellectual disabilities in mental health counseling. The participants were told that they would be asked about five aspects of counseling. They were encouraged to let the interviewer know if they needed clarifications, definitions, or breaks from the interview. No participants declined to do the interview nor were any interviewed terminated early.

While the primary researcher conducted the interview, the Otter recording app was used to audio record and transcribe the interview. After each interview, the researcher made notes, reflecting on the research progress (as part of the bracketing and reflexivity process). Also, the researcher compared the transcriptions to the recorded audio files to check for errors; edits were made when needed.

Recruitment continued while interviews were conducted. Recruitment stopped after the researcher exhausted all potential contacts. Twelve people were interviewed. Later, the researcher found out that the age of one of the participants was outside of the 18-to-40-year age range. Accordingly, this data was removed from the analysis. So, the sample size was 11. A sample of 10 participants or more can allow for saturation of

qualitative data according to many qualitative researchers (cf. Moser & Korstjens, 2018; Groenewald, 2004).

After participants were interviewed and data analysis began, the researcher noticed that participant responses to questions were often quite short. The researcher realized that she may have proceeded from one question to another too quickly (perhaps due to anxiety), not allowing for participants to think and expand upon their answers. Accordingly, the researcher contacted guardians and their adult children to see who would be available to be re-interviewed. Eight individuals were re-interviewed. These took place in the same settings as the first interviews for all but one participant. This emancipated participant recently moved to a different city in Indiana. So, while she was originally interviewed face-to-face, the second interview took place via phone. During these second interviews, the researcher explained that she was re-asking the interview questions to see if the participants had more to share. The researcher was cognizant to give the interviewees time to think and answer fully. The researcher again used the Otter app to record and transcribe the interviews.

Data Analysis

In Interpretive Phenomenological Analysis, data analysis is a process that begins during data collection. This is because phenomenological researchers take notes and reflect on interview data as it is collected, and continuously work to prevent bias from affecting the data analysis. Epoche, also known as bracketing, is a method used to prevent bias in qualitative research (Creswell & Poth, 2018).

Epoche or Bracketing

IPA begins with epoche or bracketing (referred to as bracketing going forward), and this continues throughout the research process (Creswell & Poth, 2018). Bracketing

is when a researcher assesses her own experiences and biases surrounding a study's subject matter and attempts to separate these from the research (Creswell & Poth, 2018; Chan, et al., 2013). While it is impossible for any person to be completely objective, there are actions that a researcher can do to decrease prejudice (Chan et al., 2013). Chan et al. (2013) recommended the following components of "BRACKETING":

> Begin with a mentality assessment of the researchers' personality; Reflexivity helps the researchers to identify areas of potential bias; Analyze data in IPA using Colaizzi's method; Comply with the prevailing gate-keeping policy when deciding the scope of the literature review; Keep a reflexive diary, helping to awaken the researchers' own preconceptions; Engage participants in bracketing during the data collection process when indicated; Thorough research planning before data collection; Interview the participants using open-ended questions; adopt a Not-knowing stand to maintain the curiosity in the participants; Generate knowledge from participants via semi-structured interviews. (pp. 6-7)

These guidelines were used throughout the research process to help reduce the effect of researcher biases on the study results.

Conducting Interpretive Phenomenological Analysis

While using bracketing throughout the study, the researcher employed Smith et al.'s (2022) process for interpretive phenomenological analysis. As summarized in Olsen, et al. (2023), the steps involved in this process were as follows.

> "(1) Verbatim transcriptions were read and reread to understand participants' narrative descriptions… (2) …Descriptive annotations

represented events, relationships, and values through the eyes of the

participants. Linguistic annotations paid particular attention to the words,

phrases and expressions – the specific use of language – participants use.

Conceptual annotations began to interpret participants' understandings and

perceptions of their experiences. (3) … Experiential statements

summarized individual participant stories. (4) … The experiential

statements that clustered into a single cohesive idea were combined to

form personal experiential themes. (5) … The transcripts were read, noted,

and personal experiential themes compiled independent of other

participants' data. (6) … All personal experiential themes … were

compared to each other. These comparisons led to the generation of a list

of … themes" (p. 5).

After these six steps of interpretive phenomenological analysis are complete, the

generated list of themes can guide a composition of a narrative account of the topic.

Below, the IPA process completed by this researcher is summarized and findings are

detailed.

First, the researcher reviewed each line of data for emerging themes, now called

"experiential statements" (Smith & Nizza, 2021). Using guidelines provided in Smith, et

al. (2022), experiential statements for each interview were noted in the margins of the

transcripts. Notes taken were regarding "content (what is actually being discussed),

language use (features such as metaphors, symbols, repetitions, pauses), context, and

initial interpretative comments" (Pietkiewicz & Smith, 2014, p. 367). Then, similar

experiential statements were clustered and "personal experiential themes" (PETs) were

formed[3] (Smith et al., 2022).

The personal experiential themes were then arranged to make a case level

summary. Each case was reviewed independently. This means that the researcher tried to

put aside previously reviewed data when reading another case to decrease bias. The

researcher reviewed the case level summaries and looked for themes across these. These

clusters of cross-case personal experiential themes became group experiential themes.

The researcher finally composed a narrative account of the phenomenon, which is in

chapter four of this dissertation. The researcher employed an emic and etic perspective

throughout the analysis; this means that the data was examined both through the context

of relevant theories (etic) and from an outside, bracketed, perspective (emic) (Pietkiewicz

& Smith, 2012). Relevant quotes from the interview transcripts were included throughout

this narrative account (Pietkiewicz & Smith, 2014). These quotes served to both allow

readers to "assess the pertinence of the interpretations" and to better understand

participants' experiences (Pietkiewicz & Smith, 2014, p. 368).

Ensuring Trustworthiness

When the process of IPA is complete, the goal is that the description of the

phenomenon accurately reflects the experiences of the participants. The concept of

trustworthiness in qualitative research involves the validity, "consistency and integrity"

of a study design (Carcary, 2009, p. 14). These mechanisms / tools can be used by

qualitative researchers for increasing the validity and trustworthiness of the study:

reflexivity, member-checking, peer debriefing, auditing, prolonged engaged engagement,

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[3] Smith et al. (2022) served as a reference for the latest IPA terminology; examples of their modern phrases include "experiential statements" and "personal experiential themes."

and quality and verification (Alase, 2017; Lietz et al., 2006). Creswell & Poth (2018) recommend that at least two of these strategies be used in any given qualitative study. In the paragraphs below are descriptions of these tools and how they were used in the current study.

Reflexivity

Reflexivity involves reflecting on one's experiences with the phenomenon being studied and and how one's experiences affect how they interpret the phenomenon (Creswell & Poth, 2018, p. 229). Qualitative researchers must "acknowledge who we are as individuals, and as members of groups, and as resting in and moving within social positions" (Bourke, 2014, p. 3). This means that researchers are not blank slates and that life experiences can lead to biases in perception. This researcher used a reflexivity journal to reflect on her own experiences in relationship to the study topic.

Member-Checking

Member-checking is another tool for increasing trustworthiness in qualitative research. While interpreting data collected during qualitative interviews, it can be helpful to consult with participants to see if interpretations are correct (Creswell & Poth, 2018). This provides interviewees with the opportunity to clarify their perspectives and provide more accurate statements. In this study, member-checking was utilized. After participants answered each interview prompt, the interviewer shared her interpretation of the client's thoughts and encouraged participant feedback about the accuracy of the interpretation. Participants agreed that the researcher understood them; no changes were suggested.

Peer Review/Debriefing

In addition to the use of member-checking, the trustworthiness of a qualitative study can be improved using peer review/debriefing. Peer debriefing is when a researcher

consults with a person or people who are not involved in the study but who have related knowledge/experience with the phenomenon or related research (Creswell & Poth, 2018). These peers are encouraged to challenge the researchers with difficult queries about the research process (Creswell & Poth, 2018).

For this study, the researcher consulted with two peers who are mental health professionals. One peer has a doctorate in Counselor Education and Supervision and recently retired from working in the field conducting assessments. This peer's dissertation was a phenomenological study of interdisciplinary teams providing palliative care. While the subject matter was much different than that of the researcher, this peer's experience in using IPA was helpful. This peer recommended some of the texts which were referenced for this dissertation.

The other peer with whom the researcher consulted is a colleague who provided peer support regarding sampling and recruitment procedures. This colleague is a psychologist who works with individuals with intellectual and developmental disabilities. She has worked with Medicaid waiver participants in Indiana for over twenty years. When this research study was being designed, this colleague made sure that waiver provider rules would not preclude the researcher from recruiting participants for a study using the methods detailed above. She consulted with state regulations and allowed the researcher to send out the IRB-approved recruitment email.

Quality and Verification

Alase (2017) suggested that a qualitative researcher assess the quality of the study continuously. "Quality of research data and the ability to verify and authenticate the data and findings in a research study are very important in a qualitative research study… [and] requires stronger commitments to data accuracy and transferable and verifiable research

findings" (Alase, 2017, p. 17). This phenomenological researcher verified the quality of research practices as recommended by Alase (2017). This included ensuring that participants meet the sample guidelines; for example, when it was discovered that an interviewed participant was older than 40, his data was removed from the study. This also involved exhausting every lead for more information. For example, after the researcher was already well into data analysis and narrative write-up, she received notification of a potential participant. The researcher responded and included that participant in the analysis.

Ethical Considerations

As with all research studies, the researcher must assess and address potential ethical problems with a study. Researchers have found strategies for improving ethics in research. Creswell and Poth (2018) suggest multiple strategies for decreasing ethical problems; these are defined below.

Define Interview Purpose

Participants and guardians must be made aware of the purpose of the research study (Creswell & Poth, 2018). In this study, the researcher fully described the collaborative nature of qualitative interviews. Participants were reminded that the purpose of the interview is not to evaluate any mental health counselors or clients. Instead, the participant and researcher explored the topic of mental health counseling together.

Informed Consent

Participants in a study must be given full information about the study's procedures; the researcher must not be deceptive (Creswell & Poth, 2018). Through the process of informed consent, participants learn about the study, the role of the researcher,

the role of the participant, and their rights. Participants are encouraged to ask questions. If an incentive is offered, the participants must be told what they must do to receive the incentive. No incentive was offered in the current study.

These policies are included in the IRB-approved informed consent documents for this study. See Appendix D and Appendix E to view the documents for emancipated participants and guardians, respectively. Note that only the guardians were required to sign the document to consent. The IRB authorized participants to provide verbal consent at the beginning of their interviews. The document was reviewed verbally with each participant and guardian. The researcher explained that participation is voluntary, and that the interview could stop at any time.

Confidentiality / Privacy

Confidentiality is very important in research, especially regarding topics of mental health and treatment. Participants need to know that their privacy is being respected. In this study, the researcher explained that code names are used on interview protocols. Only the researcher is privy to the identity of the participants. The researcher explained that while participant information will not be revealed, some answers that they provided were included in the research paper. The process of informed consent took place throughout the study, as did opportunities for participants to ask questions.

Conflict of Interest

It was possible that the researcher would have a dual relationship with some of the interviewees despite the participants not being from the researcher's behavior management caseload. Because behavior management services are home- and community-based services, the behaviorist / researcher has been attending day programs, sheltered workshops, and supported living homes for over a decade, and has met many

waiver participants. It is possible that the interviewees viewed the behaviorist as peer-like, as the behaviorist tries to appear relaxed and approachable on-site. This could have had the potential to decrease the power differential and vulnerability (Bourdeau, 2000). However, some interviewees may have still felt a power differential if they saw the researcher as their therapist's work colleague or as someone who trains their direct support providers. The researcher made consistent efforts to keep participants informed about the role of the researcher as well as study procedures and participant rights.

CHAPTER IV: FINDINGS

The purpose of this study was to examine the experience of mental health counseling for individuals with mild intellectual disabilities between the ages of 18 and 40. The previous chapters provided a review of relevant literature and an explanation of the methodology used in this study. In this chapter, the results of the study are presented, starting with sample characteristics.

Sample Characteristics

Data collected from 11 participants were analyzed ($N = 11$). Three participants identified as male ($n = 3$) while the rest of the participants identified as female ($n = 8$). Two participants identified as Black ($n = 2$); nine participants identified as White ($n = 9$). Six participants were emancipated ($n = 6$); guardians of five participants signed their consent for their adult children's participation ($n = 5$). All 11 participants provided verbal consent for participation ($n = 11$).

Participants and guardians chose the setting of the interviews. Four participants were interviewed via phone call ($n = 4$), three participants chose video call ($n = 3$), and four participants had an in-person interview ($n = 4$). One face-to-face interview took place at the participant's home ($n = 1$); the other in-person interviews ($n = 3$) took place at two adult day programs. Interviews lasted from approximately five to 20 minutes, not including discussions of informed consent. All interviews were recorded and transcribed using the Otter application for iPhone / iPad. The researcher reviewed the audio recordings and transcripts and made corrections to the transcripts as needed. A pseudonym was assigned to each participant to protect anonymity.

Participant Experiences: A Narrative Account

The process of interpretive phenomenological analysis, as described in the third chapter of this paper, yielded a narrative account of themes found in the data. As recommended by phenomenological researchers, this narrative account of participants' experiences in mental health counseling is described and exemplified with interview excerpts (Pietkiewicz & Smith, 2014). The narrative below is organized by themes and subthemes. Themes are identified using level three headings and subthemes are listed in level four headings; these headings are in accordance with American Psychological Association's publication manual guidelines (APA, 2020).

Beginning Counseling

Participants provided insight about how they began receiving counseling. They shared whether they choose to go to counseling on their own accord, under the direction of another, or due to a joint decision (between the participant and another). Participants also spoke about how they felt about seeing a counselor and what they expected from the process. Participants' expectations that counseling would lead them to meaningful changes in their lives varied; however, more than half of the participants were hopeful and expected positive changes to result.

Choice. Participants were asked who decided they would attend counseling when it began. Maya, Gail, and Elena ($n = 3$) stated that they made the decision to get counseling in recognition of their need for help. Elena shared the following explanation of how she began receiving counseling:

> It was my choice. I needed it… I graduated high school without taking any medication. And then there was this one summer after I had graduated high school… I had a really big major mental breakdown and I was pretty bad… I

hadn't been sleeping… The house that we were living in had a finished basement.

Like it was really nice and had like rooms down there and stuff…. I would sit on

the stairs, going downstairs to the basement, and I would just stare at the wall all

night. That's what I sit there and did. And then it got to the point where I had a

real bad mental breakdown. And I ended up calling the police on myself. And

when the police got there, Mom showed them who I was. And I was bawling,

like, really bad. I was crying… That was the first time I went into the mental

hospital… I stayed there and when I got discharged… they set me up with a

psychiatrist and a therapist.

Elena described experiencing a serious mental illness when she began receiving

counseling which seemed to make the decision an easy one for her.

Liam, Jeff, Reign, and Talen ($n = 4$) said someone else signed them up for

counseling. Liam said his parents signed him up for counseling. Talen said his mom

made the choice for him to receive counseling. Jeff and Reign did not specify who

enrolled them in counseling, they simply indicated that it was not their own decisions.

Reign stated, "It was not my choice. At the time I had to go because of a couple of things

I had did. They weren't suicidal or anything like that, but it was just a couple things I had

did wrong…."

Ashley, Callie, and Bridgett ($n = 3$) shared that they made the joint decision to

attend counseling with family / guardian. Kirsten could not remember who made the

choice for her to go to counseling. These participants did not elaborate further about the

decision to seek counseling.

Desire to Attend. Interviewees were asked how they felt about attending

counseling. One participant ($n = 1$) described counseling with indifference. This

participant, Callie, reported that she was young when she started counseling and was not sure how she felt about going.

Two participants ($n = 2$) stated that they did not want to go to counseling when it first began. Reign felt she did not need the service and objected to attending. Despite deciding with her guardian to attend counseling, Ashley said that she "didn't want to go" either.

The rest of the participants ($n = 8$) felt positively about attending counseling. For example, while Talen "didn't know what to expect" to happen in counseling, he said he felt "good" about going. Bridgett explained that "to get help felt good." Bridgett was "a little bit nervous, anxious, but afterwards [she] was very open."

Change and Hope. Participants were also asked if they expected that counseling would lead to meaningful changes in their lives. Reign ($n = 1$) was the only participant who firmly stated that she did not expect life changes to occur from counseling. When asked if she expected counseling to lead to helpful life changes, Reign said, "No, I didn't. I didn't want to make changes, but I did anyway."

Four participants ($n = 4$) – Ashley, Callie, Maya, and Kirsten expressed being unsure about what they expected to result from counseling. Ashley said that she wanted to learn "to treat people right" but she was ambivalent about how successful she thought counseling would be in helping her achieve that goal. Maya also hoped for change. When asked about her expectations, Maya said about her counselor: "I thought she would help me a lot with my problems." However, like Ashley, Maya was ambivalent about what outcomes to expect. Callie shared that before she attended counseling, she thought change was a possibility, and that she wanted change to happen, but she "wasn't exactly sure" if it would. Kirsten also felt hopeful but was not sure if she should expect change.

Liam, Jeff, Bridgett, Gail, Elena, and Talen ($n = 6$) all affirmed that they expected that they would make changes because of counseling. Jeff said, "I was enthusiastic. High hopes I guess." Jeff shared that he hoped, and expected, that he would get help with his goals, his ability to take care of himself, and life skills overall. Bridgett also expected counseling to lead to change. She elaborated that she wanted help with, "Just like my emotional, my mood, my mental stuff and my schizoaffective bipolar, and all that stuff." Bridgett hoped to be able to express her emotions and improve her emotional stability. While Talen did not know what to expect of the counseling process, he was hopeful that positive change would result. Elena expressed that she "needed" to go to counseling and make changes in her life, but that she knew "it was gonna take some time." Elena expressed that when she began counseling, she was ready to do the therapeutic work necessary to restore her mental health.

Factors Contributing to Change

Participants were asked to share personal characteristics and characteristics of their environments that they thought would help them in making meaningful changes in their lives. In other words, they were asked to share what they could draw on, in addition to counseling, to make personal progress. Kirsten said that she did not have an answer to this question, but the other 10 participants described at least one factor that they believed contributed – or at least had the potential to contribute - to meaningful changes.

The Role of Family and Other Caregivers. Six participants ($n = 6$) – Ashley, Callie, Reign, Elena, Bridgett, and Liam – listed caregivers, such as family members, teachers, and direct support staff, as contributing to the meaningful changes in their lives. Elena listed several factors, but one of these was her supportive family members, particularly her mom and sister. Ashley also mentioned a family member as a

contributing factor for change. She said that her aunt provides support, advice, etc.; Ashley's aunt even housed her temporarily when Ashey was exploring group home placement years ago.

Bridgett lives in a supported living environment which means that staff work at her home to help her with her daily living tasks. When asked what factors have or could contribute to change in her life, Bridgett shared, "My staff in supported living will probably help me and they're trying to help me now but it's just hard sometimes." Liam mentioned more than one contributor to change. He shared that teachers and staff at school helped him grow as a person, as well as his family.

Callie was also asked about the factors that had the potential to help her make changes in her life. Instead of describing a helpful advocate (as Ashley, Bridgett, and Liam had), Callie described an unhappy relationship with a parent. She shared that this unhealthy relationship motivated her to become more independent. Callie shared the following:

> …One day, I mean, becoming an adult, I would have to choose. I would have the choice to move out on my own or the choice to stay there with someone who was very mean. He was harsh; that's how my dad's always been to a certain degree. I mean, sometimes he could be nice, but when he's mean, he's mean.

Similar to Callie, Reign said that unhealthy relationships motivated her to change and grow. She shared that along with attending counseling, her purposeful separation from some unhealthy people allowed her to make personal growth. She described, "I got rid of a couple of people that I should not have had and it's just a lot easier now to deal with things… I needed to be able to breathe without them… They were smothering me."

Self-Efficacy. Self-efficacy is "concerned with judgments of how well one can execute courses of action required to deal with prospective situations" (Bandura, 1982, p. 122). Whether or not a participant listed him- or herself as a factor for change is arguably a sign of the participant's self-efficacy for change. Ashley and Talen both showed signs of low self-efficacy for change. When Ashley and Talen were asked if there were parts of their personalities that they thought may help them make changes, they both simply stated, "no." Alternatively, several participants identified personal characteristics that they thought were beneficial for meaningful change. Bridgett shared that she believed she has coping skills that allow her to make positive change in her life. She stated, "I do my coping skills like I like to write in my diary, or draw or do things I like doing, or reading… Listen to music, go on YouTube, just those things… go on my iPad." Liam said that he believed that "getting older" and maturing may have helped him grow as a person. Jeff suggested that his optimism helped him make personal progress while receiving counseling. He shared, "I tried to… make the day happy or… go to the meeting happily, if that makes sense." Gail credited herself and her choices when asked about factors contributing to meaningful change. She summarized, "I found a better place for me to live and change a little bit." Elena shared a sentiment similar to Gail's; she explained that her desire for independence helped motivate her to enact change. According to Elena, moving out of her family's home has been important part of her personal development. Maya shared that she wanted to work on her anger and suggested that her empathy for others may have helped her improve the way she expresses anger in interpersonal relationships. She explained:

> Like when I get mad, I go off on people. I should think before I do it. Because I
> know it's easy to go off people… I know they have feelings too but I'm not

thinking that. I'm thinking me. It's me. It's all about me. If I go hurt someone

now, I don't care. I'm not thinking…I don't care about their feelings, you know? I

need to think about their feelings too, and not just mine.

Other External Factors. In addition to the subthemes listed above, some other

factors contributing to change were mentioned by participants. Jeff and Talen identified

environmental factors they suspected affected their ability to make change during their

counseling experience. Talen said, "It was like my environment." When asked to specify

what he meant, Talen said, "By environment, I mean my work and school." Jeff pointed

out the role that the community played in his personal growth. He said, "…I think it's

always good to get rooted in where you live and find out what outlets [there] are…"

Elena mentioned a unique factor: her psychotropic medications. Elena suggested that her

psychiatric medication regimen has been a key contributor to her personal growth. She

said, "I had that one testing done - the genotype test. Like which medicines is good for

me. All the medicines that I'm on right now are good for me."

Relationships with Counselors

Participants were asked to describe their relationships with their counselors. Liam,

Jeff, Bridgett, Reign, Kirsten, and Talen ($n = 6$) stated only positive things about their

relationships with their counselors. Ashley, Callie, Maya, and Elena ($n = 4$) described

both good and bad in their therapeutic relationships. Gail ($n = 1$) was unable to describe

her relationship with her counselor. She stated, "I forget. It was a long time ago." Review

of the participants' transcripts regarding relationships with counselors revealed the

subthemes of personality compatibility and communication.

Personality Compatibility. Some participants mentioned their personalities and

the personalities of the counselors; when were was a personality clash, this relationship

was considered negative. Ashley described a personality clash with a counselor. The opposite is also true – participants who said their personalities meshed well with their counselors also described those counselors positively. Jeff shared an experience like this one: "I had a lot of good experiences… They just have their own personality, each counselor, and it just fits in good." Callie alluded to experiencing both types of counseling relationships. She said, "…Some of them were pretty positive and some of them… It wasn't the best fit, some of them."

Communication. The relationship between open, honest communication between a counselor and a client and a satisfactory, helpful counseling relationship was alluded to by several participants. Ashley, who described both positive and negative therapeutic relationships, was asked what subpar counselors could have done to improve the relationship with her. "Communicating with us. Doing stuff with us, talking with us," Ashley replied. When describing a counselor with whom Ashley felt she had a strong therapeutic relationship, Ashley said the following.

> We were really close. Like, we wouldn't have therapy like everyday. She would pull us aside and talk about what's going on and all that. There was more connection with her than there was with anyone else I seen. It would kind of fall in line with getting to know her and all that.

Bridgett also spoke highly of her relationship with counselors: "They listened to me. They gave me good advice… They've helped me with all my peers and all my abilities to get better and change." When asked to describe her relationship with her counselors, Kirsten said simply, "Good. I would talk to them." Reign also positively described the communication between herself and her counselor:

He is a very good person. He takes some time to talk to me once a month. It's

been good because he knows that I need it now. And it's been a good relationship

so far with him… He knows what to ask and I know what to say. I guess I think

it's a good relationship because he takes his time with me and I make sure that I

take my time with him. It's just gotten a lot easier to talk to him…"

Alternatively, Maya mentioned that something she did not like about her counselor was
that she would talk to others during their sessions. When asked about her relationship
with her counselor, she said:

It was fine but she didn't do much. Like when she took me out and took me to eat

and came back, she's supposed to sit in there and talk to me but she's always on

the phone talking to other people when we only have so much time to talk and she

doesn't talk to me. And she talks to, you know, her family. And I'm like… Okay

this is not helping me. You're supposed to talk to me, not them. You can talk to

them on your own time.

Callie, who reported having both effective and ineffective therapeutic relationships, also
described a therapeutic relationship seemingly having been damaged from
communication issues. Callie shared:

I've had some experiences with certain counselors that weren't the greatest, like

the last one I had. He thought I was having a smelling hallucination. I went to a

neurologist and they determined I was pretty much healthy. I could smell my

Grandpa's tobacco burning and he thought it was just bologna.

Callie's brief description does not allow the reader to fully understand the interpersonal

dynamics at play in her last therapeutic relationship. However, if Callie was left thinking

that her counselor did not believe her (and thought that her experience was "bologna"),

there seems to be a problem with the therapeutic alliance. In summary, several participants related communication with the strength of a therapeutic relationship.

Counseling Activities / Process

Participants were asked to share their thoughts about counseling session contents. This included goals, activities, homework assignments, etc. Callie said that she couldn't remember the content of the counseling sessions. She simply stated, "It was alright."

Two participants (n = 2) – Ashley and Maya – shared both positive and negative experiences with counseling activities. Ashley described an experience with a community mental health center where she felt the counselors did not provide enough support. She shared, "They just want[ed] us to like play with toys and it just was frustrating because they just weren't doing their job and I got mad and went off on them." In addition to that negative experience, Ashley also described positive experiences with therapeutic activities at an inpatient mental health center. She said, "The hospital that I went to… They did a lot more helping when I was in a lockdown facility." When asked what made this process more effective than her outpatient treatment, she said, "They just actually talked to me and we actually communicated and had like family time."

Maya also shared both positive and negative experiences. She shared that she was upset with how her counseling relationship ended. The counselor recommended that Maya take a break from having a cell phone as she had gotten into some legal trouble for harassment. Maya was upset with this recommendation and terminated the relationship. So, it is difficult to tell if Maya's judgment of counseling is clouded by this last experience. Maya did say that she and her counselor agreed on treatment goals and that activities were "okay." However, when asked which counseling topics were helpful, she said, "Nothing we talked about really helped."

Most participants (n = 8) spoke only positively about the counseling process; these participants were Liam, Jeff, Bridgett, Reign, Gail, Kirsten, Elena, and Talen. None of these participants could think of any activities that they found unhelpful. Talen reported, "We agreed on the goals we worked on." Liam, Bridgett, Reign, and Maya made similar statements about goal alignment. Elena and Talen mentioned game-playing and talking (respectively) and described them as activities they valued. Bridgett did not list any specific counseling interventions but described treatment activities overall as "helpful and inspiring."

The Importance of Life Skills Development. Not all participants chose to name specific topics they worked on with their counselors. However, those who did list topics that could arguably be considered life skills such as vocational exploration, budgeting, and social skills for being in the community. Participants reported these activities as being helpful for their personal growth. Liam said that he found it "fun to do the activities" and that he enjoyed discussing cooking and exploring his job options with his counselor. Jeff shared some of the goals he worked on in counseling including spending money wisely and quitting smoking. Jeff shared that he learned about "being in like a dollar store and try not [to] leave things open and be nice to other people and stuff like that and being considerate." Reign shared that her counselor prompts her to engage in a modified version of journaling which she finds therapeutic. She said, "I draw pictures because I can't read nor write really well. And he made sure that I… do that. So, I understand what I'm doing."

Impact / Outcomes from Mental Health Counseling

What resulted from the participants receiving mental health counseling? Participants were asked to share their counseling outcomes. Although all participants

reported experiencing at least minor positive change, the degree of change varied. In this section, the participants' perspective of the impact of mental health counseling will be discussed under two subthemes: social skills development and personal growth.

Communication / Social Skills. When Talen was asked how he was affected by his counseling experience, he responded, "Good… It helped me a lot." Similarly, Bridgett described the outcomes from counseling: "It was just good stuff, good qualities, these good things that helped me get to where I am now." Reign gave a very positive report of counseling and provided an example of a skill she acquired in counseling. She stated:

> It affected me in a very good way. I wasn't expecting that… it's been very good for quite a few years. I appreciate [the counselor] and he has always helped me. I enjoy it now more than I did…. I know how to choose better on who is friends and who is not.

Jeff shared, "It definitely kept me busy and it helped me out… I've just been [a] better speaker and … communication…" Ashley said, "I don't know how to explain it. It was just a change right then and there…" She said she "just got better over time." When asked how she "got better," Ashley said her communication skills improved through her counseling experience.

Personal Growth. Personal growth "is commonly taken to include a tendency to realize one's potential, to be open to new experience, and to continually develop oneself as a person" (Straume & Vitterso, 2015, p. 150). Several participants mentioned components of personal growth as an outcome of counseling. For example, Elena denied any aversive / side effects from counseling and detailed, "I've had some good outcomes, good ones… Like, she showed me how to…They pretty much showed me how to keep calm." Liam stated that counseling helped him become a "better person" overall. He

stated, "I was able to go out and do the job I wanted to." Kirsten described getting better at speaking up and asking for help when she needs it. Callie stated that the major impact that counseling had on her was that she learned: "I'm not the problem. Most of the [problems] could be from my environment." Maya believes that counseling did not affect her much but that she made a bit of positive change in treating people a bit better when she is feeling anxious or angry. Gail shared that she changed a little bit but did not elaborate on this change other than to say she made a move.

Conclusion

In this chapter, the findings of this qualitative study were provided. The sample characteristics were described. A narrative description of the experience of the participants in mental health counseling was provided. Themes and subthemes organized this narrative. The following are the themes and accompanying subthemes: Beginning Counseling (Choice, Desire to Attend, Change and Hope); Factors Contributing to Change (The Role of Family and Other Caregivers, Self-Efficacy, Other External Factors); Relationships with Counselors (Personality Compatibility, Communication); Counseling Activities / Processes (The Importance of Life Skills Development); Impact / Outcomes from Mental Health Counseling (Social Skills Development, Personal Growth). The study findings will be compared to the literature in the next chapter.

CHAPTER V: DISCUSSION

This qualitative study was exploratory in nature. Rather than conduct experimental research with variables in a controlled environment, an exploratory study was utilized to examine a phenomenon (Singh, 2021). This phenomenon is the experience of individuals with intellectual disabilities in mental health counseling. More specifically, the analysis was completed to understand how individuals with mild intellectual disabilities experience the four common components of psychotherapy that contribute to change and counseling outcomes. Semi-structured interviews were conducted with participants between the ages of 18 and 40 who have been diagnosed with a mild intellectual disability and have experienced mental health counseling. The data was analyzed using Smith et al.'s (2022) process of interpretive phenomenological analysis (IPA). IPA yielded important themes and a narrative account of the phenomenon. In this chapter, the themes identified through interpretive phenomenological analysis are summarized and findings are compared to existing literature on intellectual disability and mental health counseling. Then, research challenges, implications of findings, and recommendations for research and practice are presented.

Primary Themes

Beginning Counseling

Participants in the current study gave feedback about whose choice it was for them to attend counseling. There was a mix of participants who sought counseling on their own, those who made the choice to get counseling with another, and those who were

enrolled by a parent / guardian. Regardless of whose decision counseling enrollment was, the majority of participants both did not object to going and expected that meaningful change would occur as a result of the counseling experience.

Lambert (1992) estimated that approximately 15% of client change comes from their own hopefulness and expectancy to be successful. Dohaney and Miller (2000) explained that the power of the placebo effect – when patients improve (or at least perceive improvements) despite only receiving a benign treatment – is evidence for the power of expectancy. The power of expectancy was evident in this study. When discussing potential change in the participants' lives, "hope" was a theme that arose often. Participants were hopeful that counseling would lead them to something positive.

The importance of hope in counseling is well-documented in counseling research (Larsen & Stege, 2012). Larsen and Stege (2012) performed a qualitative analysis of how participants experienced hope in the first three sessions of counseling. They found that participants' sources of hope included: a hope-fostering relationship (including a client feeling safe and accepted, feeling that the counselor understands them and believing that the counselor is invested in the therapeutic process), positive identity development (through the clients being aware of their agency, developing new understandings of themselves, feeling the embodiment of hope, and worthiness) and perspective change (helping clients see their potential, think about the future, explore possibilities, and reframe difficult circumstances in the client's lives) (Larsen & Stege, 2012).

While many studies about the role of hope in counseling exist (Westburg & Boyer, 1999), there is a paucity of research conducted with participants who have intellectual disabilities. In fact, only one other empirical study was located that included an investigation of hope in counseling for individuals with intellectual disabilities. This

study was a thesis about significant moments in therapy for individuals with intellectual

disabilities (Wills, 2019). The current qualitative study adds to the small amount of

research that exists which shows the power of hope in counseling for this population.

Factors Contributing to Change

Participants were asked to share what aspects of themselves and / or their

environment contributed to their ability to make meaningful change. The purpose of this

question was to inquire about how the participants perceived their extra-therapeutic

factors in relationship to their ability to make change. Research reporting client

perspectives of the factors of change is limited (Han, 2023). Thomas (2006) surveyed

dyads of clients and therapists and asked them to estimate the proportion of change

caused by each of the four factors; large discrepancies were found between clients and

therapists. Thomas (2006) suggested further studies on the four factors were needed,

specifically including people of various groups / categories of difference. The purpose of

these suggested studies was to provide "clinicians with the awareness of the benefits of

common factors with each client category, specifically with regard to distinct cultural

differences" (Thomas, 2006, p. 208)

Trustam et al. (2021) conducted such a qualitative study (like those suggested by

Thomas, 2006). The authors investigated the experience of individuals with intellectual

disabilities in recovery-based mental health care. Participants identified extra-therapeutic

factors that affected the participants' mental health and recovery. These included bullying

and a lack of both emotional and practical support (which participants stated led to

negative outcomes). Alternatively, improved interpersonal relationships were connected

to better outcomes for the participants. The importance of close relationships was found

in Trustam et al.'s (2021) study as well as this current study. Several participants

mentioned relationships with family / other caregivers as having contributed to the changes they made in their lives.

Trustam, et al. (2021) also highlighted the importance of self-efficacy in the lives of those with mild intellectual disabilities (p. 257). Self-efficacy seemed to be important for the participants in this study as well. Over half of the participants listed a personal characteristic as an important contributor to meaningful change.

Relationships with Counselors

Most participants in this study emphasized the importance of their relationships with their counselors. Specifically, participants emphasized open, healthy communication with their counselors as contributing to their ability to make changes in their lives. According to the four-factor theory of change in counseling, approximately 30% of change in clients can be attributed to the therapeutic relationship (Miller at al., 1997). "Working alliance" was a concept first proposed by Bordin (1979). This concept - now often called "therapeutic alliance" - refers to "the therapist's and client's mutual collaboration and agreement on the goals and task of the therapeutic work during the treatment process, along with a secure bond between the dyad" (Mosavi et al., 2023, p. 1). Therapeutic alliance has proven to be a strong predictor of therapeutic outcomes in several meta-analyses (Mosavi et al., 2023).

In this current study, participants were asked to describe their therapeutic relationships with mental health counselors. The findings in this study were in line with the aforementioned research; therapeutic alliance – agreement on tasks and goals and bond between therapist and client – was positively related to therapeutic outcomes. The findings of this study support the importance of therapeutic alliance in mental health counseling for individuals with intellectual disabilities.

Clients' positive perception of healthy therapeutic relationships was also reported in several of the studies reviewed earlier in this dissertation. For example, Pert et al. (2013) conducted a qualitative study of Cognitive Behavior Therapy for adults with borderline or mild intellectual disability. They found that "participants valued the opportunity to talk about problems with their therapist and benefitted from therapeutic relationships characterized by warmth, empathy, and validation" (Pert et al., 2013, p. 359). Cameron et al. (2020) completed a qualitative analysis of therapists' and clients' (with intellectual disabilities) experience of therapeutic alliance. They found evidence for using Bordin's model in understanding counseling for individuals with intellectual disabilities and that "there was clear overlap within most dyads in the description of the characteristics of the bond, the tasks undertaken, and the goals of therapy" (Cameron et al., 2020, p. 169).

Some participants in the current study alluded to personality compatibility as to why a counseling relationship was viewed as helpful and effective. Personality clashes were linked to dissatisfaction with counseling while similar personality traits (in counselor and client) were linked to client satisfaction. Existing research supports the link between personality and attachment styles and therapeutic outcomes (Shir & Tishby, 2023). In their quantitative analysis of patient and therapist dyads, "when patients and therapists scored either high or low on neuroticism and conscientiousness, we found a decrease in symptoms from beginning to end of therapy. When patients' and therapists' combined scores were either high or low on attachment anxiety, we found an increase in symptoms" (Shir & Tishby, 2023, p. 1). Both this study and Shir & Tishby's (2023) study suggest the utility of a personality prescreen to help match clients with the most effective therapists for them.

Counseling Activities / Processes

Miller et al. (1997) estimated that therapeutic model / technique contributes to approximately 15% of therapeutic change. Model / technique refers to a counselor's "theoretical orientation, therapeutic methods, strategies, or tactics" used to help a client make change (Thomas, 2016, p. 203). In this study, participants were not asked to comment on the theoretical orientation employed by their mental health counselors. However, participants were asked to comment more generally about their experience with counseling activities. Participants generally spoke positively about the counseling process / session content. Agreement between the client and counselor on tasks and goals for sessions was frequently reported. These participants described session activities as being helpful, fun, and enjoyable.

Some participants shared that their counseling sessions included content surrounding practical / life skill topics such as cooking and nutrition, job-seeking, budgeting, store etiquette, and smoking cessation. These topics may not be commonly considered to be a part of mental health counseling, but the participants generally reported these as being helpful session content. This exemplifies how counselors may need to incorporate non-traditional interventions into sessions when appropriate (and within state licensing board guidelines). Some published research supports the combination of life skills and mental health treatment in care plans. For example, Klymkiw et al. (2024) and Saha et al. (2020) found that clients benefited from receiving life skills training and mental health counseling in an integrated youth service center and a psychosocial rehabilitation center, respectively.

Impact / Outcomes from Mental Health Counseling

When asked about the impact mental health counseling on the lives of the study participants, no negative effects were reported. Alternatively, several client-perceived positive effects from counseling were named. Study participants self-reported improved communication skills, better understandings of family dynamics, increased abilities to build and keep healthy friendships, acquisition of new coping skills, and more.

Understanding how individuals with intellectual disabilities perceive the impact of counseling is important. Currently, few published studies exist wherein participants with intellectual disabilities have been asked to share insight through qualitative interviews. This current study contributes to the limited amount of qualitative research regarding mental health counseling and individuals with intellectual disabilities.

Limitations and Challenges

Recruitment & Saturation

The researcher struggled to get colleagues to recruit participants for the study. It took several months for 10 interviews to be completed. After completing 10 interviews, the researcher began analyzing the data and noticed that the answers given by the participants were very short. While reviewing the recordings, the interviewer concluded, likely due to discomfort / nerves, she did not allow for silence in between questions. In attempt remedy this problem, participants who were available / willing were re-interviewed.

One participant (given the pseudonym Kirsten) was not reachable. The guardian of another participant (with the pseudonym Callie) gave permission for her daughter to be interviewed, but the participant did not return the researcher's messages. One participant was not re-interviewed because the researcher found out that he was older than the 18 –

40 age range; his data was excluded. While the remaining participants were re-interviewed, a colleague referred one more participant to the researcher.

Eleven participants' interview data remained for analysis. While this number of interviews yielded several consistent themes, it is difficult to argue that saturation has been fully reached. However, since this is an exploratory study, it was already expected that future research will be needed to find out more information about this phenomenon.

Finally, it is important to acknowledge that the sample was only homogenous in regard to mild intellectual disability, experience in mental health counseling, and age range. To properly investigate the essence of mental health counseling for individuals with mild intellectual disabilities, it seemed important to include individuals of varying ethnicities, genders, and other categories of alterity. However, researchers have identified differences in the experience of mental health counseling for individuals from different groups, such as racial and ethnic groups (Meyer & Zane, 2013; Trahan & Lemberger, 2014). So, the experiences of mental health counseling for the participants in this study were likely affected by more than just their mild intellectual disability. The goal of the study was not to determine a causational relationship between intellectual disability and experience in mental health outcomes; instead, the purpose of the study was to explore the experiences in counseling for a group of recruited participants who were diverse in many ways, but similar regarding the main variable of interest, mild intellectual disability. Future research is needed to investigate how intersectionality is involved with how individuals with intellectual disabilities experience counseling.

Other Methodological Issues

There are ways in which the methods employed in this study may have affected the results. Participants were not asked about the theoretical orientation used in their

counseling treatment. This means that their counselors could have used any number of therapy approaches. This is important because a participant who received Interpersonal Therapy, for example, may be more likely to mention relationships as being important to their change processes than someone who received CBT or another form of therapy less focused on interpersonal relationships. Future research may benefit from including asking participants about the form of therapy they received or even employing the use of interviewing both therapists and their clients for more comprehensive understandings of the therapeutic content.

Participants were given the choice of having a phone, video chat, or in-person interview. This was conducted for participant comfort, and there is some research-based support for this decision. For example, Elwood and Martin (2000) stated that "participants who are given a choice about where they will be interviewed may feel more empowered in their interaction with the researcher" (p. 656). However, there is potential for a difference in results based on setting. For example, some participants may be more likely to give fuller, more detailed responses when they see the researcher. Alternatively, some participants may feel more comfortable being open in an interview setting wherein the most anonymity is preserved (which, in this case, is through phone call). Further research on this topic could help us understand the effect of setting on results.

Eight participants were interviewed twice, as mentioned previously. This was not planned but occurred in response to the researcher finding initial interview data to seem truncated. While these second interviews did yield fuller results, it is unknown if these second interviews affected results in anyway. The interviewer asked the same questions during both sets of interviews. Did any participants find this second interview odd and feel they needed to change their answers? Did extra time to ponder the questions between

first and second interview affect the results for those interviewed twice? While no

evidence for these effects has been noted, the potential exists.

Participant Speech Impairment

People with intellectual disabilities are at an increased risk for speech and

language disorders (Memisevic & Hadzic, 2013). Two participants (Talen and Callie) had

significant speech difficulties. Efforts were made to minimize any miscommunication,

but it is still possible that errors were made. Callie was difficult to understand on the

phone. The researcher was able to listen to the recordings multiple times until the data

was deciphered as much as possible. Talen's speech issues make him quiet to hear and

the audio recording did not pick him up. However, the researcher noticed this during the

interview and made sure to make notes during the interview so that data was not lost. The

researcher also repeated back Talen's answers to both make sure she understood and give

her time to write his response. Talen did not correct the researcher.

Participant Comprehension

As mentioned previously in this dissertation, efforts were made to make interview

questions clear, succinct, and without any unnecessarily challenging language. It seemed

that two participants – Gail and Kirsten – seemed confused about some of the interview

questions but did not admit to such. Both responded to questions with, "I don't know" a

lot. Gail is a strong English speaker, but it is not her first language. Gail was one of the

many participants who was interviewed twice (in order get a chance to gather more data).

During the second interview, the researcher tried to slow down the questions to increase

comprehension. Kirsten has a genetic disorder in addition to her mild intellectual

disability. (In order to preserve her anonymity, the condition will not be named.)

However, this condition can affect socialization. The needs of other people appeared

important to Kirsten, so it is possible that this contributed to her not expressing

difficulties with understanding questions to the interviewer.

Other Limitations

It is difficult to know if participants ever skewed their answers in a positive way;

they knew that the interviewer is a mental health professional and knew that the research

involved evaluating their experience with other mental health professionals. Many

participants were also aware that the researcher is a co-worker of their behavior

consultant or music therapist (due to the recruitment process). The researcher attempted

to minimize this potential influence by explaining that the research was being conducted

to help the field of counseling, that the interviewer was interested in all participant insight

positive and negative. However, there is no way to know whether participants' answers

were intended to be complementary to the interviewer's colleagues or the field of mental

health counseling in general.

Arguably the most challenging limitation to this study is the potential of

subjectivity affecting the study findings. Adequately bracketing can be difficult for

phenomenological researchers (Emiliussen, et al., 2021). The methods taken to increase

study trustworthiness were previously described; these included reflexivity and

bracketing, member-checking, peer review, and quality verification. Despite utilizing

these methods, potential for bias remains.

An important part of increasing study trustworthiness in qualitative research is the

researcher acknowledging their own positionality. I, the researcher, have experienced

being both a part of the oppressed and the oppressor. I have experienced feeling like the

other but have also benefitted from my position in American society. Through this

dissertation research process, I learned that it is much easier for me to discuss issues of

power and oppression when the topic is one in which I am part of the oppressed group. I am comfortable discussing how gender affects a person's experience with counseling as I have experienced gender-based discrimination. While I have been lucky to not experience an intellectual disability personally, I have worked with this population for so long that discussing how this category of alterity may affect a person's experience with counseling also feels comfortable. I have been more hesitant about discussing race-related issues. I have worried that it is not my place to discuss race relations due to being white. However, an important part of being culturally competent is addressing these issues openly. Therefore, I feel it is important, particularly as a researcher employing a critical lens, to acknowledge all categories of difference and their effect on the experience of mental health counseling. The following quote summarizes what I have learned.

> "White students must understand that it is not possible for them to develop a non-racist consciousness or to extricate themselves from a system of oppression that advantages them. However, in order to use one's privilege in the service of social justice (e.g., using one's position of power to facilitate the development of more just policies or connecting a client of Color to helpful resources) and in order to avoid perpetuating acts of racism (e.g., by colluding with White clients' racist views or invalidating the experience of a client of Color), ongoing self-awareness is key. White students must commit to exploring their mainstream and marginalized identities (embedded in an understanding of intersectionality, rather than an additive multicultural model), recognize their internalized biases, and become aware of the ways in which they perpetuate, benefit, and collude with the status quo (assuming that all three occur on a regular basis)" (Bartoli et al., 2015, p. 256).

My hope is that this new understanding will help decrease this limitation of bias in my future research.

Implications and Recommendations

The findings from this study suggest that participants generally found value in their experiences with mental health counseling. Many were motivated to make change and felt they had had the tools they needed to do so. Participants' experiences showed evidence for the importance of the therapeutic alliance; agreement on goals and tasks with the counselor, as well as bond with the counselor, were themes that arose in the data. Participants reported mostly positive outcomes / impact from mental health counseling including improved skills; these included coping skills and assertiveness, decrease in unhealthy behavior such as self-harm, and more. This data provides support for the use of mental health counseling for individuals with intellectual disabilities.

Not all of the participants' reflections on mental health counseling were positive. None of the participants reported feeling that counseling was detrimental to them, but some reported not experiencing much improvement. Both negative and positive experiences described by participants provide valuable lessons for counselors and counselor educators. Suggestions for counseling and counselor education (including teaching, research, service, and supervision) based on study findings are provided below.

Mental Health Counseling Implications

Therapeutic Purpose of Activities. Ashley reflected on a counseling group wherein the counselor led the group in playing games. These games may have had a therapeutic purpose, but, if so, the participant was unaware. She reported believing that the counselors were not "doing what they were supposed to do." If the counselor had taken a moment to explain the therapeutic purpose of the game, the participant may have

felt better about her experience. Relatedly, Elena mentioned card games as being "helpful" activities; she seemed to understand that the games had a therapeutic purpose. Mental health counselors should ensure that their clients understand the therapeutic purpose of activities, particularly those that may not appear therapeutic on their surface.

Victimization Awareness. During their interviews, two participants mentioned being victimized; one reported having been physically abused by a family member while the other reported sexual assault from a stranger. These were reported to the interviewer despite victimization not being a topic of inquiry. Other participants may have also faced abuse or assault in their pasts. As mentioned earlier in this dissertation, individuals with I/DD are much more likely to be abused than their non-disabled peers (Jones, et al., 2012). This interview data can serve as a reminder that counselors should monitor clients for signs of abuse, particularly their at-risk clients. Counselors should also create a non-judgmental environment wherein their clients may feel comfortable sharing safety concerns (Branson, 2021).

Needs Outside of Counseling. Several study participants in this study mentioned valuing counseling that included topics atypical to the mental health counseling setting such as budgeting, cooking, and applying for jobs. This suggests that counselors should assess the broad needs and desires of their clients. Clients' desired skills can be taught and practiced in counseling sessions when appropriate (based on the counselor's abilities, the setting, billing / insurance issues, etc.); the counselor can be prepared to refer clients to outside resources when the desired skill is outside the breadth of the counselor's work.

Relatedly, counselors should remember that many individuals with intellectual disabilities live in poverty (Boat & Wu, 2015). None of the participants in this study worked full-time; most were unemployed and completely dependent on Social Security

Income. Counselors should both assess the needs of their clients (outside of mental health) and be prepared to refer to affordable or free local resources as needed.

In summary, this study reminds mental health counselors of the value of awareness, assessment, and preparation. Counselors should be aware of the problems for which their clients are at-risk. Counselors should assess whether the client's basic needs are being met. If a client is being abused, not eating, unable to pay bills, not getting prescription medications regularly, etc., counseling is unlikely to lead to results. Counselors need to be prepared to refer clients for additional support when clients' needs are outside of the mental health counseling domain. Examples include contact information for local food pantries, domestic violence shelters, medical cab companies, law and accounting firms offering pro-bono work, city / county health clinics, pharmacies that deliver, meals-on-wheels services, etc.

Counselor Education Implications

Teaching. Counselor educators are responsible for teaching professional etiquette to counseling students. In this study, one participant expressed negative feelings about a counselor's behavior during sessions. Maya shared that her previous mental health practitioner sometimes used her phone during their sessions. Due to the popularity of cell phones, smart watches, etc., it can be easy for anyone to be easily distracted; counselors are no exception. However, Maya's interview data is a reminder that clients notice when counselors get distracted, and clients may interpret the distraction as a negative action toward them. Clients can feel ignored or rejected if a counselor does not provide them with appropriate attention and focus. Teachers should teach their counseling students to silence devices and minimize distraction.

More broadly, counselor educators are also in charge of designing curriculum that adequately prepares students to become counselors. Earlier in this dissertation, the importance of disability-related content in curriculum and disability-related experiences (through practicums and internships, for example) was discussed (Feather and Carlson, 2019). Unfortunately, researchers found that many counselor-preparation programs do not include those elements (Feather and Carlson, 2019). Counselor educators need to include enough disability – related curriculum and experiences to adequately prepare graduates to work with individuals with intellectual disabilities.

Research. This study is an important step toward understanding the experience of mental health counseling for individuals with mild intellectual disability. Further research is needed. A larger number of participants would likely provide a fuller picture of the phenomenon. Another method for gathering richer data may be modifying the interview questions to include more follow-up questions. In the event of another study, other elements could be explored. For example, participants could be asked more specifically about the treatment methods the interviewees were exposed to, the amount of counseling exposure the participants have had (how many counselors, how many sessions, etc.), goals from sessions, and more. Participants could be given the opportunity to discuss the salience of their identity as someone with an intellectual disability. Questions about counselors' and clients' personalities could be added to future interviews to better understand how these may impact therapeutic relationships and dynamics. Ideally, interviewers would be unknown to the participants to decrease interviewee's bias in responding.

Also valuable is future research on how other categories of alterity impact the counseling experience for individuals with intellectual disabilities. For example,

researchers have found that certain cultural elements in counseling affect the experience of racial minorities (Meyer & Zane, 2013). Racial match between counselor and counselee, counselor understanding of prejudice and discrimination, and discussion of race and ethnicity in counseling have been "identified by cultural confidence experts as important elements of care" and affect counseling experiences and satisfaction with treatment for racial minorities (Meyer & Zane, 2013, p. 894). Would such findings be replicated in a study of participants who have intellectual disabilities? How may the intersection of race and intellectual ability affect the experience of counseling? Future research should examine how the intersections of the various categories of difference may be related to experiences with mental health counseling.

Service. Counselor educators may provide continuing education to counselors about serving individuals with intellectual disabilities. Such training could involve educating counselors about evidence-based approaches to assessment and treatment for this population. While the research on counseling for this population is lacking, researchers have determined:

> "…The research that does exist has demonstrated the need to adjust the mode of therapy provided to fit the developmental level, dependence needs, and verbal/cognitive abilities of each individual patient receiving treatment. This requires clinicians to be flexible in their approach and adapt interventions to accommodate for differences in intellectual ability to effectively provide mental health services to this population (Porcelan et al., 2019, p. 14)**.**

Arguably, even many seasoned counselors could benefit from learning and practicing modified techniques for serving this population.

Another potential role for counselor educators is making connections in the community. Individuals with intellectual disabilities and guardians of adult children with intellectual disabilities may not be aware that mental health counseling is an option for them. Counselor educators could make connections with providers of services for individuals with intellectual disabilities - such as adult day programs – to connect individuals needing counseling with appropriate counselors (those who are trained and comfortable with serving this population).

Counselor educators who are involved in academia are often affiliated with professional organizations like American Counseling Association. As of this writing, there is not a division of ACA devoted to intellectual disabilities. Counselor educators are in a position to advocate for such a division. This could lead to an increase in scholarship and awareness about counseling for individuals with intellectual disabilities.

Finally, counselor educators can participate in service by engaging in political advocacy. As discussed earlier in this dissertation, changes in policy have led to change in the lives of individuals with disabilities. While many legal changes have led to improved living for individuals with disabilities – such as decreases in institutionalization and increased access to appropriate education – threats to decrease the rights of individuals with disabilities have arisen. For example, in recent years, well-meaning policymakers advocated for a decrease in sheltered workshops for individuals with disabilities; they argued that it was unfair for anyone to work for less than minimum-wage pay. When some of these sheltered workshops closed, the unfortunate effect was that many individuals who lost their sheltered workshop jobs were unable to obtain or keep community employment. Some of these individuals feel disappointed that they cannot continue piecework since it provided them with a routine, a place to meet and

socialize with peers, and an opportunity to make some money to supplement their SSI. Counselor educators can help by forming or participating in advocacy groups that address such sociopolitical issues.

Supervision. Counselor supervisors provide assessment, education, support, feedback, and more to their supervisees. Due to high levels of victimization among individuals with intellectual disabilities, counselors serving this population may hear traumatic stories. Accordingly, supervisors should monitor their supervisees for symptoms of vicarious trauma (Trippany et al., 2004; Storlie, 2013). Also, as described earlier in this dissertation, many counselors feel ill prepared to serve clients with disabilities. Counselor educators who serve as clinical supervisors need to be prepared to help their supervisees adapt their work to clients of varying abilities. Supervisors should recommend helpful continuing education opportunities in addition to providing education and references during supervision when appropriate.

Conclusion

This study was an exploration of the experiences of individuals with intellectual disabilities in mental health counseling. Participants were encouraged to share their insight about the four common factors of change - client's extra therapeutic factors, therapy model / techniques, therapeutic alliance, and hope / expectancy – and the impact of / outcomes from counseling. The study participants highlighted the power of hope and expectation, as well as the importance of therapeutic alliance. Participants spoke about their family and other caregivers being helpful while they worked to make changes. Many participants also identified strengths within themselves that empowered them. The findings from this study led to several recommendations for mental health counselors and

counselor educators. Future research will allow for a fuller understanding of how the

field of counseling can best serve this population.

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Appendix A

Recruitment Email

TITLE OF RESEARCH STUDY:

Mental Health Counseling for Individuals with Mild Intellectual Disabilities:
A Phenomenological Study of Client Perspectives

Recruitment Email

Dear colleague:

I am conducting a research study on the experience of individuals with mild intellectual disabilities in mental health counseling. Individuals who (a) are between the ages of 18 and 40, (b) have been diagnosed with a mild intellectual disability, AND (c) have participated in mental health counseling are eligible for participation. Participants will be interviewed by myself - the researcher - via video conferencing platform. The interview should take around 30 minutes. The only risk known to participation is potential discomfort surrounding discussing previous memories of mental health treatment. To offset this risk, participants will be provided contact information for mental health treatment resources.

If you serve an individual who would be interested in participating, please refer them using the instructions below:
(1) For emancipated individuals, please ask them to call or text the researcher Kathleen at 859-803-7349.
(2) For individuals with guardians, please ask the guardian to call or text the researcher Kathleen at 859-803-7349. (Please do not ask a participant with a guardian to contact the researcher directly so that the researcher can first discussed informed consent with the guardian.)

While compensation is not being provided, the benefit of the research is that it will inform counselors and counselor educators. Research helps counselors and their educators improve counseling practice.

If you have any questions, please let me know. Thank you for your consideration.

Sincerely,

Student researcher: **Primary Investigator:**

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Appendix B

Interview Protocol

TITLE OF RESEARCH STUDY:

Mental Health Counseling for Individuals with Mild Intellectual Disabilities:

A Phenomenological Study of Client Perspectives

Interview Questions

	Aim	Introduce area of focus	Prompts
1	Expectations of counseling	I am interested in your thoughts about counseling when you began receiving it.	Was going to counseling your choice, or someone else's? How did you feel about going? Did you expect that you would make meaningful change as a result of counseling?
2	Personal and environmental contributions to change	If you were interested in counseling, you likely were interested in exploring the idea of make changes to your life. If so, perhaps there were reasons why you thought you would / would not make meaningful change.	Did you want to make change in your life? If so, did you feel like you were going to be able to make those changes? What was it about you or your environment that made you feel like you were (or were not) going to make meaningful change?
3	Therapeutic relationship	I'm also interested in the experiences you've had in your counseling relationship(s).	How would you describe the relationship you had with your counselor?
4	Counseling process	Please think about the activities you completed in sessions with your counselor, the homework you were assigned, the information you were provided, etc.	What did you think about the activities, assignments, education, etc. provided / led by your counselor?

5	Outcomes from counseling	Now let's discuss what happened as a result of the counseling.	How did counseling affect you, if it did? Did it live up to your expectations?

- ☐ Follow-up
  - o Would you like to share anything else about counseling?
  - o Do you have any questions?
  - o You are invited to contact the researcher at any time.
    - ▪ Kathleen.barnett@louisville.edu
    - ▪ (859) 803 – 7349

If you know of anyone who you think would be interested in participating in this study, I would love to speak with them. Participants should be Medicaid waiver participants, be between 18 and 40 years old, have a mild intellectual disability, and have a history of receiving mental health counseling. If someone you know would qualify, please give them my contact information. If this individual has a guardian, please give the guardian my contact information. Thank you!

Research Protocol

STUDY TITLE: Mental Health Counseling for Individuals with Mild Intellectual

Disabilities: A Phenomenological Study of Client Perspectives

PROTOCOL VERSION NUMBER: 2

Background/Problem Statement

In 2018, approximately "5.1 million children ages birth to 17 years, 133,347 million young adults ages 18 to 21 years, and 1.86 million adults 22 years or older" with intellectual disabilities lived in the United States (Larson, et al., 2021, p. 32). Mental illness is three to four times as prevalent among individuals with intellectual disabilities compared to those without intellectual disabilities (Munir, 2016). The increased prevalence of mental illness (in those with intellectual disabilities as compared to the rest of the population) is pervasive throughout the lifespan (Cooper et al., 2015).

While there is a body of research supporting the efficacy of mental health counseling to decrease symptoms and behaviors in individuals with intellectual disabilities (as mentioned above), scarce research exists which describes the experiences of these individuals. There is a need for research that aims to "privilege the perspective of clients with disabilities, and how well their needs and presenting counseling issues are met" (Rivas & Hill, 2018, p. 130). The lived experiences of individuals with intellectual disabilities should be explored to inform the practice of mental health counseling (MacMahon et al., 2015).

If researchers neglect to conduct qualitative studies on the experiences of individuals with intellectual disabilities in counseling, the field of counseling will be negatively affected. The voices of an already marginalized group (individuals with intellectual disabilities) will be missing from the literature (Lloyd, Gatherer & Kalsy, 2006). Research on mental health counseling for individuals with intellectual disabilities will be lacking the depth that is possible when using a qualitative approach. The counseling field of research will lack information about "the processes that participants [with intellectual disabilities] perceive as most salient to their experiences" in counseling (McMahon, 2015, p. 343). Reciprocally, the field will cause harm to individuals with disabilities by failing to elevate the voices of these individuals. This study has been designed to contribute to the small body of literature about how individuals with intellectual disabilities have experienced mental health counseling.

Objectives

The purpose of this qualitative research study is to describe the experience of mental health counseling for individuals with mild intellectual disabilities. This interpretive phenomenological analysis is designed to gather information about how individuals with mild intellectual disabilities experience (a) the four common components of psychotherapy that contribute to change and (b) counseling outcomes. The four common factors of change include client and extra therapeutic factors, relationship factors, expectancy, and model / techniques (Lambert, 1992; Thomas, 2006).

Study Design/Methodology

To be able to describe the essence of the mental health counseling experiences for individuals with mild intellectual disabilities, a phenomenological, qualitative research design was chosen. Qualitative research involves information gathering and analyzing

with the goal of "produc[ing] rounded and contextual understanding on the basis of rich, nuanced and detailed data" (Mason, 2002, p. 3). Phenomenology is a type of qualitative research which is "descriptive and focuses on the structure of experience, the organizing principles that give form and meaning to the life world" (Laverty, 2003, p. 27). Descriptions include both "what" was experienced and "how" it was experienced (Creswell & Poth, 2018).

Participant eligibility criteria will include: (a) mild intellectual disability diagnosis; (b) a history of having received mental health counseling; and (c) willingness to discuss experiences in counseling; and (d) ages 18 to 40. Other diagnoses (such as developmental conditions like Cerebral Palsy) will not preclude participation so long as the participant is able to communicate with the researcher through speech or writing. Also, both emancipated individuals and those with guardians will be invited to participate. Guardian approval will be obtained when applicable.

Participant Recruitment Methods

Participants will be recruited from the pool of Indiana Medicaid waiver participants. The researcher is affiliated with a waiver-based service, and therefore has connections to case managers, behavior consultants, other therapists, program managers, and more for assistance in finding eligible participants. (The researcher will not attempt to recruit from her own caseload.) A recruitment email will be sent to these service providers. Providers will be provided (a) a brief summary of the study and (b) eligibility criteria for participants. Both emancipated individuals and those with guardians will be eligible to participate. Providers will be asked to give the researcher's contact information to potential emancipated participants and the guardians of those potential participants who are not emancipated. The researcher will ask that providers do not give

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researcher contact information directly to participants with guardians so that the researcher can first speak to guardians. The informed consent process will begin during this first contact. Only after a guardian signs a consent form will the participant interview be scheduled. After interviews are completed, participants will be invited to refer other waiver-users who may be interested in taking part of the study. These methods for gathering participants will be a mixed sampling approach (Creswell & Poth, 2018). Convenience sampling will occur first; the researcher will be contacting local professional contacts to help find eligible candidates. Criterion-based sampling will then allow the researcher to gather participants meeting the aforementioned eligibility requirements. Snowball / chain sampling will occur if / when participants refer others to take part in the study.

After participants are recruited, interviews will be scheduled. These will take place via video conferencing platform. A virtual setting is helpful for preserving participant privacy. Many participants may not be able to drive and meet the investigator in the community. If the co-investigator must go to a participant's home in order to conduct the interview, this may be uncomfortable for the participant. The co-investigator would be exposed to additional unnecessary information about the client, such as address and identify of family members / roommates. Virtual communication will also prevent the spread of COVID-19 and other viral illnesses.

Informed Consent Process

Interested guardians AND participants will learn about informed consent from the researcher. The co-investigator – who is also the interviewer - will explain that interview data will be coded, rather than named, to help with confidentiality. The interviewee will be told that interview data, including quotes, may be used in the research

paper, but that this will be done without use of directly identifying information. An audio recording will be taken, but this will be destroyed after the study is complete. The co-investigator will explain that it could be distressing to discuss counseling experiences; participants are encouraged to reach out to mental health resources if they experience any of this distress. These resources will be given to the participants.

An introduction to the study will follow. The co-investigator will explain that the purpose of the study is to investigate the experiences of individuals with intellectual disabilities in mental health counseling. The participant will be told that they will be asked about five aspects of counseling. They will be encouraged to let the interviewer know if they need clarifications, definitions, or breaks from the interview.

In order to assess participants' understanding of informed consent, the co-investigator will lead a brief discussion. The interviewee will be asked the following questions. Why are you participating in the study? What should you do if you're uncomfortable with a question, or with the study as a whole? What is your understanding of what information will be kept private? For emancipated participants, this informed consent process will be complete after this researcher – participant discussion. For those participants with guardians, the researcher will review informed consent first with the guardian, and will proceed to review informed consent with the participant only with the signed consent of the guardian given first.

Research Procedures

The co-investigator will interview participants through video conferencing platforms. After informed consent is discussed, interview questions will begin. The interview protocol is attached.

While the co-investigator conducts the interview, the Otter recording app will be used to transcribe the interview. The co-investigator will compare the transcription to the recorded audio to increase accuracy in reporting.

Minimizing Risks

The only known potential risk is psychological; a participant may become uncomfortable when discussing an experience in mental health counseling. To minimize this risk, participants will be given the phone numbers for two mental health hotlines, one local and one national. Both of these hotlines are open every day. These phone numbers will be on the informed consent document.

Plan for Analysis of Results

Once interviews are complete, Moustakas' (1994) method for interpretive phenomenological analysis (IPA) will be employed to analyze the data. This method includes bracketing (which takes place throughout IPA), horizontalization, the development of clusters of meaning, and the reporting of structural, textural, and composite descriptions of the phenomenon.

Research Materials, Records, and Privacy

When a potential participant is referred to the co-investigator by waiver service providers (as discussed in the recruitment section), the co-investigator will gather the potential participants' names and their contact information. This electronic list of contact information will be reviewed only by the co-investigator. The list will be saved in a password protected folder on the private computer of the co-investigator.

While conducting the interviews, the co-investigator will use the Otter app to make audio recordings and transcriptions. These audio files and transcription documents will only be labeled with a number. This number will be assigned in the order of the

interview and will only be used to pair the audio files to the transcription documents.

These audio files and transcription documents will be saved in a password protected

folder on the private computer of the co-investigator. Raw data will only be accessible to

the co-investigator. After interviews have been completed, the co-investigator will close

the study in the iRIS system. Files will be saved for the length of time required by the

IRB.

(Protocol) References

Cooper, S. A., McLean, G., Guthrie, B., McConnachie, A., Mercer, S., Sullivan, F., & Morrison, J. (2015). Multiple physical and mental health comorbidity in adults with intellectual disabilities: population-based cross-sectional analysis. *BMC Family Practice, 16*(1), 1-11.

Creswell, J. W. & Poth, C. W. (2018). *Qualitative inquiry & research design: Choosing among five approaches* (4th ed). Sage.

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Larson, S. A., van der Salm, B., Pettingell, S., Sowers, M., & Anderson, L. L. (2021). *Long-term supports and services for persons with intellectual or developmental disabilities: Status and trends through 2018*. University of Minnesota, Research and Training Center on Community Living, Institute on Community Integration.

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Lloyd, V., Gatherer, A. and Kalsy, S. (2006) Conducting qualitative interview research

    with people with expressive language difficulties. *Qualitative Health Research,*

    16, 1386-1404. https://doi.org/10.1177/1049732306293846

MacMahon, P., Stenfert Kroese, B., Jahoda, A., Stimpson, A., Rose, N., Rose, J.,

    Townson, J., Hood, K., & Willner, P. (2015). "It's made all of us bond since that

    course. . .": A qualitative study of service users' experiences of a CBT anger

    management group intervention. *Journal of Intellectual Disability Research,*

    59(4), 342–352. https://doi-org.echo.louisville.edu/10.1111/jir.12144

Mason, J. (2002). *Qualitative researching* (2nd ed.). Sage Publications.

Moustakas, C. (1994). *Phenomenological research methods*. Sage Publications.

    https://doi.org/10.4135/9781412995658

Munir, K. M. (2016). The co-occurrence of mental disorders in children and adolescents

    with intellectual disability / intellectual developmental disorder. *Current Opinion*

    in Psychiatry, 29(2), 95–102. https://doi.org/10.1097/YCO.0000000000000236

Rivas, M. & Hill, N. R. (2018). Counselor trainees' experiences counseling disability: A

    phenomenological study. *Counselor Education & Supervision, 57*, 116–131.

    https://doi.org/10.1002/ceas.12097

Thomas, M. L. (2006). The contributing factors of change in a therapeutic process.

    Contemporary Family Therapy, 28, 201–210. https://doi.org/10.1007/s10591-006-

    9000-4

Appendix D

Informed Consent – Emancipated Participants

TITLE OF RESEARCH STUDY:

Mental Health Counseling for Individuals with Mild Intellectual Disabilities:
A Phenomenological Study of Client Perspectives

Introduction and Background Information
You are invited to take part in a research study about the experiences of individuals with mild intellectual disabilities in mental health counseling. The study is being conducted under the direction of Dr. Woo at the University of Louisville**.**

Why is this study being done?
The purpose of this study is to explore how certain people experienced mental health counseling.

What will happen if I take part in the study?
Your participation in the study will involve verbally answering a few open-ended questions on the phone or video conferencing platform with this researcher, Kathleen Barnett. An audio recording of the interview will be made (which means that your voice will be recorded as you answer). Your participation in this study should last around 30 minutes. You are welcome to choose not to answer any questions that make you feel uncomfortable. You are also welcome to stop participating in the study at any time.

What are the possible risks or discomforts from being in this research study?
There are no known risks for being in this research study, other than possible discomfort talking about previous experiences in mental health counseling. If discomfort does occur, you are encouraged to reach out to a mental health professional with whom you feel comfortable. Community Mental Health Center can be reached at ANY time at (812)537-1302 or (877)849-1248. The Substance Abuse and Mental Health Services Administration's national helpline can be reached at 1-800-662-4357.

What are the benefits of taking part in the study?
The information collected may not benefit you directly; however, the information may be helpful to others.

Will I be paid?
You will not be paid for your time, inconvenience, or expenses while you are in this study.

How will my information be protected?
The data collected about you will be kept private and secure. Your answers to the research questions will be recorded on a document separate from your name. The only

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people who have access to your name are the primary investigator and co-investigator. This information will be kept in a password-protected document. Individuals from the Department of Counseling and Human Development, the Institutional Review Board (IRB), the Human Subjects Protection Program Office (HSPPO), the University of Louisville, and other regulatory agencies may inspect these study records. In all other respects, however, the data will be held in confidence to the extent permitted by law. Should the data be published, your identity will not be disclosed.

Will my information be used for future research?
Your data will not be stored or shared for future research.

Can I stop participating in the study at any time?
Taking part in this study is completely voluntary. You may choose not to take part at all. If you decide to be in this study, you may change your mind and stop taking part at any time. You will not be penalized or lose any benefits for which you qualify.

Who can I contact for questions, concerns and complaints?
If you have any questions about the research study, please contact:

Student researcher:	**Primary Investigator:**
Kathleen Barnett, M.Ed., M.Ed. NCC	Dr. Hong Ryun Woo, Ph.D.,
Doctoral Candidate	Associate Professor
kathleen.barnett@louisville.edu	H0woo001@louisville.edu
(859) 803-7349	(502) 852-0615

If you have concerns or complaints about the research or research staff and you do not wish to give your name, you may call this toll-free number: 1-877-852-1167. This is a 24-hour hot line answered by people who do not work at the University of Louisville.

If you have any questions about your rights as a research participant, you may call the Human Subjects Protection Program Office at (502) 852-5188. You may discuss any questions about your rights as a research participant, in private, with a member of the Institutional Review Board (IRB).

Acknowledgment
This document tells you what will happen during the study if you choose to take part. By answering interview questions, you agree to take part in this study.

You are not giving up any legal rights to which you are entitled by consenting to this study. You can save this consent form for your records.

Informed Consent – Guardians of Protected Adult Participants

INFORMED CONSENT

TITLE OF RESEARCH STUDY:

Mental Health Counseling for Individuals with Mild Intellectual Disabilities:
A Phenomenological Study of Client Perspectives

Introduction and Background Information
Your adult child is invited to take part in a research study about the experiences of
individuals with mild intellectual disabilities in mental health counseling. The study is
being conducted under the direction of Dr. Woo at the University of Louisville**.**

Taking part in this study is completely voluntary, and your adult child does not have to
participate. Take your time to decide.

Why is this study being done?
The purpose of this study is to explore how certain people experienced mental health
counseling.

What will happen if I take part in the study?
If you consent to your adult child participating in the study, (s)he will verbally answer a
few open-ended questions on the phone or video conferencing platform with this
researcher, Kathleen Barnett. An audio recording of the interview will be made.
Participation in this study should last around 30 minutes. Your adult child is welcome to
choose not to answer any questions that make him/her feel uncomfortable. Participants
are also welcome to stop participating in the study at any time. Results of the overall
research study will not be shared with participants.

What are the possible risks or discomforts from being in this research study?
There are no known risks for being in this research study, other than possible discomfort
talking about previous experiences in mental health counseling. If discomfort does occur,
you are encouraged to reach out to a mental health professional with whom you and your
adult child feel comfortable. Community Mental Health Center can be reached at ANY
time at (812)537-1302 or (877)849-1248. The Substance Abuse and Mental Health
Services Administration's national helpline can be reached at 1-800-662-4357.

What are the benefits of taking part in the study?

The information collected may not benefit you or your adult child directly; however, the information may be helpful to others.

What other choices do I have if I do not take part in the study?
Instead of taking part in this study, you could choose for your adult child to not participate in the study.

Will I be paid?
Neither you or your adult child will be paid for your time, inconvenience, or expenses while you are in this study.

How will my information be protected?
The data collected about your adult child will be kept private and secure. Your adult child's answers to the research questions will be recorded on a document separate from his or her name. The only people who have access to your adult child's name are the primary investigator and co-investigator. This information will be kept in a password-protected document.
Individuals from the Department of Counseling and Human Development, the Institutional Review Board (IRB), the Human Subjects Protection Program Office (HSPPO), the University of Louisville, and other regulatory agencies may inspect these study records. In all other respects, however, the data will be held in confidence to the extent permitted by law. Should the data be published, your identity will not be disclosed.

Will my information be used for future research?
Data will not be stored or shared for future research.

Can I stop participating in the study at any time?
Taking part in this study is completely voluntary. You may choose not to take part at all. If you allow your adult child to participate, and he or she decides to be in this study, your adult child may change his or her mind and stop taking part at any time. There will be no penalties or loss of qualified benefits. You and your adult child will be told about any new information learned during the study that could affect your decisions to continue in the study.

Who can I contact for questions, concerns and complaints?
If you have any questions about the research study, please contact:

Student researcher:	**Primary Investigator:**
Kathleen Barnett, M.Ed., M.Ed. NCC	Dr. Hong Ryun Woo, Ph.D.,
Doctoral Candidate	Associate Professor
kathleen.barnett@louisville.edu	H0woo001@louisville.edu
(859) 803-7349	(502) 852-0615

If you have concerns or complaints about the research or research staff and you do not wish to give your name, you may call this toll-free number: 1-877-852-1167. This is a 24-hour hot line answered by people who do not work at the University of Louisville.

If you have any questions about your rights as a research participant, you may call the Human Subjects Protection Program Office at (502) 852-5188. You may discuss any questions about your rights as a research participant, in private, with a member of the Institutional Review Board (IRB).

Acknowledgment and Signatures
This document tells you what will happen during the study if you choose to allow your adult child to take part. Your signature and date indicate that this study has been explained to you, that your questions have been answered, and that you agree to take part in the study. You are not giving up any legal rights to which you are entitled by signing this informed consent document. You will be given a copy of this consent form to keep for your records.

_____   _____   _____
Printed Name of Guardian   **Signature of Guardian**   **Date**

_____
Participant Name (printed by guardian)

_____   _____   _____
Printed Name of Investigator   **Signature of Investigator**   **Date**

CURRICULUM VITA

Kathleen Nagle Barnett
859-803-7349
kathleen.nagle.barnett@gmail.com

LICENSURE

LMHC Licensed Mental Health Counselor - Indiana (November 2022 – Current)

EDUCATION

PhD Counselor Education & Supervision (Concentration: Mental Health Counseling), University of Louisville, Louisville, Kentucky (May 2024).

 Dissertation: "Mental Health Counseling for Individuals with Mild Intellectual Disabilities: A Phenomenological Study of Client Perspectives"

M.Ed. Mental Health Counseling, University of Louisville, Louisville, Kentucky (December 2011).

M.Ed. School Psychology, University of Cincinnati, Cincinnati, Ohio (June 2007).

B.A. Psychology (Minor: Philosophy), University of Louisville, Louisville, KY (May 2006, summa cum laude).

EMPLOYMENT

Behavior Consultant, Ellison Behavior Consulting, Connersville, IN, April 2014 – Current

 Duties:
- Collect behavioral data using observation and interview of client and his/her family, coworkers, etc. in natural environment
  - Functional behavior analysis

- Identify target behaviors

- Select replacement behaviors
- Design interventions and skills training activities
- Set goals for behavior change
- Engage clients in appropriate interventions
- Provide trainings on appropriate responses to behavior, behavioral interventions, and documentation to caregivers
- Collect behavioral data and prepare progress reports
- Attend treatment team meetings (with clients, guardians, case managers, day program coordinators, residential program coordinators, music therapists, recreational therapists, nurses, vocational rehab staff, advocates, etc.)
- Consult with psychiatrists and psychiatric nurse practitioners as needed to provide care coordination for client's mental health care
- Collaborate with teachers and other school staff when working with children
- Advocate for clients' rights and encourage development and independence
- Serve on human rights committee to review restrictions (medications, monitoring, physical response to aggression, etc.)
- Train new behavior consultants

Population Served:
- Individuals of all ages with developmental and /or intellectual disabilities

Supervisor:
- Dr. Amy Meyer, Clinical Psychologist

Behavior Consultant, Booth & Company, Ft. Wayne, IN, November 2012 – April 2014

Duties:
- Collect behavioral data using observation and interview of client and his/her family, coworkers, etc. in natural environment
  - Functional behavior analysis
- Identify target behaviors
- Select replacement behaviors
- Design interventions and skills training activities
- Set goals for behavior change
- Engage clients in appropriate interventions
- Provide trainings on appropriate responses to behavior, behavioral interventions, and documentation to caregivers
- Collect behavioral data and prepare progress reports
- Attend treatment team meetings (with clients, guardians, case managers, day program coordinators, residential program coordinators, music therapists, recreational therapists, nurses, vocational rehab staff, advocates, etc.)
- Consult with psychiatrists and psychiatric nurse practitioners as needed to provide care coordination for client's mental health care
- Collaborate with teachers and other school staff when working with children
- Advocate for clients' rights and encourage development and independence

Population Served:

- Individuals of all ages with developmental/intellectual disabilities
  Supervisor:
  - Dr. Amy Meyer, Clinical Psychologist

INTERNSHIP EXPERIENCE

Booth & Co., Ft. Wayne, IN (May 2013 – August 2013)
  Duties:
  - Collect behavioral data using observation and interview of client and his/her family, coworkers, etc. in natural environment
  - Identify target behaviors
  - Set goals for behavior change
  - Select replacement behaviors and interventions for clients and implement in meetings with client
  - Provide residential/day program staff and family trainings on appropriate responses to behavior, behavioral interventions, and documentation
  - Collect behavioral data and prepare reports of progress
  - Attend treatment team meetings (with clients, guardians, case managers, day program coordinators, residential program coordinators, music therapists, recreational therapists, nurses, advocates, etc.)
  Population Served:
  - Individuals of all ages with developmental/intellectual disabilities
  Supervisor:
  - Dr. Amy Meyer, Clinical Psychologist

Holy Trinity School, Louisville, KY (January 2012 – May 2012)
  Duties:
  - One-on-one counseling
    - Interventions included social skills training, coping skills training, and more
  - Group counseling provided via "Second Step" (research-based intervention designed to increase prosocial behaviors)
  Population:
  - Grades K-8
  Supervisor:
  - Laura Probus, School Counselor

Central State Hospital, Louisville, KY (May 2011 - August 2011)
  Duties:
  - Assessed suicide risk, mental status, IQ
  - Conducted brief supportive counseling focused on symptom management
  - Wrote court outlines for psychologists petitioning for MIW's
  - Conducted psycho-educational groups with topics such as depression and anxiety
  - Conducted skills-building groups for coping, self-esteem, and social functioning

Population Served:
- Adults with paraphilic disorders, substance abuse problems, suicidal ideation, serious mental illnesses including schizophrenia and bipolar disorder, dual diagnoses (intellectual disabilities and psychiatric conditions), and more
- Individuals deemed incompetent to stand trial due to mental illness and individuals deemed not guilty due to mental illness (and mandated to receive inpatient mental health treatment)

Supervisors:
- Dr. Nancy Schrepf, Clinical Psychologist
- Dr. Rebecca Harvey, Psychologist

Center for Women and Families, Louisville, KY (August 2010-May 2011).
Duties:
- Conducted individual counseling with adult women
- Used a variety of assessments to track progress in individual counseling (progress in the therapeutic relationship as well as symptom relief)
- Assisted in scoring children's assessments
- Compiled curriculum for coping skills group
- Assisted with children's play therapy group
- Helped with other counseling groups: DV & Kids, DV & Anger, and more

Population Served:
- Victims of domestic violence and/or sexual assault (adults and children)

Supervisors:
- Kristy McCauley, MSW (on-site supervisor, Aug. 2010-March 2011)
- Susan Selby, MSW (on-site supervisor, April-May 2011)
- Dr. Nancy Cunningham, Counseling Psychologist (university supervisor)

Archdiocese of Louisville's Family Ministries Counseling, Louisville, KY (May 2010 - August 2010)
Duties:
- Conducted intake interviews
- Led individual and family therapy sessions

Population served:
- Adults and children in the community with a variety of concerns including substance abuse problems, depression, anxiety, familial interpersonal problems, and more

Supervisors:
- Dr. Tom Robbins, Marriage and Family Therapist (on-site supervisor)
- Dr. Abby Shapiro, Psychologist (university-hired supervisor)

St. Aloysius School, Louisville, KY (Fall 2009)
Duties:
- With a team, delivered "Stix and Stones," a bullying prevention program

Population served:
- 5th grade students

Supervisor:

- Dr. Nancy Cunningham

OTHER PROFESSIONAL EXPERIENCE

Doctoral Internship in Counselor Education, Department of Educational and Counseling Psychology, University of Louisville, Fall 2011-Summer 2012
  Duties:
- Assisted (lectures, grading) with the following courses:
  - ECPY 619: Empirical and Theoretical Foundations of Counseling and Psychotherapy (Fall 2011)
  - ECPY 663: Multicultural Issues in Counseling
- Group supervision provided in:
  - ECPY 672/673/682/683: Practicum/Internship in Clinical Mental Health Counseling/Counseling Psychology
- Review relevant counselor education research and write reflection essays
- Develop a course syllabus and two lesson plans for a multicultural counseling course

Senior Graduate Assistant, Departments of Teaching and Learning & Special Education, University of Louisville, Fall 2011–Summer 2012
  Duties:
- Point of contact for new GA's/TA's
- Edited grant submissions and papers for publication
- Literature reviews
- Course preparation and grading of assignments and tests
  - EDSP 443: Instructional Methods for Students with Moderate/Severe Disabilities
  - EDSP 545: Exceptional Children in the Regular Classroom
  - EDSP 609: Moderate/Severe Disabilities Curriculum and Methods
  - EDSP 670: Autism – Introduction and Understanding
  - EDSP 671: Autism – Strategies and Techniques
  - EDSP 673: Asperger's Syndrome
  - EDTP 640: Teaching Reading Special Education P-12
- Data collection
- Data entry
  Supervisors:
- Dr. Terry Scott
- Dr. Nicole Fenty
- Dr. Monica Delano
- Latricia Bronger, M.Ed.

Graduate Assistant, Department of Special Education, University of Louisville, Fall 2010-Summer 2011
  Duties:
- Edited grant submissions and papers for publication
- Literature reviews

- Course preparation and grading of assignments and tests
  - EDSP 337: Collaboration, Inclusion, and Transition
  - EDSP 443: Instructional Methods for Students with Moderate/Severe Disabilities
  - EDSP 545: Exceptional Children in the Regular Classroom
  - EDSP 609: Moderate/Severe Disabilities Curriculum and Methods
  - EDSP 670: Autism – Introduction and Understanding
  - EDSP 671: Autism – Strategies and Techniques
  - EDTP 640: Teaching Reading Special Education P-12
- Data collection
- Data entry
- Gathered research-based methods for increasing diversity and building a positive campus climate (for faculty diversity committee)

Supervisors:
- Dr. Terry Scott
- Dr. Nicole Fenty
- Dr. Monica Delano

Graduate Assistant, Department of Teaching & Learning, University of Louisville, Fall 2009-Summer 2010

Duties:
- Observation/data collection for CARS: Center for Adolescent Research in Schools
- Assisted electronically with online course
  - EDSP 639: Education Research in P-12 Setting

Supervisors:
- Dr. Terry Scott
- Dr. Regina Hirn

Graduate Teaching Assistant, Department of Women's & Gender Studies, Arizona State University, Fall 2008-Spring 2009

Duties:
- Prepared and gave lectures
- Proctored exams
- Graded exams and writing assignments

Courses:
- WST 100: Women and Society
- WST 360: Women as Healers
- WST 460: Women and the Body
- WST 494: Politics of Women's Health

Supervisors:
- Dr. Rose Weitz
- Dr. Ann Hibner Koblitz
- Michelle McGibbney Vlahoulis, MA

401(k) Specialist (Series 6 & 63 licenses), Fidelity Investments, August 2007-August 2008

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Duties:
- Educated clients about retirement saving
- Provided clients information about their 401(k) plans
- Initiated trades and withdrawals, changed contribution rates, etc.

Research Assistant, Department of Philosophy, University of Louisville, Fall 2005-Spring 2006.
Duty:
- Edited the following anthology: Potter, N. (2006). *Truth, Trauma, and Reconciliation: Healing Damaged Relationships*. New York, NY: Oxford University Press

Supervisor:
- Dr. Nancy Nyquist Potter

PUBLICATIONS

Fenty, N.S., & Barnett, K.N. (2013). Using alternate texts to support comprehension of the core content curriculum. *Intervention in School and Clinic*, 48(4).

GRANTS

University of Louisville Vice President for Research Undergraduate Research Scholar Grant, $200 (funded).

PRESENTATIONS & CONFERENCE INVOLVEMENT

Cunningham, N.J., **Barnett, K.N.**, Rossman, H.K., & Hardesty, P.H. (2013). Roots of resilience: Protective factors in the sexual and gender identity development of LGBTQ youth. Presentation at the American Counseling Association Annual Conference.

Cunningham, N.J., Hardesty, P.H., Rossman, H.K., & **Barnett, K.N.** (2012). A look at protective factors in the family and school lives of LGBTQ youth. Poster presentation at the American Psychological Association Annual Conference.

Rossman, H.K., **Barnett, K.N.**, Cunningham, N.J., & Hardesty, P.H. (2012). Research for Change. Presentation at Come Together Kentucky.

Barnett, K.N., Rossman, H.K., & Cunningham, N.J. (2012). Developing an LGBTQ identity. Paper presentation at the Spring Research Conference at the University of Louisville.

Guest lecturer in developmental psychology course at Gateway Community & Technical College, 11/16/11. Topic: Middle adulthood. (Course instructor: Janet Brewer, M.A.)

Cunningham, N.J., **Barnett, K.N.,** Rossman, H.K., & Hardesty, P.H. (2011). Creating Resilience During Sexual Identity Development for LGBTQ Youth. Presentation at the Kentucky Counseling Association Annual Conference.

Cunningham, N.J., Hardesty, P.H., Horn, A., Rossman, H.K., **Barnett, K.N.,** Taylor, M.P., & Buford, B.W. (2011). Protective Factors in the Development of Sexual Identity in LGB Youth: A Pilot Study. Poster presentation at the American Psychological Association Annual Convention.

Student facilitator at the Kentucky Counseling Association Annual Conference, 2009.

Nagle, K.M., Potter, N., Mast, B. (2006). Gender and Levels of Depression in Young Women. Poster presentation at the University of Louisville Undergraduate Research Symposium, Spring 2006.

Chair for Fifth Annual Stephen Humphrey Student Philosophy Colloquium, University of Louisville, 2005.

HONORS AND AWARDS
- Dean's List/Honor Roll, University of Louisville: Fall 2002, Spring 2003, Fall 2003, Spring 2004, Fall 2004, Spring 2005, Fall 2005, Spring 2006
- Provost Hallmark Award (tuition, room, board, books), University of Louisville: Fall 2002-Spring 2006
- Member of the Honorable Order of the Kentucky Colonels, 2005

RELEVANT SERVICE
- Special Education Faculty Search Committee, Fall 2011 – Spring 2012.
- Editorial Assistant for the *Kentucky Teacher Education Journal*, Fall 2011 – Present.
- Counselor Education Program Selection Committee (Student Representative), Spring 2011
- Tutor at Rockdale Academy (Cincinnati Public Schools), 2006-2007. Used direct instruction to help at-risk kindergartners and second graders become fluent readers (through University of Cincinnati's School Psychology program).
- Volunteer caregiver and California Area Family Development Center, Louisville, Kentucky, Fall 2004. Assisted with activities and feeding in the classroom for one-year-old toddlers. Observed socio-economic factors that influence child development (done in correlation with Honors Developmental Psychology course, University of Louisville).
- Co-organizer and leader of LEGOS Conference (Kenton County Schools), Spring 2000. With a team, developed and implemented a leadership intervention for high school students.
- Member of leadership committee for Students Taking a Right Stand (Dixie Heights High School), Fall 1998-Spring 2002. Planned and participated in service projects in the Northern Kentucky area. This included presenting a brief substance abuse prevention program to students in Kenton County Schools.

- Staff member for the Beginning Leaders Conferences (Kenton Country Schools), Summer 1999 and Summer 2000. Led elementary school students in activities promoting pro-social peer relationships.
- Staff member for the Creating Leaders Conferences and Teen Leadership Conferences, 2001-2002. Led middle and high school students in activities promoting pro-social behaviors and peer relationships.

PROFESSIONAL DEVELOPMENT
- Continuing Education:
  - Increasing the Effectiveness of Suicide Prevention Strategies, Quantum Units Education, 2023.
  - The Effects of Child Maltreatment on Brain Development, Mindful Continuing Education, 2023.
  - Collective Trauma and the Social Construction of Meaning, The Association for Advanced Training in Behavioral Sciences, 2022.
  - Ethics and Boundary Issues, CE4Less, 2022.
  - Legalized Cannabis and PTSD Treatment Enduring August 2022, 2022.
  - PeaceHealth Sacred Heart Medical Center, 2020
    - Depression in Primary Care
    - Intimate Partner Violence
    - Emotional Intelligence
  - Relias, 2020
    - Medication Nonadherence: America's Other Drug Problem
    - Motivational Interviewing: Helping Patients Make Lifestyle Changes
  - Ethics and Boundary Issues, CE4less, 2020
  - Improving Cultural Competency for Behavioral Health Professionals, Cine-Med, 2019.
  - From Bench to Bedside: Novel Strategies Addressing the Negative Symptoms of Schizophrenia to Improve Clinical and Functional Outcomes, CME Outfitters, 2019.
  - Autism Case Training: Identifying, The Centers for Disease Control and Prevention, 2019.
  - Life on Purpose: How Living for What Matters Most Changes Everything, American Psychiatric Nurses Association, 2019.
  - Whole Health Begins with Mental Health, American Psychiatric Nurses Association, 2019.
  - Practical Ways to Bolster Resilience: A Life-Span Perspective, American Psychiatric Nurses Association, 2019.
  - 3C Institute, University of Maryland School of Medicine, 2018.
    - Systems of Care (Module #1)
    - Engaging Communities (Module #2)
    - Partnering with Youth & Families (Module #3)
    - Promotion, Prevention, & Early Intervention Strategies for Children and Youth (Module #4)
    - Child & Adolescent Development (Module #5)
    - The Adolescent Brain (Module #6)
    - Substances of Abuse (Module #7)

- - - Substance Abuse Disorder (Module #8)
      - Child & Adolescent Mental Health Disorders (Module #9)
      - Screening & Assessment (Module #11)
    - Screening Tools and Referral Training (START) Introductory and Guidance Videos, 2017.
    - 3C Institute, University of Maryland School of Medicine, 2017
      - Introduction to Reflective Practice in Infant and Early Childhood Services (Module #1)
      - Early Childhood Development (Module #2)
      - Understanding and Addressing Trauma in Early Childhood (Module #3)
      - Culturally Competent Clinical Considerations for Child Development and Parenting Practices (Module #4)
      - Aiding Parents and Professionals in the Transition to Kindergarten (Module #5)
      - Background & Overview (Module #1)
      - Strategies to Facilitate Youth Transitions from Inpatient Psychiatric Care to the School and Community (Module #2)
    - Quantum Units Education, 2016
      - Resilience Factors for People Who Use Drugs
      - Increasing the Effectiveness of Suicide Prevention Strategies
      - Dual Diagnosis: Understanding Co-Occurring Mental Illness and Substance Use Disorders
    - Bariatric Surgery & Mental Health, Advancing Knowledge in Healthcare, 2016
    - Appropriate Use of Psychotropic Medications for People with IDD: Helping Individuals Get the Best Behavioral Health Care, Vanderbilt University Medical Center, 2016.
    - Healing Hands – Housing Solutions for People Experiencing Homelessness, Vanderbilt University Medical Center, 2016.
    - PeaceHealth Sacred Heart Medical Center, 2016
      - Multidisciplinary Approach to Pain Management: Physician, Physical Therapy, and Psychology
      - Digital Tools for Patient Management
      - Traumatic Brain Injury: The Role Medical Rehabilitation
      - First Episode of Psychosis
- Safe Environment Training through the Archdiocese of Louisville. February 16th, 2012. Training involved identifying signs of child sexual abuse and policies for reporting.
- In-service at the Center for Women and Families, Louisville, KY, Fall 2010- Spring 2011. Topics included the effects of strangulation, domestic violence themes in pop music, and misogyny in hip-hop culture.
- KASAP Sexual Assault and Domestic Violence Training, The Center for Women and Families, Louisville, KY, Fall 2010. Completed a number of modules about the effects of domestic violence and assault, as well as methods for helping these survivors.

- Graduate Teaching Associate Training, University of Louisville, Fall 2010. Learned about Blackboard and other IT-related issues, campus resources, plagiarism, ethics in research, programs, policies, and more.
- Blackboard Training, Arizona State University, Spring 2009. Learned about how to best use the Blackboard system when teaching courses.
- Teaching Assistant/Associate Development, Arizona State University, Fall 2008. Completed training and assessments regarding the following topics: FERPA, diversity, academic integrity, sexual harassment, universal design, classroom assessment techniques, classroom management, and cooperative learning.