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Clinicians' Perceptions of Trauma Treatment for People with Intellectual Disabilities

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Walden University

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Abstract

Clinicians' Perceptions of Trauma Treatment for People with Intellectual Disabilities

by

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M.A., Regis University, 2002

B.S., University of Northern Colorado, 1982

Dissertation Submitted in Partial Fulfillment

of the Requirements for the Degree of

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Clinical Psychology

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Abstract

People with intellectual disabilities (ID) experience trauma and posttraumatic stress disorder (PTSD) in similar ways as individuals in the general population. The purpose of this phenomenological study was to explore and describe clinicians' perceptions of trauma treatment for people with ID. Theories of trauma, PTSD, and stigma were part of the conceptual framework from which interview questions were developed. Purposive and snowball sampling were used to recruit 8 participants in the Denver, Colorado area. Four participants had experience working with people with ID, and 4 participants did not have this experience. Participants sat for semi structured open-ended recorded interviews, which were used to gather data for interpretation. Eight essential themes were identified: (a) chosen field, (b) lack of training, (c) stigma and stereotypes, (d) they're just folks like us, (e) preying on their vulnerabilities, (f) PTSD and trauma symptoms are the same with people with ID, (g) EMDR and the adaptive information processing theory, and (h) mindfulness interventions. The participants dispelled myths such as people with ID do not experience trauma and PTSD, and people with ID cannot participate in trauma therapy such as EMDR. Participants who had experience working with people with ID wanted more training on adaptations for treatment interventions, and participants without this experience welcomed advanced training on trauma treatment for people with ID. This study adds to the research on trauma treatment for people with ID and may affect social change by inspiring more conversations among clinicians on appropriate trauma treatment for people with ID. Clinicians with experience can build stronger relationships with community mental health centers, and continue to educate, clients, families, direct care providers, and agency personnel on trauma-informed care.

Clinicians' Perceptions of Trauma Treatment for People with Intellectual Disabilities

A Qualitative Study

by

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Dedication

I dedicate this dissertation to people with intellectual disabilities who have crossed my path and ignited my passion to work with this population for over three decades. I also dedicate this dissertation to my family; my parents, Tom and Joyce Schoech and my brothers; Karl, Kirk, Kris, and Kenny and their families. I am truly grateful for your love and support.

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Chapter 1: Introduction to the Study

Almost every day, we hear or read about a world that is engaged in war, bombings, school shootings, violent criminal acts, domestic violence, child physical and sexual abuse, hurricanes, earthquakes, and debilitating car and motorcycle accidents. Some people survive these catastrophes and horrendous events unscathed from psychological, emotional, and physical damage. Others relive, hold onto, and live their lives with symptoms and sensations associated with trauma and posttraumatic stress disorder (PTSD) (Foa, Keane, & Freidman, 2004; Razza & Sobsey, 2011; Taylor, S., 2006; van der Kolk, 1996). There is a huge body of literature in which researchers have discussed, described, and promoted models of treatment for trauma and PTSD for people in the general population, veterans, and survivors of abuse (Foa et al., 2004; van der Kolk, 1996). However, the body of literature that acknowledges and speaks to the diagnosis and treatment of trauma and PTSD for people with intellectual disabilities (ID) is in its infancy (Newman, Christopher, & Berry, 2000; Razza & Sobsey, 2011).

Researchers in the field of ID suggest that trauma and PTSD affect people with ID similar to people in the general population, but there is a need to keep in mind the individual's developmental level (Bradley, Sinclair, & Greenbaum, 2012; Esralew, 2006; McCarthy, 2001). Possible barriers that have contributed to the lack of appropriate care and treatment for people with ID who have experienced trauma and PTSD include stigma and negative attitudes towards people with ID, and mental health issues. Myths, misunderstandings, and misconceptions of people with ID, the lack of funding and resources, the over use of behavior modification techniques, the use of medications, and mental health professionals' lack of training and experience in working with people with

ID and trauma-related issues continue to present challenges for people with ID seeking access to mental health services (Esralew, 2006; McCarthy, 2001; Mitchell & Clegg, 2005; Potter, 1965; Prout & Strohmer, 1998; Taggart, McMillan, & Lawson, 2010; Werner & Stawski, 2012).

This qualitative phenomenological study adds to the small body of literature on clinicians' perceptions of trauma treatment for people with ID. Researchers in the field of ID have suggested that people with ID deserve access to evidence-based treatment and practices just as the general population, but that approaches and techniques need to be adapted to meet their needs (Doyle & Mitchell, 2003; McCarthy, 2001; Newman, Christopher, & Berry, 2000). In this study, I aimed to describe, interpret, and capture the perceptions and lived experiences of clinicians in their understanding of people with ID who have experienced trauma. The social implications of this study include the potential to inspire and encourage clinicians who do not have experience working with this population to work with people with ID who have experienced trauma and PTSD, and to dispel myths about people with ID who have experienced trauma. This study also provides a platform to advocate for people with ID to have the right to access trauma treatment just as the general population.

In the background information section of Chapter 1, I have included a historical overview of people with ID and mental illness, as well as the controversies over the efficacy of psychotherapy with people with ID, and how the theories of trauma and PTSD were developed. Each of these sections are expanded in Chapter 2. In the background section, I also introduce the phenomenological approach and provide a brief overview of the different schools of phenomenology.

The background section is then followed by the identification of the problem statement, the purpose of the study, and the research questions. A multi-faceted conceptual framework is also presented in this chapter. I then describe the nature of the study, provide key definitions used in the study, and identify assumptions, the scope and delimitations, and limitations of this study. Chapter 1 closes with a discussion of the significance of the study, a summary of the main points, and a transition into Chapter 2.

Background

Historically, the plight of people with ID was tied to the culture and the research information of the era in which they lived, which usually meant death or institutionalization. Not until the 1960s did researchers suggest that psychiatric conditions were common among people with ID, and that, like the average person, emotional disturbances were caused by interpersonal experiences with the environment, lack of educational resources, personality development, coping skills, social and community interactions, and the lack of resources and supports for families, not by ID or organic brain dysfunction (Menolascino, 1965; Philips, 1967). Studies on the prevalence of emotional problems and psychiatric disorders with people with ID increased in the late 1970s and early 1980s, as did the evidence that indicated people with ID have higher rates of psychiatric disorders (Reiss, Levitan, & McNally, 1982). However, having a diagnosis of ID often overshadowed the co-occurring psychiatric disorder and predisposed clinicians to overlook possible psychopathology and credit the behaviors to the developmental or social delays of the individual (Fletcher, Loschen, Stavrakaki, & First, 2007). The need for mental health services became the message of these studies,

and researchers identified barriers for people with ID and mental illness in receiving adequate services.

The most information on PTSD for people with ID was generated at the beginning of the 21st century, and researchers have suggested that people with ID have a long history of abuse, neglect, and trauma, and are more likely than non-disabled persons to be abused physically, emotionally, or sexually (Sobsey, 1994). McCarthy (2001) suggested that cognitive and emotional capacities are risk factors for developing PTSD in people with ID, and identified other factors such as language and communication deficits, institutionalization, and poor and abusive care. Esralew (2006) suggested that PTSD and other trauma-related symptoms are under-recognized, under-reported, and under-treated in the ID population. She suggested that clinicians need tools and training to identify trauma-related symptoms in people with ID. Esralew also advocated for the timely access to competent, comprehensive, and relevant trauma treatment for people with ID.

The controversy over the efficacy of psychotherapy for people with ID continues to be a heated debate, especially after Sturmeay (2005) claimed that “behavioral approaches must remain the preferred treatment options for people with ID” (p. 56). Sturmeay’s statement brought about many responses and critical commentary regarding the use of psychotherapy for people with ID, and is expanded upon in Chapter 2. Studies using psychoanalytical and cognitive-behavioral approaches were the most cited for efficacy, and recommendations for further research were a common theme throughout the literature (Beail, 2003; Salvadori & Jackson, 2009). In three separate studies, researchers found that the use of eye movement desensitization and reprocessing (EMDR) facilitated healing from trauma for people with ID, with outcomes that indicated EMDR has

potential effectiveness for treating PTSD in clients with mild ID (Barol & Seubert, 2010; Giamp, 2003; Mevissen, Lievegoed, & de Jongh, 2011).

The literature on PTSD and other mental health issues in people with ID is expanding, but the literature on the perceptions of clinicians and other professionals in the mental health field regarding trauma treatment for people with ID is very small (Fletcher, Loschen, Stavrakaki, & First, 2007; Werner & Stawski, 2012). In this study, I describe and interpret the lived experiences of behavioral health professionals in regard to their knowledge, attitudes, and training in trauma treatment, and address how their lived experiences relate to their perception of trauma treatment for people with ID.

PTSD and Trauma

Historically, what has come to be called PTSD has been characterized by a variety of symptoms and defined by the psychological practice and theory of the era. As early as the third century B.C., writers noted in ancient Mesopotamian literature accounts of traumatic experiences of facing death and witnessing death in battle (Birmes, Hatton, Brunet, & Schmitt, 2003). Other ancient literature, such as Homer's *Iliad* (850 B.C.), included descriptions of nightmares and traumatic dreams, dissociative flashbacks, the lack of awareness of time and place, losing time, feeling like the event was unreal, and feelings of body distortions, confusion, and numbing (Homer, 1950). The 19th and early 20th century saw the creation of terms such as *railway spine*, *hysteria*, *shell shock*, and *war neurosis* to describe and diagnose this psychological condition of trauma and PTSD (Lasiuk & Hegadoren, 2006; van der Kolk, Weisaeth, & Van der Hart, 1996). The latter two terms were developed to characterize trauma related to the extreme conditions of World War I.

After World War II, practitioners and researchers found that responses to different types of psychological trauma were similar. In 1980, the American Psychiatric Association (APA) added the diagnosis of Posttraumatic Stress Syndrome (PTSD) to the Diagnostic and Statistical Manual of Mental Disorders-Third Edition (DSM-III) and included the phrase “almost anyone” for the first time to indicate whom stressors can evoke distress (APA, 1980, p. 238). The fourth edition of the DSM broadened the definition of PTSD, and the fifth edition of the DSM structured the symptoms along eight criteria and divided these symptoms into four criteria clusters. The DSM-5 also separated out dissociative symptoms to be specifiers. In Chapter 2, I expand on the history, diagnostic criteria, and theories of PTSD.

Phenomenology

The origins of phenomenology are rooted in the philosophical disciplines and have been described as a human science, a movement, a method, and an approach (Giorgi, 2009; Moustakas, 1994; Vagel, 2014; van Manen, 2014). Phenomenological research is part of the qualitative research paradigm and has been increasingly used in the schools of psychology, education, nursing, health care, and management (Moustakas, 1994; van Manen, 2014). Under the umbrella of phenomenology are diverse versions of phenomenological philosophies and alternative ways of understanding the meaning of “meaning,” prereflection of experiences passed, and the experience of day-to-day “lifeworlds.”

Edmund Husserl is considered the father of phenomenological research, which was born out of protest against positivism principles that reality was rational, logical, and independent of human interaction (Dowling, 2007; Ehrich, 2005; Reiners, 2012). Husserl

believed that reality was conscious, subjective, naturalistic, and based on the meaning of the individual's experiences (Lavery, 2003; Reiners, 2012; Zahavi, 2003). Husserl was influenced by his teacher, Franz Brentano, and also embraced Brentano's concepts of descriptive psychology, phenomenology, and intentionality as the fundamental practices for classifying conscious acts and experiential mental actions (Dowling, 2007; Moustakas, 1994; Zahavi, 2003). Husserl believed that every mental action is related to an object, and that all perceptions have meaning (Moustakas, 1994; Zahavi, 2003).

Husserl criticized psychology for attempting to apply natural science methods to human issues such as ordinary communication and understanding (Dowling, 2007; Lavery, 2003; Zahavi, 2003). His goal was to make phenomenology the "new science," and he devised a rigorous, unbiased method to study things as they appear based on the concept that the experiences of an individual's lifeworld are prereflective (Zahavi, 2003). Husserl developed a strategy called *bracketing* to look at and describe the essential features of our conscious experiences and suspend our acceptance of the natural attitude. That is, the goal of bracketing is to bracket the content of one's consciousness (Smith, Flowers, & Larkin, 2009, p.14). Husserl termed the process which entails the suspension of natural realistic inclinations, preconceptions, prejudices, and presuppositions, "*epoché*."

Martin Heidegger (1889-1976) was a student of Husserl, but he moved away from Husserl's descriptive phenomenological approach and was the first to look at phenomenology through a hermeneutic lens (Smith, Flowers, & Larkin, 2009). He disagreed with Husserl's descriptive view of phenomenology and felt that the understanding of lived experience needed to be explored from an ontological view, in that

lived experience was an interpretive process (Dowling, 2007; Reiners, 2012). His main focus was on “Being” or “Dasein,” his preferred term, and he held that being-in-the-world is the way human beings exist or act rather than knowing the world. Heidegger rejected the ideas of suspending preconceptions and presuppositions, and contended that reduction was impossible because “relatedness to the world” is always already a function of interpretation (Kafle, 2011; Vagel, 2014).

Heidegger adopted the concept of the hermeneutic circle to demonstrate the reciprocal activity of preunderstanding and understanding (Dowling, 2007). The hermeneutic circle is widely used by hermeneutic phenomenological researchers to look at the relationship between the part and the whole at a series of levels (van Manen, 2014; Vagel, 2014; Smith, Flowers, & Larkin, 2013). In Chapter 3, I expand on the hermeneutic circle.

Max van Manen is considered a modern hermeneutic phenomenologist. He was influenced by “the Dutch School” of phenomenology, and he considers the phenomenology of practice the Dutch contribution to phenomenology (van Manen, 2014). Van Manen (1990) sees phenomenon and experience as the same thing, and has stated that “the purpose of the phenomenological reflection is to try to grasp the essential meaning of something” (p. 77). He has defined his phenomenological method as “consisting of the ability, or rather the art of being sensitive – sensitive to the subtle undertones of language, in the way language speaks when it allows the things themselves to speak” (van Manen, 1990, p. 111). I discuss van Manen’s influence, other hermeneutic phenomenologists, and other schools of phenomenology in Chapters 2 and 3. This study is important because it adds to the small body of literature on people with ID and trauma

treatment, while specifically looking at how the experiences of trained clinicians influence their perceptions of trauma treatment for people with ID.

Problem Statement

Over the past 20 years, important progress regarding people with ID and mental health issues has been made, but research regarding PTSD and people with ID is very limited, and the extent of the evidence in general is considered low (Tomasulo & Razza, 2007). Therefore, much of the literature I reviewed for this study is over 5 years old.

According to the National Survey on Abuse for People with Disabilities, people with intellectual disabilities are more vulnerable to abuse and neglect than those in the general population (Baladerian, Coleman, & Stream, 2012). The National Disability Authority (2008) suggested that people with ID are more vulnerable for abuse and neglect due to factors such as being more isolated from friends and family, being dependent on caregivers, having multiple caregivers, lacking access to sex education and sexual health programs, having limited communication skills, and feeling disempowered to make complaints or be taken seriously if they do complain.

People with ID experience trauma and PTSD in similar ways to people in the general population; however, their responses to trauma such as self-abuse, aggression, rageful outbursts, and property destruction are categorized as challenging behaviors, and the underlying root of these behaviors is often missed (Barol & Seubert, 2010; Fletcher, Loschen, Stavrakaki, & First, 2007; Harvey, 2012; McCarthy, 2001). In this study, I explored the perceptions of clinicians regarding the diagnosis, symptomology, and treatment of trauma and PTSD for people with ID.

Counseling or psychotherapy was recommended as part of a trauma treatment protocol developed by Ryan (1994); however, common myths regarding people with ID in relation to accessing psychotherapy for trauma and PTSD continue to include the ideas that (a) persons with ID have limited verbal capacities and cannot be treated in individual psychotherapy, (b) persons with ID do not really suffer after trauma, (c) persons with ID “forget” trauma, or (d) persons with ID are not capable of emotional insight (Bradley, Sinclair, & Greenbaum, 2012; Brown & Turk, 2006; Fletcher & Poindexter, 1996; Hollins & Sinason, 2000; Mitchell & Clegg; Ryan, 1994).

Nezu and Nezu (1994) concluded that the available literature on psychotherapy for people with ID was “sorely lacking” (p. 34). Other leaders in the field have concluded that research investigating trauma and PTSD in people with ID has been limited (Doyle & Mitchell, 2003; McCarthy, 2001; Newman et al., 2000). However, modifying and adapting evidence-based treatment approaches have been the recommendation of researchers throughout the literature (Doyle & Mitchell; Fletcher, Loschen, Stavrakaki, & First, 2007; McCarthy).

The lack of funding for people with ID who experience trauma, PTSD, and other mental health issues is a barrier for them to access treatment. According to the Colorado Developmental Disability Services’ rules and regulations (2011), behavioral services are services that are specifically related to their developmental disability and are designed to help the client acquire or maintain appropriate interactions with others. The rules and regulations state that a person with an ID and mental health diagnosis needs to access the mental health system, and payment is excluded from the developmental disability funding. The National Association of Mental Health Program Directors (NAMHPD,

2004) report of 2004 indicated that both mental health systems and developmental disability systems are reluctant to allocate scarce funding for a high-needs population, and point their fingers at each other for the responsibility of providing services for this population.

Finally, the lack of education and experience of clinicians working with people with ID also poses a problem for people with ID needing access to treatment for trauma and PTSD (Butz, Bowling, & Bliss, 2000; Fletcher, Loschen, Stavrakaki, & First, 2007; Reiss, Levitan, & McNally, 1982; Ryan, 1994). Studies have shown that professionals in the field of ID are rarely trained outside of their specific field of expertise and often categorize mental health problems as challenging behaviors, while mental health professionals are often unaware of issues facing people with ID (VanderShie-Bezyak, 2003; Werges, 2007). This theme in the literature indicated the need for well-trained clinicians specializing in PTSD who also possess expertise in the field of ID (Esralew, 2006; Mevissen, Lievegoed, Seuburt & de Jongh, 2011). In this hermeneutic phenomenological study, I described and interpreted the lived experiences of clinicians regarding their perceptions of trauma treatment for people with ID. This study contributes to the literature on trauma and PTSD in people with ID.

Purpose of the Study

The purpose of this qualitative phenomenological study was to describe and interpret the lived experiences of clinicians with and without experience with people with ID, and to capture their perceptions of trauma treatment for people with ID. I used a hermeneutic approach and an ontological focus to describe how the participants' presence in the world and life experiences shaped their perceptions of people with ID and with

trauma treatment. An epistemological approach (how we know what we know) implies that my research study makes a contribution to knowledge itself (Kafle, 2011). Using an axiological approach, I have incorporated my own values and experiences in the process to generate knowledge (Mingers, 2003). Van Maren (2014) suggested that forgetting one's pre-understandings is not possible, and that various assumptions and interests are part of phenomenological reflection. My goal in this study was to capture the essential meanings of the lived experiences of participants and how those meanings are applied to their perceptions of people with ID and trauma treatment. Hopefully, my interpretation of the rich text of the participants' stories and experiences provides the possibility of new meanings, new perceptions, and liberated expressions that open up a new understanding of people with ID and trauma treatment.

Research Questions

Van Maren (1990) took from Gadamer (2004) the idea that to question something means to find ourselves deeply interested in that which makes the question possible in the first place. Van Maren stated that in phenomenological research, "to truly question something is to interrogate something from the heart of our existence, from the center of our being" (p. 43). Working with people with ID is my passion, and helping people with ID heal from trauma truly comes from the center of my being. Therefore, exploring, describing, and interpreting clinicians' lived experiences to capture the meaning of their perceptions of trauma treatment for people with ID were my focus in this study. The research questions for this study were as follows:

1. For clinicians who do not have experience working with people with ID, what are their lived experiences and perceptions of providing trauma treatment for people with ID?
2. For clinicians who have experience working with people with ID, what are their lived experiences and perceptions of providing trauma treatment for people with ID?

Theoretical Framework for the Study

Husserl and early phenomenologists distrusted theory and believed that phenomenology was not a deductive discipline, but a descriptive discipline (Zahavi, 2003, p. 67). Hermeneutic phenomenologists such as Heidegger (1962), Gadamer (2004), and van Manen (2014) believed that hermeneutics is the theory of interpretation, and each puts his own personal twist on the meaning of interpretation, which I discuss more in Chapters 2 and 3. Vagel (2014) suggested that hermeneutic phenomenologists can neither avoid bringing theory into qualitative research, nor should they try given that human beings are interpretative beings in an interpretative world. Van Manen (2014) suggested that the phenomenological approach shielded against strengthening, correcting, or renewing existing theories, but that theory can be brought in to enhance how theory and phenomenology intersected in the understanding of human phenomena.

First, as trauma symptoms began to be categorized and defined, theories of how trauma and PTSD manifested were put into models for implementation of treatment guidelines. In this study, clinicians' theoretical orientations to trauma may vary; therefore, I have included an overview of several different theories of trauma in Chapter 2. This overview includes Horowitz's (1986) schema theory, Foa's (1986, 1993, 1995)

fear network theory and integrated emotional processing theory, and Brewin's (1996) dual representation theory, to mention a few. To introduce trauma theory as part of the lived experiences, perception, and understanding of the clinicians I interviewed regarding trauma treatment for people with ID, in this section I have included discussions of Horowitz's schema theory of PTSD and Shapiro's adaptive information processing theory of trauma. The second theory to be explored by the clinicians was stigma theory, first articulated by Erving Goffman in the 1960s.

One of the earliest theories of PTSD came out of the psychoanalytic work of Horowitz, who used applications of schema theory (Dalgleish, 2004). Schema theory suggested that schemas are a way of mentally representing knowledge, and it was suggested that representations of past experiences (schemas) act as filters through which new experiences were processed (Dalgleish, 2004). Horowitz (1986) formulated the "stress response syndromes" and suggested that trauma-related information needed to be processed to completion. When trauma information processing is not completed, the trauma memories, images, and thoughts cannot be organized within the current structures (Horowitz, 1986, p. 86).

The information processing theory of PTSD has its origins in Lang's theory of emotional imagery and is based on a network model of PTSD (Lang, 1979). Most theorists agree that information processing consists of numerous sub-system modules that each have their own limited capacity, and are hierarchically organized (Lang, 1979). Dalgleish (2004) suggested there are two types of processing, the first being top down processing, which is conceptually driven, and the second, bottom-up processing, which is directed by patterns of stimulus input.

Francine Shapiro combined concepts from Bower (1981), Lang (1979), and Lazarus (1993) with her own information processing theory, and developed an adaptive information processing (AIP) model called EMDR, which has become a leading comprehensive treatment approach for trauma and PTSD (Barrowcliff, Gray, MacCulloch, & Freeman, 2004; Eloffson, von Scheele, Theorell, & Sondergaard, 2008; Shapiro, 2001). Shapiro theorized that pathologies are derived from earlier life experiences that develop into a continued pattern of affect, behaviors, cognitions, and identity structures (Shapiro & Maxfield, 2002). The problem begins when distressful experiences are inadequately processed and are influenced by early experiences. These experiences are frozen in state-specific form in their own neural network, unable to connect with neural networks that hold adaptive information (Shapiro, 2006; Solomon & Shapiro, 2008). The negative behaviors, personality characteristics, attitudes, emotions, and physical sensations are not just reactions to past events, but manifestations of the physiological perceptions stored in memories that have not been adequately processed (Shapiro, 2001). In Chapter 2, I expand on EMDR.

Conceptual Framework of the Study

The components of the conceptual framework are embedded within the interpretation and meaning of this hermeneutic phenomenological study. Specifically, this study is underwritten by the concepts that people with ID do experience trauma and PTSD, and that people with ID can engage in trauma treatment. A final component relates to the training of clinicians in trauma treatment and with people with ID. Miles and Huberman (1994) defined a conceptual framework as “laying out key factors, constructs, or variables and presumed relationships among them” (p. 440). Jabareen

(2009) defined a “conceptual framework as a network, or ‘plane’ of interlinked concepts that together provide an understanding of a phenomenon or phenomena” (p. 51). He further stated that “every concept has components and is defined by them, and every concept has a history” (p. 50). He posited that every concept contains “bits” or components originating from other concepts. Guba and Lincoln (1994) suggested that each concept within a conceptual framework played a specific role in phenomenological research, such as the ontological role of the “way things are,” or the “the nature of reality” (p. 108). The epistemological role relates to “how things really are” and how things really work,” and the hermeneutic role relates to describing and interpreting the insights and meaning in people’s lives. Van Manen (2014) suggested, “Phenomenology tries to show how our words, concepts, and theories inevitably shape and give structure to our experiences as we live them” (p. 58). Therefore, the first concept of this hermeneutic study was that the everyday lived experiences of the clinicians and their perceptions of trauma treatment for people with ID would appear or give themselves to us, and would be presented in a descriptive, interpretive, linguistic, and hermeneutic manner that shows the lived quality or significance of the experiences in a fuller and deeper manner (see van Manen, 2014, p. 26).

A second component of the conceptual framework for this study was based on the concept that people with ID do experience trauma symptoms and PTSD (see Bowman, 1999; McCarthy, 2001; Ryan, 1994). Mitchell and Clegg (2005) suggested there was a need (a) for more and better clinical descriptions of the way adults with ID reacted to traumatic life events, and (b) to establish how such material can be gathered for research purposes. Early research on psychotherapy with people with ID found favorable

psychotherapy outcomes for people with moderate and mild levels of ID (Reiss, Levitan, & McNally, 1982). Hollins and Sinason (2000) maintained that people with ID suffer mental disorders and can productively engage in psychotherapy. A third component of the conceptual framework for this study was guided by the principle that people with ID can engage in trauma treatment; however, the treatment approach may need to be adapted to meet their needs. Beail's (2005) review of the post-1985 literature indicated that psychodynamic psychotherapy and cognitive-behavioral therapy provided positive treatment effectiveness, and that therapeutic gains were maintained at follow-up. Clinicians working with people with ID may have to adapt or modify treatment techniques and approaches (Beail, 2005, Hurley, 2004; Lynch, 2005). Prout and Strohmer (1998) have advocated for developmental adaptations such as modifying the language, goals, strategies, and tasks of therapeutic techniques for people with ID. In Chapter 2, I provide a more detailed review of issues related to trauma, PTSD, and psychotherapy with people with ID.

A fourth component of the conceptual framework for this study was related to the participants' training in trauma and PTSD, and training in regard to people with ID. Salyers, Evans, Bond, and Meyer (2004) suggested that in community mental health centers, clinicians may lack awareness of PTSD or lack specific knowledge about symptoms needed to diagnose PTSD. Werner and Stawski (2011) suggested that barriers to accessing mental health treatment for people with ID include lack of knowledge about psychopathology in people with ID among professionals, and negative attitudes held by professionals towards mental health services for individuals with ID. Barriers to

accessing mental health services, the diagnoses of PTSD for people with ID, and clinician training on PTSD and ID are expanded on in Chapter 2.

The components of the conceptual framework and my use of semi-structured interview questions provided information on how the lived experiences of clinicians with or without experience working with people with ID have shaped their perceptions of trauma treatment for this population. The hermeneutic phenomenological approach I took in this study provided a framework for interpreting and understanding the meaning of the clinicians' lived experiences in relation to their perceptions of trauma treatment for people with ID.

Nature of the Study

I selected the human science approach of phenomenology for this study. Finding the essence or meaning of the clinicians' experiences as they live them in their everyday lifeworld provided deep and rich structures of meaning in regard to their perceptions of people with ID and trauma treatment. A hermeneutic approach was the best way to meet clinicians where they are naturally engaged in their worlds (van Manen, 1990). The nature of this qualitative study was in the hermeneutic phenomenological tradition, and I built it upon the hermeneutic approaches of Heidegger (1962), Gadamer (2004), and van Manen(2014). Therefore, this study was descriptive, interpretive, and reflective in nature.

Van Manen (2014) noted that many of the phenomenological scholars warned against using a methodological set of standard strategies or techniques, and stated that it was difficult to describe phenomenological research methods because there was not just one phenomenology (p. 41). He quoted Gadamer (2004) who pointed out "there is no method to human truths" (p. 30). From the phenomenological perspective, the interview

was my primary source of data, but data collection was different than standard methods in the social sciences (see Kvale, 2009; Smith, Flowers, & Larkin, 2013, Vagel, 2014; van Manen, 2014). Kvale suggested that the conversational interview provides an opportunity for the researcher to get to know the individual's experiences, feelings, hopes, and the world in which he/she lives. He posited that the research interview was an "inter-view," which is an interchange of views between two persons conversing about a theme of common interest (p. 5). Vagel (2014) suggested that it was not necessary to ask the same questions in the same way, but to look at the interview as an opportunity to learn something important about the phenomenon I conducted audio-recorded semi-structured interviews to promote a dialogue of openness, meaning, and understanding of the clinicians' lifeworld regarding their perceptions of trauma treatment for people with ID. I also incorporated memoing (field notes) as another research strategy. Miles and Huberman (1984) suggested that the use of field notes was important and enabled one to capture what was seen, heard, experienced, and thought in the course of collecting and reflecting on the process. From a hermeneutic perspective, field notes are part of reflective journaling and are integrated into the data analysis process.

Participants for my study were selected purposively and included behavioral health professionals and clinicians who had experience working with people with ID, and professionals who did not. I contacted some of the potential participants because they were personal contacts, and approached others via snowballing sampling, which amounted to asking if the participants knew of others who might want to participate in the study. Overall, the sample size was small compared to a quantitative sample. Smith,

Flowers, and Larkin (2009) suggested that participants represent a perspective, not a population, but also recommended that the sample be fairly homogeneous.

Van Manen (2014) suggested that hermeneutic phenomenological research consists of empirical and reflective analysis of the data. Empirical methods include personal descriptions of experiences, interviewing for experiential accounts, and observing experiences. Reflective methods include thematic reflection, linguistic reflection, etymological (the study of origins of words), reflection, conceptual reflection, and exegetical (interpretation of texts) reflection. Data analysis of the empirical and reflective methods is then put into the hermeneutic circle of reading, reflective writing, and interpretation in a rigorous manner (Kafle, 2011). The hermeneutic circle is a representation of movement between understanding and interpretation of the parts (data) and the whole (understanding of the phenomenon) in a circular and iterative manner. The hermeneutic circle provides opportunities for understanding different levels of meaning of a given text (Ajjawi & Higgs, 2007; Kafle, 2011; Smith, Flowers, & Larkin, 2013). Van Manen (1997) suggested orientation, strength, richness, and depth as the major quality concerns.

My data analysis plan began with listening to the audio recordings of the interviews, transcribing the recordings, reading the verbatim transcriptions of the interviews, and becoming immersed with the text as a whole. The transcribed text was then numbered and read line-by-line to delineate units of general meaning that might be important to describe and interpret. Subsequent readings of the line-by-line text were completed to develop anecdotal narratives to then identify relevant units of meaning. The units of relevant meanings were transitioned into clusters of meanings that were then

analyzed to identify if the clusters of meaning marked central themes related to the essence of the clusters and the phenomenon. Throughout this process, I incorporated the hermeneutic circle. I expand upon the data analysis plan in Chapter 3.

Definitions

Developmental disability: A federal definition that means a severe, chronic disability of an individual 5 years of age or older that is attributable to a mental or physical impairment or combination of mental and physical impairments; manifested before the individual attains age 22; is likely to continue indefinitely; and results in substantial functional limitations in three or more of the following areas of major life activity: self-care, receptive and expressive language, learning, mobility, self-direction, capacity for independent living, and economic self-sufficiency (Developmental Disabilities Assistance and Bill of Rights Act, 2000).

Diagnostic overshadowing: A term first introduced by Reiss, Levitan, and Szyszko (1982) to suggest that psychiatric symptoms tend to be overshadowed by the presence of the intellectual disability or anomalous or atypical behaviors associated with intellectual disability

Hermeneutics: The theory and practice of interpretation. It is derived from the Greek god Hermes, who was responsible for communicating messages from the gods to ordinary mortals (Colman, 2006; van Manen, 1997).

Intellectual disability (ID): A disability distinguished by considerable limitations both in intellectual functioning and in adaptive behavior, including conceptual, social, and daily living skills. Standardized testing is used to indicate an IQ score of approximately 70 or below and deficits in two of the following adaptive areas:

communication, self-care, home living, social/interpersonal skills, use of community resources, self-direction, functional academic skills, work, leisure, and health and safety; the onset of the disability is before the age of 18 (APA, 2002; American Association of Intellectual and Developmental Disabilities, 2010; Fletcher, Loschen, Stavrakaki, & First, 2007). The *DSM-5* identifies four levels of severity based on IQ testing: mild, moderate, severe, and profound intellectual impairment. Colorado Revised Statute (CRS) states that the onset of the disability is before the age of 22 (CRS 27-10.5-102). (Please note that the terms intellectual disabilities, developmental disabilities, mental retardation, and learning disabilities are interchangeable throughout this study in context with the terms used in the cited literature.)

Intentionality: Originating with German psychologist and philosopher Franz Brentano, and then Husserl, it is the inseparable connectedness of the human being to the world. It is the fundamental structure of consciousness (Colman, 2006; van Manen, 1997).

Learning disability: A term used by the British Psychological Society (like the U. S term *intellectual disability*) to diagnose and classify people who meet three core criteria of significant impairment of intellectual functioning, significant impairment of adaptive/social functioning, and the age of onset is before adulthood (The British Psychological Society, 2000)

Method: Refers to the way or attitude of approaching a phenomenon (van Manen, 2014, p. 26).

Mental retardation: A disability characterized by significant limitations both in intellectual functioning and in adaptive behavior as expressed in conceptual, social, and practical adaptive skills. This disability originates before the age of 18 (AAMR, 2002).

National Association for Dually Diagnosed (NADD): A membership organization for professionals, caregivers, and families to promote the understanding of and services for individuals who have developmental disabilities and mental health needs. NADD has been influential in the development of appropriate community-based policies, programs, and opportunities for addressing the mental health needs of persons with mental retardation (NADD, 2010).

Phenomenology: A combination of the Greek words *phainomenon* and *logos*, it is the study of phenomena. It implies the activity of giving an account of the various ways in which things can appear (Colman, 2006). (Note that the term *phenomenology* has different meaning for the different schools of phenomenological study and will be expanded on in Chapter 2.)

Posttraumatic stress disorder (PTSD): A serious psychiatric condition manifesting as a delayed and protracted response after experiencing or witnessing a traumatic event involving an actual or threatened death or serious injury to self or others. Symptoms of PTSD can include recurrent, intrusive recollections; flashbacks; nightmares; forms of avoidance; numbing; hyper-arousal; hypervigilance; insomnia; concentration difficulties; exaggerated startle response; and irritability and anger (APA, 2013).

Psychotherapy: The treatment of mental disorders by trained psychotherapists to aid a client in the relief of mental distress. There are many different orientations of

psychotherapy to include psychodynamic therapy, behavior therapy, cognitive therapy, and humanistic therapy. Therapy can be conducted individually, in groups, and with families (Colman, 2006).

Trauma: A physical or emotional infliction. In psychology, trauma refers to an experience that is emotionally painful, distressful, or shocking, which often results in lasting psychological and physical effects (Colman, 2006).

Assumptions

Several assumptions were inherent in this hermeneutic phenomenological study. First, I assumed that the lived experiences of clinicians with and without experience of working with people with ID are not commonly known, and that the knowledge generated from their lived experiences may not generalize to other lived experiences of other clinicians. However, the clinicians' lived experiences were important to the study because they provided meaning and information to interpret in relation to their perceptions of trauma treatment for people with ID. I also assumed that the participants actively participated in the interview process honestly and reflectively, but that the lack of understanding about people with ID may have complicated their ability to answer the interview questions honestly and reflectively. Third, I assumed that the data gathered from the participants would sometimes conflict, and that they may have included misperceptions regarding people with ID. Again, the lack of knowledge about trauma and PTSD in people with ID, personal theoretical orientations to trauma treatment, and stigma may have appeared to conflict with the research regarding trauma and PTSD in people with ID and my own personal knowledge and experience working with people with ID.

Scope and Delimitations

In this hermeneutic phenomenological study, I looked at clinicians' perceptions of (a) how people with ID experience trauma and PTSD; (b) the lack of research regarding trauma treatment for people with ID; (c) the funding barriers for people with ID to access trauma treatment; and (d) the lack of training in trauma in general, and trauma treatment for people with ID in particular. Specifically, these concepts were important for interpreting the clinicians' lived experiences and how these concepts have shaped their perceptions of trauma treatment for people with ID.

This study was limited to a small number of clinicians, either in private practice or in small behavioral health agencies in the metropolitan area of Denver, Colorado. I did not intend their perceptions to be generalized to the majority of behavioral health professionals. Large federally-funded community mental health organizations were excluded because the information from this small hermeneutic phenomenological study sets the stage for a larger study that will include the complexities of federally-funded community mental health organizations. My criteria for purposive sampling are detailed in Chapter 3.

The brain's functioning and neurobiological systems and theories of trauma and PTSD were beyond the scope of this study. I provide an overview of some of the theories of trauma and PTSD, but the detailed components of each theory are beyond the scope of this study. The clinicians interviewed did not have the same theoretical orientations to trauma and PTSD, and capturing their theoretical orientations was important for understanding their perceptions of trauma treatment for people with ID. Lincoln and Guba (1985) suggested that transferability was not the burden of the researcher, but rather

of the reader who is considering applying the findings to his or her own circumstances, which was the goal of this study. Smith, Flowers, and Larkin (2013) described transferability as when the reader links the rich, transparent, and contextualized analysis to the accounts of the participants (p. 51). Participants with different orientations or graduate study were selected, which may have resulted in a wide variation in their perceptions of people with ID and trauma treatment.

Limitations

I acknowledge that I am a novice when it comes to hermeneutic phenomenological research, and my interpretation of hermeneutics may not have been as in-depth as those of a more experienced phenomenological researcher. Another limitation was the small body of research on the perceptions of clinicians about people with ID and trauma treatment. Also, the transferability or the ability to replicate the study may have been limited. I also acknowledge that I have my biases regarding psychotherapy for people with ID and that potential controversies may have arisen, but I am confident that the hermeneutic methodology of reflection helped me identify those biases, and that I have appropriately documented them as part of the results and discussion sections of Chapter 4 and 5.

Dependability is the qualitative counterpart to reliability. To enhance dependability, I used the Nvivo software program as a database for all of the material related to this study. A limitation of dependability was that while the use of an independent auditor was desirable, my financial situation did not allow for this process. However, dependability was enhanced by having transcripts of tape-recorded sessions and semi-structured interviews that provided a record of naturally occurring interactions

and contributed to accuracy and consistency. I addressed the issue of dependability by identifying my personal biases, describing the design of the study, outlining the data gathering and data analysis plan as a decision trail, and specifying the choices for such decisions.

Significance

This phenomenological study adds to the body of literature regarding trauma treatment for people with ID and the perceptions of clinicians about trauma treatment for this population. Hopefully, this study serves to dispel myths regarding the diagnosis of PTSD in the ID population and promotes the importance of trauma-informed care, treatment, and healing for this population.

Social Change

This study may open a discussion for universities and training venues to provide students, clinicians, and other health professionals with more training on the identification and treatment of trauma and PTSD for people with ID. Information gained from this study could change how services are provided to people with ID and trauma and PTSD, support the implementation of collaborative funding mechanisms, and promote the best practices for the treatment of trauma and PTSD for people with ID. Several researchers have claimed that there is a lack of training for community professionals in trauma, mental health disorders, and other ID issues (Beail, 2005; Beasley, 2004; Butz, Bowling, & Bliss, 2000; Doyle & Mitchell, 2003; Reiss, Levitan, & McNally, 1982). This study serves to advocate for the rights of people with ID to have the same access to psychological therapies and approaches as the general population.

Summary

People with ID experience the same types of trauma that the general population experiences and have a higher risk for developing PTSD (Bowman, 1999; McCarthy, 2001; Ryan, 1994). However, the literature on the assessment and treatment for people with ID who have experienced trauma and PTSD is in its infancy (Doyle & Mitchell, 2003; First, 2007; Fletcher, Loschen, Stavrakaki, & McCarthy, 2001). PTSD and trauma have been under-recognized, under-reported, and under-treated in adults with ID (Esralew, 2006). Controversies on the effectiveness of psychotherapy for people with ID have created a barrier for research on assessment and treatment strategies for PTSD and trauma in people with ID (Beail, 2005; Hollins & Sinason, 2000). Critics of psychotherapy for people with ID maintain that there is a lack of empirical data showing effectiveness, and manuals or protocols have not yet been created for therapeutic orientations to be implemented. However, the lack of training for professionals on people with ID and on trauma and PTSD has also been identified as a barrier for access to treatment for people with ID who experience trauma and PTSD (Salyers, Evans, Bond, & Meyer, 2004).

The purpose of this qualitative phenomenological study was to describe and interpret the lived experiences of behavioral health professionals with and without experience with people with ID, and to capture their perceptions of trauma treatment for people with ID. I used a hermeneutic phenomenological approach influenced by van Manen's methodology of description and interpretive phenomenology.

Chapter 2 provides an introduction to the literature review and the literature search strategies. In the chapter, I also review literature relating to some of the different

theories of trauma and PTSD, the conceptual framework and key variables and concepts of phenomenology, PTSD, and people with ID. A historical overview of people with ID and the recognition of mental health issues, specifically trauma and PTSD, and the historical overview of the different schools of phenomenology is also provided. In the literature review, I identify controversies regarding psychotherapy for people with ID, and discuss the controversies of quantitative versus qualitative research with an emphasis on phenomenological methods. Chapter 2 ends with a summary and conclusion.

Chapter 2: Literature Review

Introduction

The NADD (2007) reported that approximately 30-35% of all people with ID have a mental disorder. Treatments for psychological trauma and PTSD have been widely studied and researched for over two decades since the inclusion of the criteria for PTSD in the *DSM-III* published in 1980 by the APA (Deville, 2005; Foa, Rothbaum, Riggs, & Murdock, 1991; Kessler, Sonnega, Bromet, Huges, & Nelson, 1995; LaGreca, Silverman, Vernberg, & Prinstein, 1996; van der Kolk, Spinazzola, Blaustein, Hopper, Hopper, Korn, & Simpson, 2007). However, the research on psychological trauma and PTSD for people with ID is scant, especially regarding how trauma and PTSD may manifest in people with ID and treatment modalities that are efficacious for people with ID (Fletcher, Loschen, Stavrakaki, & First, 2007; Reiss, Levitan, & McNally, 1982; Ryan, 1994).

Stigma, prejudices, and discrimination have been widely documented for people with mental illness and intellectual disability, but the stigma of having both an intellectual disability and a mental illness such as PTSD is twofold. A person with ID is more likely to be misdiagnosed when symptoms of trauma and PTSD are mistaken for “behavioral problems,” or given no diagnosis at all (Esralew, 2006; McCarthy, 2001; Werner & Stawski, 2012). Other barriers to accessing care and treatment include the lack of caregiver education on how to identify and communicate symptoms of PTSD, and the lack of trauma training on people with ID among medical and mental health providers (Taggart, McMillan, & Lawson, 2010; Werner & Stawski, 2012).

Common myths regarding people with ID in relation to accessing psychotherapy for trauma and PTSD continue to include the ideas that (a) persons with ID have limited

verbal capacities and cannot be treated in individual psychotherapy, (b) persons with ID do not really suffer after trauma, (c) persons with ID “forget” trauma, and (d) persons with ID are not capable of emotional insight (Bradley, Sinclair, & Greenbaum, 2012; Fletcher & Poindexter, 1996; Hollins & Sinason, 2000; Mitchell & Clegg, 2005; Ryan, 1994; Turk & Brown, 1993).

The purpose of this qualitative hermeneutic phenomenological study was to describe and interpret the lived experiences of mental health clinicians with and without experience with people with ID, and to capture their perceptions of trauma treatment for people with ID. Merleau-Ponty (2002) asserted that perceptions blend and confirm each other and are embedded in history, and that “we cannot do or say anything without its acquiring a name in history” (p. xxii). Therefore, in this literature review I provide a brief history of the development and theories of PTSD, a historical overview of how people with ID have been treated, and overview of the intellectual disability/mental health movement. In this chapter I explore stigma and negative perceptions of people with ID, and discuss the controversies surrounding psychotherapy for people with ID. The literature review also includes discussions of the issues relating to the training of mental health professionals on trauma and PTSD, and identification of psychopathological trauma for people with ID. Phenomenology, the different schools of hermeneutics, and the on-going controversies of qualitative research versus quantitative research methods are presented. In this chapter, I review qualitative studies, quantitative studies, meta-analyses, and case studies to investigate outcomes related to my study.

Literature Search Strategy

My strategy for searching the literature included a primary focus on peer-reviewed journal articles retrieved from multiple databases such as Psych INFO, Psych ARTICLES, PsychBOOKS, Academic Search Complete, SocINDEX with FULL TEXT, the American Medical Association, the American Psychiatric Publishing, OVID, and ProQuest Central. I used text books from specific disciplines such as phenomenology, hermeneutics, and diagnostic criteria for ID/MI and PTSD from the *DSM-IV-TR* when information was not obtainable from peer-reviewed articles. Professional organization websites such as the American Association of Intellectual and Developmental Disabilities (AAIDD), (NADD), and the Eye Movement Desensitization and Reprocessing International Association (EMDRIA) were used sparingly for supportive information regarding positions on psychotherapy, intellectual disabilities, and evidence-based therapeutic techniques. I also used training manuals and audio presentations from past conferences. The literature review contains primary sources written within the last 10 years and seminal sources to provide historical background information and to acknowledge a progression of studies that have added to the ID and PTSD literature. Key terms I used for the literature search included: *intellectual disabilities, learning disabilities, developmental disabilities, mental retardation, trauma, emotionally disturbed, PTSD, mental health, EMDR, counseling techniques, treatment, psychotherapy, treatment outcomes, counseling effectiveness, qualitative analysis, thematic analysis, qualitative research, phenomenology, hermeneutics research methods, and stigma.*

Theoretical Foundation

To understand how the theories of trauma and PTSD were developed, I explored the historical archives regarding the symptoms on which the many different theories of PTSD have been based. Understanding the historical development of how theories of trauma and PTSD were developed also keeps with Gadamer's (2004) suggestion that understanding is possible only if embedded in historical consciousness. Therefore, I provide an overview of how researchers have identified and developed theories about trauma and PTSD. Following the historical overview, I introduce the theories that comprised the trauma and PTSD framework for this study, including Horowitz's schema theory, Foa and Kazak's emotional processing and expanded fear network theory, Brewin's dual representational theory, Ehler and Clark's appraisal of on-going threat theory, Scar's whiplash experience theory, and Shapiro's adaptive information processing theory. Goffman's stigma theory is also included in the framework of this study.

Historical Overview of Trauma and PTSD

Historically, what has come to be called PTSD was described according to a variety of symptoms and defined by the psychological practices and theories of the era in which they were embedded. As early as the third century B.C., the ancient literature of Mesopotamia included descriptions of the traumatic experiences of facing death and witnessing death in battle (Birmes, Hatton, Brunet, & Schmitt, 2003). In this literature, authors described symptoms of persistent re-experiencing of recurrent and intrusive thoughts. Feelings of detachment and foreshortened future were also observed (Birmes et al., 2003). Other ancient literature (Homer's *Iliad*, 850 B.C.) included descriptions of nightmares and traumatic dreams, such as Achilles' recollections and agitated sleep due

to the death of his friend Patroclus during battle (Birmes et al., 2003). Froissart, the French chronicler, described the nightmares and dissociative flashbacks of Peter of Bearn, who required servants to look after him when he would brandish his sword while having traumatic dreams (Birmes, et al., 2003).

Dissociative symptoms such as stupor, disorientation, the absence of movement, the lack of awareness of time and place, losing time, feeling like the event was unreal, feelings of body distortions, confusion, and numbing were described in letters about the eruption of Vesuvius in 79 A.D. by Charles IX of France, and by soldiers in the Napoleonic wars (Birmes et al., 2003; Lasuik & Hegadoren, 2006). Even Shakespeare wrote of posttraumatic stress symptoms of nightmares in *Romeo and Juliet*, and dissociation and flashbacks in *Macbeth* (Birmes et al., 2003).

In the 19th century, some of the first references to the effects of psychological trauma are found in the work of Dr. Willer Lewis (1861), who termed symptoms of sleep disturbances, nightmares of collisions, tinnitus, and chronic pain as “railway spine” (Birmes et al., 2003; Lasiuk & Hegadoren, 2006; Van der Kolk, Weisaeth, & van der Hart, 1996). Due to the flimsy construction of railway cars and the violent rocking of the cars on the tracks, there was a high incidence of railroad crashes and death. Those who survived these railway crashes reported severe and lasting disabilities with the absence of external signs of injury or neurological damage (Birmes et al., 2003). Physicians and psychiatrists clashed on whether the symptoms of “railway spine” were related to organic causes or were psychological in origin (Birmes et al., 2003; Van der Kolk et al., 1996). Dr. Hermann Oppenheim believed in the psychological origin and renamed the condition “traumatic neurosis,” which was the first time the word “trauma” was used in psychiatry

(Lasuik & Hegadoren, 2006). In America during the Civil War, the term “nostalgia” was the diagnosis for soldiers and civilians who experienced lethargy, withdrawal, fits of hysterics, and conversion reactions (Lasuik & Hegadoren, 2006). Symptoms of extreme fatigue, difficulty breathing, heart palpitations, sweating, and tremors were associated with the biological response to the stress of battle and were given the term “soldier’s heart” by Arthur Meyers in 1870 (Birmes et al., 2003).

The controversy of whether the disorder of “railway spine” was due to the specific event or to weakness in the individual became an on-going debate in the late 19th century, especially regarding women. The term “hysteria” categorized symptoms of paralysis, tremors, spasms, and respiratory, digestive, and cardiovascular disorders, with or without mental symptoms (Marlowe, 2000). Many physicians found that the symptoms of “railway spine” were similar to hysteria and that men and women reacted differently to trauma (Lasuik & Hegadoren, 2006). In France in 1887, Jean-Martin Charcot and his student, Pierre Janet, found that female patients who experienced hysteria and somatic symptoms would experience altered states of consciousness when remembering traumatic events. Janet would later call this “dissociation,” which could be induced and relieved through hypnosis (Van der Kolk et al., 1996). Janet was the first to hypothesize that traumatized individuals were not capable of integrating traumatic memories and the associated emotions into their narrative memory. These memories would remain unconscious until the affected individuals were exposed to stress in their present lives, upon which they would react with agitation, behavioral outbursts, and dissociative problems (Van der Kolk et al., 1996). In Vienna, Sigmund Freud reached similar conclusions about hysteria. Both Freud and Janet found that these symptoms could be

relieved when the traumatic memories and emotions were integrated and put into words, which was the beginning of psychoanalysis (Lasuik & Hegadoren, 2006).

Most of the interest regarding trauma was associated with war (Lasuik & Hegadoren, 2006). In World War I (WWI), soldiers were constantly faced with their own deaths and the deaths of their fellow countrymen. The literature depicted soldiers acting like hysterical women, screaming uncontrollably, or becoming frozen and not being able to move (Herman, 1996). A British psychiatrist, Charles Samuel Meyers (1915), coined the term “shell shock” to describe the symptoms and postulated that the symptoms were due to cerebral concussions from exploding shells (Lasuik & Hegadoren, 2006). However, when he found the same symptoms in soldiers not directly involved in battle, he separated “shell concussion” (a neurological disorder) from “shell shock,” a psychological condition brought about by extreme conditions of war (Van der Kolk et al., 1996). An American psychiatrist, Abram Kardiner (1941), coined the term “war neurosis” (Lasuik & Hegadren, 2006). He found that soldiers often developed amnesia for traumatic events while behaving as if they were still in the event (Lasuik & Hegadren, 2006). Kardiner acknowledged that symptoms of “war neurosis” were similar to hysteria, but refused to associate the two words. He would go on to provide the criteria for PTSD for the *DSM-III* in 1980 (APA, 1980).

After WWI, the United States military began to screen soldiers to identify personnel who were not psychologically fit to face battle (Lasuik & Hegadoren, 2006). New hostilities in the world jolted new ideas about psychological trauma and the treatment and prevention of psychiatric casualties. Herbert Spiegel found that soldiers who trusted their combat group and their immediate leadership and had the necessary

degree of readiness and were deemed fit to face battle. Spiegel's work paved the way for "frontline psychiatry" (Marlowe, 2000; Van der Kolk et al., 1996). Mobile army hospitals near the front line were established to treat and resolve immediate problems and have soldiers return to their units as quickly as possible (Lasuik & Hegadoren, 2006).

Environmental factors and interpersonal relationships began to influence the psychiatric doctrine by the 1960s (Lasuik & Hegadoren, 2006). After WWII, clinicians and psychiatrists began to work with the survivors of the Holocaust, rape survivors, battered children, and Vietnam veterans. Independently, these researchers and practitioners found similar effects of different types of psychological trauma, but it was not until the 1970s that these bodies of work would join to influence the third version of the *DSM* to include both civilian and military response syndromes under the diagnosis of PTSD (Lasuik & Hegadoren, 2006).

In 1980, the APA added to the *DSM-III* the diagnosis of Posttraumatic Stress Syndrome and included the phrase "almost anyone" for the first time for whom stressors can evoke distress (APA, 1980, p. 238). The writers of the *DSM-III* interpreted the event or stressor as in combat, rape or assault, man-made disasters, or natural disaster to meet the criteria for the disorder (McNally, 2003). The *DSM-IV* (APA, 1994) broadened the definition to include trauma exposure as having been experienced, witnessed, or confronted by events that involved actual or life-threatening injury which evoked "intense fear, helplessness, or horror" (APA, 1994, p. 427).

The current criteria for PTSD, according to the *DSM-5* (APA, 2013), structure the symptoms along eight criteria. First, a person must experience a traumatic event that was actually or believed to be life-threatening to the person or to others and/or involved

serious injury, sexual violence, or repeated exposure to aversive parts of the traumatic incident (APA, 2013). Symptoms are also divided into four criteria clusters. The re-experiencing of intrusive thoughts about the trauma, nightmares, and flashbacks define the first cluster. The avoidance cluster includes avoiding thoughts, memories or feelings associated with the trauma, and avoiding people, places, and situations that arouse distress associated with the traumatic experience. The third cluster affects cognition and mood associated with the traumatic event and includes difficulty remembering facts about the trauma, feeling detached or estranged from others, developing distorted cognitions that lead to blame, and having persistent negative emotions such as fear, anger, guilt, and shame (APA, 2013). The fourth cluster includes sleep disturbance, exaggerated startle response, difficulty concentrating, and hypervigilance. The last two criteria specify that the duration of symptoms must be more than one month and the symptoms must cause clinically significant distress or impairment in functioning (APA, 2013).

As trauma symptoms began to be categorized and defined, theories of how trauma and PTSD manifested were developed and put into models for implementation of treatment guidelines. An overview of several theories is presented, but specific details of these theories are beyond the scope of this study.

Schema Theory

One of the earliest theories of PTSD came out of the psychoanalytic work of Horowitz and used applications of schema theory (Dalglish, 2004). Horowitz (1986) suggested that schemas were a way of mentally representing knowledge and that representation of past experiences (schemas) acted as filters through which new

experiences were processed. Horowitz formulated the “stress response syndromes” and suggested that trauma-related information needed to be processed to completion. When trauma information processing was not completed, the trauma memories, images, and thoughts could not be organized within the current structures (Horowitz, 1986, p. 86). He suggested that psychological defense mechanisms kept the traumatic information in what he called “active memory,” and broke through psychological defenses as flashbacks, nightmares, and intrusive thoughts. Horowitz argued that the repeated pattern of the active memories caused individuals to fluctuate between phases of intrusion and denial as the traumatic material assimilated into long-term schematic representation (1986). However, some individuals did completely assimilate the traumatic material and developed chronic PTSD.

Schema theory critique. Dalgleish (2004) suggested that Horowitz’s theory provided a good explanation for the course and severity of PTSD, and why treatment may fail some individuals. However, it did not address the automaticity of trauma symptoms and the emotions associated with PTSD. Horowitz’s schema theory of PTSD also utilized exposure therapy, and Ehler and Clark (2000) suggested exposure therapy could make some clients worse because trauma related perceptions could be more than the client was prepared to handle.

Emotional Processing and Fear Network Theory

Foa and Kozak’s (1986) early emotional processing theory borrowed from Lang’s “bio-informational fear” theory and Bower’s information network theory, which provided an explanation for how pieces of information could activate each other and lead to a production of effects (Bower, 1980). Foa and Kozak distinguished between normal and

pathological fear structures, where normal fear structures were activated when danger was present but led to an adaptive resolution by the individual to avoid danger. A pathological fear structure encompassed links of stimuli and responses that were distorted and triggered excessive response elements (Foa & Kozak, 1986). They proposed that the “fear network” was a “fear program” with associative networks that contained stimulus information about the feared object; information about cognitive, behavioral, and physiological responses to the feared object; and information that linked the stimulus and response elements together (Foa, Huppert, & Cahill, 2006). The extinction of the fear response was completed by repeated exposure to the feared object and then by the integration of new cognitive meanings into the network by habituation to the feared object (Foa et al., 2006).

Foa and Kozak (1986) expanded their theory using the “fear network” model and integrated it with schema-based foundations to form the emotional processing model which included three core components. Foa and Kozak addressed the first controversy regarding the types of mental representations in the form of “memory records,” which were disorganized and disrupted the information processing at the time of the traumatic event (Foa, Steketee, & Rothbaum, 1989). Foa, Molnar, and Cashman (1995) found that exposure therapy decreased the disorganization and PTSD symptomatology of the individual’s narratives throughout the treatment process. The second component addressed the issue of the lack of explanation for how prior traumatic events affected an individual. Foa et al. (1989) suggested that memory records contained many stimuli and meanings in the representation of the traumatic event, and when trauma memories are triggered, other memories related to prior traumatic events became associated with

danger and the current traumatic event. Thirdly, Foa et al. (2006) argued that repeated exposure therapy sessions allowed the individual to change the cognitive meaning of the traumatic event and it was a cognitive process rather than a mental representation.

Emotional processing and fear network theory critique. Dalgleish (2004) suggested that Foa and Kozak's (1986) theories provided a notable description of PTSD symptomology, an explanation of how the techniques of exposure therapy could be used as a treatment approach, and a model of connectivity between different network representations. However, Foa and Kozak's theory lacked an explanation of how the process of exposure worked on the content of the representations and how the cognitions were integrated and changed within the theory (Dalgleish, 2004). The theory also does not have an explanation for how pre-trauma risks or prior traumatic experiences affect the fear networks of individuals vulnerable to PTSD (Dalgleish, 2004).

Dual Representation Theory

In contrast to the single/unitary representational model of PTSD, Brewin's (1989) dual representation theory (DRT) suggested that there was more than one type of representation of a single or repeated traumatic experience. Brewin proposed that traumatic experiences contained interacting cognitive subsystems, which held conscious and unconscious memories of the traumatic event. Brewin, Dalgleish, and Joseph (1996) defined conscious traumatic experiences as *verbally accessible knowledge* (VAMs), which were retrieved from autobiographical memories that contained some sensory, emotional, and physiological experiences for perceived meaning. *Situationally accessible knowledge* (SAMs) could only be deliberately accessed when the individual was in context with physical features or similar meanings to the traumatic experience. Brewin et

al. (1996) also suggested that the VAMs and SAMs were encoded in parallel at the time of the trauma but had different processing capacities. Brewin et al. concurred with Foa that emotional processing of the traumatic event was necessary for recovery from PTSD, but proposed that the VAMs needed to be consciously integrated with preexisting beliefs and views of the world to restore a sense of safety and control. SAMs were activated by exposure to cues of the event and were transformed by integrating new, non-threatening information into the SAMs to create new SAMs.

Dual representation theory critique. Dalgleish (2004) suggested that Brewin's DRT had similar conceptualizations of Horowitz's schema theory and Foa's network theory, but added an explanation for how cognitive beliefs and meanings were transformed and processed, and provided an evolutionary leap from a single representation model to a dual representation format. However, Brewin's theory did not address the question of other types of network representations, such as visual representations, in the model. Dalgleish (2004) also suggested that the DRT had a problem with how the components of the VAMs and SAMs interacted with each other.

Appraisal of On-Going Threat Theory

Ehler and Clark's (2000) theory focused on the persistence of PTSD symptoms. They proposed that individuals with persistent PTSD have distinctive negative appraisals of the traumatic events and created a sense of current serious threat. These appraisals can be internal or external and maintained PTSD by producing negative emotions such as anxiety, depression, or anger, which, in turn, produced negative coping strategies that enhance PTSD symptoms (Ehler & Clark, 2000).

The second component of Ehler and Clark's (2000) theory was the nature of traumatic memories that contributed to a sense of on-going threat. They suggested that traumatic memories were not integrated into the autobiographical memory systems, which led to fragmented and poor narrative accounts of the traumatic event. These fragmented autobiographical memories contained stimulus elements strongly connected (S-S connected) to the traumatic event and triggered the strong responses (S-R connected) experienced at the time of the trauma (Ehler & Clark, 2000). Ehler and Clark posited that their model presented a typology of behavioral and cognitive responses that, in the short term, enhanced an on-going sense of threat, but in the long-term blocked cognitive change and work to maintain PTSD.

Appraisal of on-going threat theory critique. Dalgleish (2004) suggested that Ehler and Clark's (2000) theory was influenced by traditional network theories, like that of Foa and Kozak (1986). Their theory provided a process for analyzing thoughts and appraisals of the traumatic event and provides two theoretical components for the maintenance of PTSD. However, Dalgleish (2004) argued that Ehler and Clark's theory lacked an explanation for the transformation of meaning after the traumatic event, its schema structures were not a central part of their theory, and pre- trauma, trauma, and post trauma appraisals were bundled together.

Whiplash Experience Theory

Although the theories discussed above acknowledged the physiological symptoms as part of PTSD, none of the theorists provided a theory of how these physiological symptoms manifested. Robert Scaer's hypothesis operated on a body/ brain/ mind continuum that he called the "whiplash experience," developed through his experiences

treating motor vehicle accident victims (Scaer, 2001, p. 33). He posited that the neurophysiological changes that occurred when a person experienced threat, shock, injury, or psychological trauma were stored in unconscious procedural memories in a cumulative order (Scaer, 2001). Scaer suggested that a number of pains and gastrointestinal, sexual and psuedoneurological symptoms that caused significant impairment in functioning were a result of emotional or psychological stress that was internalized and presented as physical symptoms. Scaer (2001) also posited that the traumatic experience of helplessness and the inability to fight or flee led to a frozen or dissociative response, which was driven by the parasympathetic nervous system and endorphins. The memories linked to a threat of life occurred in a high state of arousal and become conditioned quickly and were resistant to extinction. Scaer borrowed from ethology in reference to his “freeze” or immobility response that suggests that prey animals become limp and immobile, but their parasympathetic nervous system and endorphinergic levels are high. Scaer also built on the work of van der Kolk (2001) and Levine (1997) in relation to how individuals who experienced traumatic events stored the somatic and autonomic responses such as trembling, perspiring, and deep breathing, which were used to perpetuate a sensory-motor message of life threat when triggered by events that may or may not be related to the original trauma.

Whiplash experience theory critique. Dr. Robert Lewis (2007) suggested that Scaer’s (2001) theory described many of the symptoms his patients experienced, but there were no rigorous empirical studies to support Scaer’s theory. Lewis also suggested that Scaer’s data sample relied heavily on patients with isolated traumatic events and motor vehicle accidents. Lewis suggested that Scaer’s theory posited that posttraumatic

syndromes are sensory messages and motor reflexes, which Lewis contradicted with how exposure therapy can progressively reduce symptoms of PTSD.

Adaptive Information Processing Theory

Francine Shapiro (2001) is the originator of EMDR, and she told the story of having disturbing thoughts while walking in the park in 1987. She noticed her disturbing thoughts were not as upsetting when brought back up. Paying attention to what she was doing, she noticed that when disturbing thoughts came to mind, her eyes spontaneously started to move rapidly back and forth. As she continued to bring up disturbing thoughts, they disappeared, or their negative charge had been greatly reduced. She originally called her technique Eye Movement Desensitization (EMD) and introduced EMD in her first controlled study in 1989 with 22 rape, molestation, or Vietnam combat veterans who suffered from traumatic memories. Shapiro (2002) reported her study showed two marked changes in one session: a decrease in anxiety and an increase in positive beliefs about themselves. According to Shapiro (2002), her initial pilot study was one of the first published controlled studies assessing PTSD symptomology. She admitted that her initial study had limitations and flaws due to the lack of standardized measures and blind evaluations and emphasized that EMD did not eliminate all PTSD symptoms or provide coping strategies (Shapiro, 1989). Shapiro also recognized that the positive treatment effects warranted refinement of the procedures and further evaluations. Early on, after her first pilot study, and hundreds of case study reports later, Shapiro recognized that the specific procedural guidelines and protocol she created with simultaneous desensitization, restructuring of memories, clients' immediate insights, and increased self-efficacy, were a product of the adaptive processing of disturbed memories.

In 1990, Shapiro changed the name of EMD to EMDR (Eye Movement Desensitization and Reprocessing), adopting an adaptive information processing model (Shapiro, 2001, p. 13). Some researchers considered EMDR a therapeutic technique (Deville, Spence, & Rapee, 1998; Lohr, Tiolin, & Lilienfeld, 1998). However, Shapiro has held that EMDR is a psychotherapy approach that is based on how the brain processes and stores memories (Shapiro, 2001; Shapiro, 2006; Solomon & Shapiro, 2008). The adaptive information processing (AIP) model provided a theoretical framework and principles, predicted successful clinical outcomes, and guided case conceptualization and treatment procedures. The Shapiro model suggested that most pathology was derived from earlier life experiences that developed into a continued pattern of affect, behaviors, cognitions, and identity structures (Shapiro & Maxfield, 2002). The problem began when distressful experiences were inadequately processed and were influenced by early experiences. These experiences were frozen in state-specific form in their own neural network, unable to connect with neural networks that held adaptive information (Shapiro, 2006; Solomon & Shapiro, 2008). The negative behaviors, personality characteristics, attitudes, emotions, and physical sensations were not just reactions to past events, but were manifestations of the physiological perceptions stored in memories that had not been adequately processed (Shapiro, 2001). Shapiro (2006) also posited that dysfunctional stored information and memories transmute as they linked to adaptive memory networks toward an adaptive resolution by using the EMDR protocol and bilateral stimulation.

Adaptive information processing theory critique. Several researchers (Bergmann, 1998; Lohr, Klienknecht, Tolin, & Barrett, 1995; Rosen, Lohr, McNally, & Herbert, 1998) questioned Shapiro's methodology and the efficacy of her initial study, which began a 20-year controversy about the efficacy of EMDR, which is the most researched theory of PTSD (Luber & Shapiro, 2009). The methodology and efficacy of Shapiro's study brought attention to issues of research and clinician training to the forefront of studying trauma and PTSD, and it brought about rigorous standards for treatments to be researched. One of the main controversies of EMDR began with the purported necessity of eye-movements. Shapiro contended that the multi-saccadic eye movements seemed to unlock the nervous system to allow the brain to process traumatic memories (Shapiro, 2001). Several early studies were completed and concluded that the eye movements used in the EMDR protocol were not essential to treatment outcome. Shapiro did concede that eye movements were not the only form of stimulation that could be used and suggested that other forms of bilateral stimulation could be used, such as hand taps, tones, or music (Shapiro, 2001, p. 337). Shapiro maintained that eye movements were the most effective modality when processing trauma (Luber & Shapiro, 2009).

Summary of PTSD theories

The overview of the literature on the theories of trauma and PTSD illuminated a consistent pattern of how later theorists were influenced by earlier theorists, borrowed theoretical components from earlier theorists, or expanded pre-existing theories. This was the rationale for giving an overview of some of the different theories of trauma and PTSD, which may be part of the theoretical orientation to trauma and PTSD that the

clinicians being interviewed use as they implement trauma therapy. Another observation I found throughout the literature was that the theories of PTSD are multi-theoretical in nature.

Lazarus and Beutler (1993) suggested that, as early as 1933, French (1933) addressed the multi-theoretical approach of Freud's psychoanalytic orientation to include stage theory and personality theory, and further discussed the interrelations between psychoanalytic and behavioral principles in psychotherapy and psychopathology. Historically, Thorne (1957) was the first to suggest that psychotherapy did not follow consistently from theory (Lazarus, Beutler, & Norcross, 1992). Agras (1987) suggested the integration of psychodynamic and behavioral theory may have been of value and that the action-oriented theories and methods of behavioral change, combined with the details of unconscious processes, went beyond the merits of either theory. However, the insight versus action clash did not provide positive results. Dalglish (2004) found this to be true when reviewing the different theories of PTSD.

Research investigating trauma and PTSD with people with ID has been limited (Doyle & Mitchell, 2003; McCarthy, 2001; Newman et al., 2000). However, the research has shown that people with ID do experience trauma symptoms and PTSD (Bowman, 1999; McCarthy, 2001; Ryan, 1994), and that people with ID can engage in trauma treatment. Therefore, the theories presented in this section could be applied to people with ID in regard to trauma treatment. The overview of the theories presented in this study provided a framework from which the clinicians being interviewed may have developed their theoretical orientations of trauma and PTSD, which, along with the

clinicians' lived experiences, may shape their perceptions of trauma treatment for people with ID.

Stigma Theory

“Stigma” originated from the Greek meaning “bodily signs designed to expose something unusual and bad about the moral status of the signifier” (Goffman, 1963, p. 1). Stigma was first articulated by Erving Goffman in the 1960s and was based on social interactionist theory. He believed that “stigma is an attribute that is deeply discrediting, and the person carrying that stigma is different from the rest or of less desirable kind” (p. 5). Goffman’s original dialogue on stigma used both psychology and social features and included not only people with mental illness but also people like ex-convicts, people with disabilities and deformities, and people with different sexual preferences. The cognitive representations of these stigmas formed the perceptions that people used and triggered emotional and behavioral reactions, and led to stereotyping and prejudice (Dijker & Koomen, 2003).

Over the decades, stigma theory has evolved into different theories such as labeling theory, discrimination theory, confirmation bias theory, and attribution theory, which are beyond the scope of this study. However, the social component of all these theories was not just limited to uninformed members of the general public, as well-trained medical and mental health professionals also subscribed to the stigmas about mental illness and intellectual disabilities (Kean, 1990). Kent (1993, p. 26) found that common attitudes of graduate psychology students were, “You can’t really do anything with those people” and “I didn’t become a psychologist to do social work.” Simpson (2002) suggested that there was a reluctance to give a psychiatric diagnosis due to the

already stigmatizing effect of having a diagnosis of “mental retardation,” and that the medical model of intervention promoted control, confinement, and sedation of persons with intellectual disabilities. However, there were differences between the stigmas of people with mental illness and people with ID, which may have been promoted by the perception that a mental illness was possibly curable but that ID is a lifelong disability. Several studies were found regarding the stigma of people with ID; however, no literature regarding the stigmas of people with both ID and mental illness was found, with the inference being that persons with ID were not fully understood by either the ID or mental health communities.

In the Netherlands, a study was completed regarding staff’s attitudes and reactions towards aggressive behaviors of clients with ID (Knotter, Wissink, Moonen, Stams, & Jansen, 2013). The authors found that staff’s cumulative attitude within the team strongly shaped how the staff interacted and implemented interventions. The author’s also found that the more negative the attitudes of the team, the more coercive the interventions. Their study supported other research that suggested that a negative informal staff culture and group perception of challenging behavior by clients with ID influenced the opinions of individual group members (Knotter et al., 2013).

Corrigan (2004) cited several surveys that suggested people with mental illness do not seek treatment, do not comply with medications, and do not receive adequate psychotherapy due to labels by the general public that yield stigma. Corrigan (2004) provided four social-cognitive processes of cues, stereotypes, prejudice, and discrimination as relevant factors for why people do not engage in treatment. He suggested that cues such as psychiatric symptoms, social-skills deficits, physical

appearance, and labels connote mental illness to the general public. These cues can also be applied to how stigma affects a person with an ID and mental illness (Ditchman, Werner, Kosyluk, & Jones, 2013). People can stereotype and classify others into social groups, which creates impressions and expectations quickly (Corrigan, 2004; Ditchman et al., 2013). Some stereotypes of people with mental illness included that they are violent or that they cannot live and work independently (Corrigan, 2000). People with ID were perceived to be dependent on others, childlike, look differently than others, and are happy and loving according to studies on stereotyping (Gilmore, Campbell, & Cuskelly, 2003; McCaughey & Strohmer, 2005).

Corrigan (2000; 2004) suggested that prejudices were negatively endorsed cognitive and emotional responses that led to discrimination, and discrimination led to avoiding people with mental illness or not providing them with opportunities such as hiring or renting to that population. For people with ID, the prejudices and discrimination also included not having opportunities to work, in that some employers believed that people with ID were “unemployable” and should be placed in special workshops. Stigma has also driven discrimination against people with ID in the form of choice making and self-empowerment, access to medical care, and the ability to participate in research due to being labeled a vulnerable population (Ditchman, Werner, Kosyluk, & Jones, 2013).

Trauma and PTSD are not immune from stigma. The United States Department of Veterans Affairs, National Center for PTSD (2015), acknowledged that stigma about PTSD occurs when people do not understand PTSD, think that PTSD is the individual’s fault and that he just needs to “get over it,” or they think PTSD makes a person dangerous. These types of beliefs make it difficult for a person with or without an

intellectual disability who suffers from PTSD or trauma to access treatment, employment, and, sometimes, housing.

For clinicians who do not have experience working with people with ID, what are their lived experiences and perceptions of providing trauma treatment for people with ID? For clinicians who have experience working with people with ID, what are their lived experiences and perceptions of providing trauma treatment for people with ID? These research questions are tied to the different theories of trauma and PTSD and stigma theory, in that they are the primary sources for exploring, describing, and interpreting how the clinicians would use their theory of trauma and PTSD in relation to trauma treatment for people with ID. Stigma theory is tied to the clinicians' lived experiences in relation to their perceptions of people with ID. My rationale to provide different theories of trauma and PTSD and stigma theory linked the concepts of the conceptual framework, provided guidelines for the interviewing process, and assisted with interpreting and analyzing the data.

Conceptual Framework

Guba and Lincoln (1994) suggested that each concept within a conceptual framework played a specific role in phenomenological research, such as the ontological role of the "way things are," or the "the nature of reality" (p. 108) The epistemological role related to "how things really are" and "how things really work," while the hermeneutic role related to describing and interpreting the insights and meaning in people's lives. As described in Chapter 1, this study had a multi-faceted conceptual framework that provided the groundwork for describing and interpreting the clinician's perceptions of trauma treatment for people with ID. The first concept of this hermeneutic

study was that the everyday lived experiences of the clinicians shaped their perceptions of trauma treatment for people with ID, and that they presented their perceptions through the interview process, in a descriptive, interpretive, linguistic, and hermeneutic manner that showed the lived quality or significance of their experiences in a fuller and deeper manner (van Manen, 2014, p. 26). A second component of the conceptual framework for this study was based on the concept that people with ID do experience trauma symptoms and PTSD (Bowman, 1999; McCarthy, 2001; Ryan, 1994). A third component was guided by the principle that people with ID can engage in trauma treatment. The fourth component regarded the participants' training in trauma and PTSD and training regarding people with intellectual disabilities. These concepts justified the importance of the current study.

Psychopathology, Trauma, PTSD and People With ID

Not until the 1960s did researchers suggest that psychiatric conditions were common among people with mental retardation and that, like the average person, emotional disturbances were caused primarily by interpersonal experiences with the environment, lack of educational resources, personality development, coping skills, social and community interactions, and family supports, not by mental retardation or organic brain dysfunction (Menolascino, 1965; Philips, 1967). Early studies by Menolascino (1965) and Philips (1967) found that psychopathology and emotional disorders that manifested in the average person also occurred in people with mental retardation. Both researchers suggested that symptoms of emotional disorders in persons with ID did not differ qualitatively from symptoms found in the average population. Menolascino (1970)

described the period from 1900 to 1960 as the “tragic interlude” in regard to the needs of people with mental retardation and psychiatric disorders.

Bessel van der Kolk, a leading expert in trauma and PTSD, concluded that trauma exposure disrupted the development of self-regulation and can lead to chronic destructive behavior towards self and others, dissociative problems, somatic complaints, and learning disabilities (McFarlane & van der Kolk, 1996). Van der Kolk also suggested that the younger the person was when the trauma occurred, the more self-injurious and aggressive the person can be. For people with ID who have suffered trauma, self-injurious behavior, aggression, disruptive or defiant behavior, sleep problems, distractibility, and agitation from an early age to adulthood can be mistaken for behavioral challenges or attention-seeking behavior.

Macklin et al. (1998) followed up on McNally and Shin’s (1995) study to determine if lower cognitive ability was a factor in PTSD symptoms. Macklin et al. (1998) pooled participants from Army and Marine Corps Vietnam combat veterans who had undergone pre-combat intelligence testing and assessment for PTSD. The researchers theorized that people with lower intelligence levels may have felt overwhelmed, helpless, and more limited in their ability to respond. Their research findings suggested that lower intelligence is a risk factor for developing PTSD. McCarthy (2001) suggested that cognitive and emotional capacities were risk factors for developing PTSD in people with ID and identified other factors such as language and communication deficits, institutionalization, and poor and abusive care. McCarthy (2001) suggested that people with borderline and mild ID may suffer PTSD symptoms similarly to the general population, but she cautioned clinicians to view the symptoms of PTSD in the context of

developmental levels and that presentations of PTSD may look different in people with ID.

Psychotherapy and People With Intellectual Disabilities

Nezu and Nezu (1994), in an early review of the literature on psychotherapy for people with ID) found limited public awareness for the mental health issues of people with ID. The authors also found that blurred funding guidelines between the mental health system and the ID system were responsible for the gap in the social need to pursue scientific attention for the effectiveness of psychotherapy for people with ID. The authors' review of the literature focused on psychodynamic approaches, behavioral strategies, and group psychotherapy. The authors found that, although the early psychodynamic literature on people with ID consisted primarily of case studies and had methodological weaknesses, the results were useful for identifying modifications and adaptations of techniques for successful psychotherapy with this population.

Lack of Trained Clinicians

Studies on the prevalence of emotional problems and psychiatric disorders in people with ID increased in the late 1970s and early 1980s. The evidence suggested that people with ID have higher rates of psychiatric disorders (Reiss, Levitan, & McNally, 1982). The need for mental health services became the message of these studies and researchers identified barriers for people with ID and mental illness to receive adequate services. One issue that was identified by researchers suggested that people with ID and mental illness are referred back and forth between mental health centers and intellectual disability centers because of the disagreement over what delivery system was responsible for the funding and for serving this population. Another problem identified was the lack

of pre-doctoral and doctoral training programs for professionals in diagnosis and treatment for this population (Reiss, Levitan, & McNally, 1982). Professional attitudes and bias towards intellectual disabilities as not being of interest to psychologists and psychiatrists resulted in a shortage of professionals to serve this population. A third problem introduced the term “Diagnostic Overshadowing,” which suggested that psychiatric symptoms tended to be overshadowed by the presence of the intellectual disability or anomalous or atypical behaviors associated with mental retardation. Almost 30 years later, the same problems exist (Fletcher, Loschen, Stavrakaki, & First, 2007).

Literature Review Related to Key Variables and/or Concepts

This literature review provided a historical overview of people with ID in relation to the identification of trauma and PTSD and the controversies regarding psychotherapy for people with ID. A brief overview of the history of hermeneutic schools of phenomenology and controversies was also given. Both quantitative and qualitative research studies were used to set the foundation for the overall study.

Historical Overview of Intellectual Disabilities and Mental Health Issues

Berkson’s (2006) research of early civilization and people with ID found an initial interpretation of mental issues as the result of the range of wetness in the brain, i.e., moist brains resulted in mental retardation, and dryness in the brain caused mental illness. Berkson (2006) suggested some researchers believed writings from ancient Greece depicted people with ID as different from people with mental illness, and people with ID were socially neglected and rejected. Stainton (2001) suggests the philosophers Plato and Aristotle introduced the first definition of ignorance and believed in a hierarchy of beings. These first definitions of ignorance and classification viewed people who were

not rational or moral as lower in value. Berkson (2006) noted that the terminology and translation for words defining mental illness and ID during that era were often unclear and inconsistent. Jewish law of the second century focused on the economic worth of a person and the inability to take responsibility for certain acts as differentiation of mental disability, and those who met these criteria were to be protected, which meant not being accepted as a full member of society (Berkson, 2006). Christian scriptures from Rome beginning in the fourth century had a more tolerant view of people with ID: individual differences were determined by God, sin was the cause of mental disability, and prayer was the cure (Berkson, 2006). By the end of the fifth century, Roman medical and legal writings differentiated cognitive disabilities from mental illness, and infants who were deformed at birth were left to die by exposure. Adults with ID were not able to marry, have property, or make a will. The Latin word “amens” was defined as mindlessness or mental retardation, and “demens” suggested an aberration of the mind or mental illness (Berkson, 2006).

English law in the tenth century continued to distinguish between people who committed criminal acts of their own free will and idiots, deeming the idiot was not to be blamed (Wickham, 2001a). In many cases, the idiot did not even appear in court due to being exonerated and charges dismissed before going to court. By the end of the twelfth century, there was a clear separation between what constituted a mental illness, which was considered temporary, and a cognitive disability, which was considered permanent. Berkson (2006) also found that people throughout early history devalued and excluded people with ID, but also found the need to protect them. As medicine and psychology evolved through the centuries, so did the classification and terms to describe people with

ID. The early colonies of North America in the early 1600s spoke of idiocy in terms of colonial law and Puritan faith. Wickham (2001b) researched historical accounts of the colonies of New England for the origins of terms and meaning of mental retardation prior to the twentieth century. He found idiocy appeared in the first laws of Massachusetts, and other terms such as natural fool, imbecile, and numbskulls began to appear to describe people with ID from scientific observations and religious texts, and these people were denied sacraments of the church.

The shift from community and family care for people with ID to custodial and institutionalized care began in the late eighteenth and early nineteenth centuries. The development of intelligence tests and placement for children into schools led to the classification of the severity of mental retardation. In 1876, the first organization for professionals and others concerned about people with mental retardation was founded and was called the American Association on Mental Deficiency (now the American Association on Intellectual and Developmental Disabilities - AAIDD). Also during this time period, Charles Darwin introduced his theory of evolution and fostered the theory of selective breeding to eliminate humans who were defective or inferior (Berson & Cruz, 2001). In 1877, eugenicists focused their movement on the beliefs that behaviors were genetically inherited and targeted criminals, the mentally ill, idiots, and the feebleminded. The eugenicists' solution was to institutionalize and segregate people with mental retardation.

Many of the new colonies' laws were derived from English law, and the practice of distinguishing idiocy, or being a "natural fool," from a distracted (mentally ill) person continued. If a person was declared an idiot, he was stripped of property, and if the

family could not provide for the idiot, overseers were appointed to provide relief and safety (Brockley, 1999). The courts deemed a distracted person could “fall into” the condition with the presumption of recovery, and he could keep his property. By the turn of the seventeenth century, clear guidelines were established between idiocy and distraction, and people with idiocy were considered a vulnerable class, protected from exploitation, were exempt for crimes, and were to be provided for by the government. Care by the government consisted of assisting families with a meager monetary amount and even legally enforcing families to take responsibility for the idiot’s relatives, but the aid was transient and determined by availability (Brockley, 1999).

In the early 1900s, terms such as imbecile, idiot, and moron were used to describe the lower levels of functioning, quantified by early intelligence testing (American Association on Mental Retardation (AAMR), 2002). People with ID and mental illness were separated by intelligence testing during World War I. Psychologists Goddard and Yerkes developed testing for military recruits in 1917. The Alpha test was used for recruits who were literate, and the Beta test was used for recruits who could not read (Smith & Lazaroff, 2006). The results of this testing, given in several military reports, indicated that 45% of the recruits were functioning mentally below 13 years of age, and yet the military determined that a recruit with the intelligence of an eight-year-old was fit for battle (Smith & Lazaroff, 2006). Soldiers with ID after World War I were then recommitted to institutions.

By 1930, the development of community care and programming for people with ID began to surface, and leaders in the ID field felt community training and supervision programs for people with ID were better than institutionalized programs but were more

expensive. Minimal funds were appropriated for community programs for people with ID. The development of community programs for people with ID increased the need for institutions due to the programs identifying more cases of ID (Davies, 1930, in Brockley, 1999). Professionals in the field of mental retardation focused their attention on understanding, defining, and classifying the condition of mental retardation, but the care and acceptance of people with ID continued to be devalued.

From ancient times through the early twenty-first century, the separation of mental illness and mental retardation was determined by the church, courts, and medical professionals. Care and provisions for people with ID were limited, and social rejection and devaluation continued to place people with ID into institutions to be locked up and warehoused. Terms such as idiot, imbecile, moron, and feeble-mindedness were created to determine the severity of mental retardation, and these terms continue to devalue people with ID today (Brockley, 1999).

According to my literature search, Canada, the United Kingdom, and the Netherlands had taken the lead with researching mental health issues for people with ID. The United States has taken steps in the last decade to address the health and mental health needs of people with ID across their lifespan, but more needs to be done (Evenhuis & Penning, 2009; Hemmings & Al-Sheikh, 2013; Weiss, Lunskey, & Morin, 2010). The inequalities of health care for people with ID include timely access to comprehensive care, affordability, specialty healthcare, psychiatric care, mobility to health care, social and attitudinal barriers, and lack of incentives for health providers to ensure the health of people with ID (Ervin, Hennen, Merrick, & Morad, 2014). However, new models of community healthcare delivery systems are beginning to develop, such as the

Developmental Disabilities Health Center (DDHC) in Colorado Springs, CO, USA. The DDHC program offers multidisciplinary healthcare that integrates primary care with acute and mental health services, behavioral health services, consultation, on-site care coordination, specialty care, health planning, and health education for patients and their caregivers (Ervin et al., 2014, p. 3). At the DDHC, people with ID and mental health issues have both the physician and mental health provider in the same room with the client at the same time, appointments are lengthened to allow adequate time to establish a relationship with the patient, and examination rooms are enlarged to accommodate wheelchairs and allow the patient to have people accompany them to help them feel safe and comfortable (Ervin et al., 2014, p. 5).

Psychopathology and People with Intellectual Disabilities

In the 1940s, the idea that people with ID could also have psychiatric disorders began to surface. Early surveys in the 1940s found that people with ID had difficulty coping with stressful situations, and due to their cognitive deficits, their inability to handle these situations led to emotional problems. Webster (1970) theorized that the limited emotional development in persons with ID could be considered an emotional disturbance and concluded that impairment of ego functions, immature personality structure, and simplicity in emotional life were symptoms of a primary psychopathological syndrome. Other professionals suspected people with ID developed emotional problems due to becoming aware of their limitations and not knowing how to react to this awareness (Dewan, 1948; Weaver, 1946, as cited in Reiss, Levitan, & Szyszko, 1982).

Wolf Wolfensberger (2008), a pioneer in the deinstitutionalization movement and of social role valorization theory for people with ID, reflected on his experiences as a doctoral student in the 1950s studying mental retardation, working in institutions as a psychologist, and observing the trends in psychology during this time. He stated that, although Darwinism and the eugenics movement had ended, their philosophy and sentiment continued to affect how people with ID were treated. Institutions had poor conditions for people with ID; 22% of the institutions had no psychologists, maybe one or two registered nurses for over 2000 residents, and one teacher and a teacher's aide for over 1000 residents (Wolfensberger, 2008). Competing with Wolfensberger's social role valorization theory and deinstitutionalization were the applied behavior analysts, who were influenced by the behaviorism of B. F. Skinner and his principles of reinforcement, extinction, and punishment (Brown & Smith, 1992). The behavior analysts used these principles by paying attention to the antecedent for a particular behavior and then applying stimulus consequences, positive or negative, to modify the behavior. From 1940 through the early 1980s, applied behavioral analysis transformed the approaches to working with people who had severe challenging behaviors, and, in a way, attempted to change the design and operation of ID services (Brown & Smith, 1992).

Throughout the late 1960s and 1970s, the legitimacy of institutions was challenged, and new concepts and theories were presented for how people with ID were to be treated. The exposure of conditions in institutions by Blatt and Kaplan's exposé "Christmas in Purgatory" in 1966 and Geraldo Rivera's exposé of Willowbrook State School in 1972 led the charge for deinstitutionalization (Taylor, 2006). The deinstitutionalization movement began with implementing normalization theory and client-centered planning.

Federal funding for community-based services, anti-discrimination laws, and rights for public education for children with ID became the forefront of the ID movement. Research on the manifestation of psychiatric disorders in people with ID continued during the deinstitutionalization movement, and some researchers suggested psychiatric disorders were more prevalent in people with ID than in the general population. Webster (1970) found that 54% of people with ID referred to his clinic for evaluations had psychiatric disorders and 28% of them required psychiatric intervention and treatment. Menolascino (1970) was the first to introduce the concept of dual diagnosis.

Reiss, Levitan, and Szyszko (1982) conducted two experiments to substantiate the phenomenon of diagnostic overshadowing. Three groups of psychologists were given hypothetical case studies involving symptom criteria from the DSM-III of three different disorders: phobia, avoidant personality disorder, and schizophrenia. The psychologists were given questionnaires requesting diagnostic impressions and recommendations for psychological interventions. The experimental group was given case studies using a person with an IQ of 58 (mild mental retardation), the control group's case studies involved a person with an IQ of 108 (average intellectual functioning), and the third group had case studies with a person with alcoholism and an IQ of 108. The results indicated significant differences between the experimental group and control groups and diagnostic overshadowing was specific to the cases of mental retardation. The second experiment suggested that, when psychologists were presented with DSM criteria, the clinical case descriptions were less likely to be diagnosed with schizophrenia or personality disorder when the individual was mentally retarded (Reiss, Levitan, & Szyszko, 1982).

The 1980s sparked renewed interest and research in psychiatric diagnoses in people with mental retardation. The National Association for Dual Diagnosis (NADD) was founded in 1983 to promote awareness of the co-existence of mental illness and mental retardation. Several researchers began to produce and review the literature on the prevalence of psychiatric disorders in people with mental retardation and found that people with mental retardation were two to five times more likely to have at least one identifiable psychiatric disorder (Heaton-Ward, 1977; Jacobson, 1982; Corbett, 1985; Frame, 1986, in Tuinier & Verhoeven, 1993). Menolascino (1988) reported the most commonly reported psychiatric disorders in people with mental retardation included schizophrenia, organic brain disorder, affective disorders, psychosexual disorders, personality disorders, and anxiety disorders. Sociocultural variables were added to the theories of etiology of psychopathology for people with ID (Matson & Sevin, 1994). Deinstitutionalization brought new and different challenges for people with ID, including an increase in daily life stressors, exposure to fearful events, loneliness, little autonomy, and limited social and vocational opportunities (Matson & Sevin, 1994).

As more people with ID were moved into community settings, the more frequent the referrals became for residential and mental health services (Borthwick, Borthwick, & Eyman, 1990). The 1990s brought a host of studies on the development of assessments of maladaptive behaviors and textbooks on the diagnosis and treatment of psychiatric disorders in people with ID, and yet very little information was given on trauma or PTSD in people with dual diagnoses. At the beginning of the twenty-first century, the most information on PTSD in people with ID was generated, but considerable research suggested that people with ID have had a long history of abuse, neglect, and trauma and

was more likely than non-disabled persons to be abused physically, emotionally, or sexually (Sobsey, 1994).

Challenges for People With ID With Trauma and PTSD

In 1990, the first case study of PTSD in a man with ID was presented. The man developed PTSD following a motor vehicle accident, suggesting PTSD should be considered in the ID population (Hudson & Pilek, 1990). Ryan (1994) provided the field of ID with the first quantitative study identifying the prevalence of PTSD in the ID population, a better understanding for identifying symptoms of PTSD, and a protocol for the diagnosis and treatment of PTSD. Out of the 310 participants in her study, 51 persons met the DSM II-R criteria for PTSD, and 16.5% of persons in the study who suffered severe trauma developed PTSD. Almost all the participants had suffered two types of trauma, the traumatic event was known by someone working with the participant, and the diagnosis of PTSD had not been considered. Ryan (1994) developed a six-point protocol based on the current work in the treatment of PTSD on non-disabled people, emphasizing medication and medical problems associated with PTSD for people with ID. Ryan (1994) recommended: (1) judicious use of medications; (2) identification and treatment of medical problems; (3) minimizing iatrogenic complications such as providing programming that inadvertently recreated the traumatic event; (4) psychotherapy; (5) habilitative changes to control dissociative triggers such as olfactory, visual, tactile, or auditory triggers that could re-traumatize the individual; and (6) education and support for staff. Ryan (1994) recommended more research in the incidence and frequency of trauma in the ID population as well as work differentiating those who suffer trauma and

do not develop PTSD to identify preventive measures and the development of assessment measures specifically for people with ID and PTSD.

Newman, Christopher, and Berry (2000) criticized Ryan's work for its lack of methodological data for symptoms and diagnosis in her study, but they acknowledged her work as the most improved study on PTSD in people with ID. Newman et al. (2000) also acknowledged the lack of assessments of PTSD specifically normed for people with ID and the infancy of research on trauma-exposed individuals with ID. Newman et al. recommended further research on different groups of people with ID who have experienced traumatic events. To date, Ryan's (1994) study is the only large scale quantitative study completed on PTSD in adults with ID.

Tsakanikos, Bouras, Costello, and Holt (2007) suggested that people with ID were more likely to experience traumatic and negative life events that can manifest symptoms of PTSD, but to date there are no valid and reliable measures for assessing PTSD normed for the ID population. The current measures for assessing PTSD in the general population are mostly based on self-report, and intellectual and communication deficits may make it difficult for the person with ID to provide a detailed narrative disclosing the traumatic experience. Wigham, Hatton, and Taylor (2011) conducted a systematic review of the effects of traumatizing events on people with ID. The authors found difficulty with identifying empirical literature relating adverse life events with PTSD in the ID population and noted that responses to trauma by people with ID were interceded by their developmental level. Wigham et al. (2011) reviewed studies that used a variety of life event assessments normed for people with ID and general population assessments to measure specific events such as sexual abuse, general life events, bereavement, and

behavioral challenges and found that the assessments normed for people with ID resulted in a causal relationship between life events and mental health issues, but did not capture symptoms specific to trauma. The studies that used assessments normed for the general population did not capture behaviors such as self-injurious behavior, aggression, disruptive or defiant behavior, sleep problems, distractibility, and agitation that are unique for people with ID who have experienced trauma (Wigham et al., 2011). The authors also noted that most of the studies reviewed were dependent on informants' accounts of traumas instead of the self-report accounts by persons with ID, which could be significantly different from that of the informant. Overall, Wigham et al. concluded that the review showed a lack of psychometrically sound assessments to identify trauma and PTSD symptoms and that the issues of diagnostic overshadowing, compromised communication skills, and lack of past history regarding trauma of the individual with ID continued to challenge clinicians with identifying trauma reactions in people with ID.

Other issues which included misdiagnosis of flashbacks being mistaken for hallucinations or autism; anger outbursts being misdiagnosed as intermittent explosive disorder; or avoidance being misinterpreted as non-compliance, lead to contrary interventions and the delay of appropriate supports and treatment (Esralew, 2006). Another challenge for diagnosing PTSD in people with ID was the lack of information following the individual. People with ID who have experienced multiple layers of trauma have had a tendency to have multiple residential placements, multiple care givers, multiple diagnoses, multiple hospitalizations, and multiple trials of different medications without this information being passed on or being considered relevant (Esralew, 2006; Russell & Shah, 2003). McCarthy (2001) and Harvey (2012) suggested there can also be

a significant time delay between the actual traumatic event and the display of PTSD symptoms, which can also obscure a diagnosis of PTSD.

Challenges for People With ID and Psychotherapy

A significant amount of literature has been produced in the last three decades on many issues that affect people with ID for which psychotherapy could be effective (Whitehouse, Tudway, Look, & Kroese, 2006; Wigham, Hatton, & Taylor, 2011). Under the umbrella of psychotherapeutic techniques used for people with ID, different types of therapy have included social skills therapy, behavior therapy, relaxation therapy, bereavement therapy, group therapy, individual therapy, family therapy, anger management therapy, music therapy, art therapy, and sex offender therapy (Willner, 2005). Theoretical modalities used with the ID population in psychotherapy have included psychodynamic, cognitive-behavioral, phenomenological, client-centered, and humanistic theories (Lynch, 2004).

The effectiveness of psychotherapy for people with ID has been questioned, but the research, although more qualitative and descriptive, suggested, that psychotherapy is both feasible and successful (Butz, Bowling, & Bliss, 2000). Lynch (2004) suggested that some clinicians had been providing psychotherapy as early as the 1950s, but the lack of published research into its effectiveness and the bias among clinicians to practice in the field of ID continued to fuel the controversy regarding the effectiveness of psychotherapy for people with ID.

Early contradictions regarding the effectiveness of counseling and psychotherapy for people with ID had been based on the lack of empirical analysis of their effectiveness and the lack of methodological consistency in earlier studies on psychotherapy with

people with ID (Nezu & Nezu, 1994). Prout and Strohmer (1998) argued the assumption of ineffectiveness may have been based on “error in logic” in the analysis of existing data and from biases regarding the appropriateness of any insight-oriented approach with people with ID. Other incorrect logical reasons that psychotherapy was ineffective stemmed from past literature that concluded that therapeutic techniques were ineffective due to the characteristics and limitations of people with intellectual disabilities and the assumption that people with ID were immune to mental illness (Prout & Nowak-Drabik, 2003). However, other researchers, such as Prout and Strohmer, have advocated for developmental adaptations such as modifying the language, goals, strategies, and tasks of therapeutic techniques for people with ID.

Nezu and Nezu (1994) separated the behavioral literature review into the categories of operant learning, respondent conditioning, and social learning approaches. Operant conditioning approaches were used with a variety of issues including fear, phobias, aggression, self-injurious behaviors, anxiety disorders, major depression, and specific deficits associated with autism. These behavioral approaches used reinforcement procedures such as token economies, punishment, time out, overcorrection, and other restrictive procedures. The authors found an increase in the amount of empirically-sound studies using operant learning and an increase in methodological rigor. However, the vast majorities of behavioral studies reviewed were conducted in institutions, classrooms, vocational centers, and day treatment centers. Maintenance and generalization of effectiveness difficulties emerged when transferring the approaches to out-patient and community settings. The lack of competent caregivers and appropriate training of interventions to caregivers were also cited as barriers to operant-based effectiveness

(Nezu & Nezu, 1994).

Treatment studies using techniques such as progressive muscle relaxation exercises, systematic desensitization, imagery, and implosive therapy were reviewed as respondent-based interventions (Nezu & Nezu, 1994). The authors found that, although most studies were single-subject case study designs or small group designs, adults with mild or moderate mental retardation had little difficulty understanding the instructions for relaxation therapy, and the intervention was effective for reducing physical and verbal aggression. Systematic desensitization results indicated significant initial improvement; however, follow-up review indicated the need for longer treatment periods or booster sessions (Nezu & Nezu, 1994).

The social-learning therapeutic approaches in Nezu and Nezu's (1994) literature review included social-skills training and cognitive-behavioral techniques such as problem-solving, assertiveness, and self-instructional training. The authors found that the methodological integrity of these studies improved the efficacy of overall treatment approaches for people with ID, and that most studies were conducted in the community or out-patient settings. The authors recognized the need for further research and offered recommendations for specific directions this research should follow, including the use of group designs with random assignment or well-designed single-case studies using changing criteria for the purpose of treatment efficacy. They recommended that samples should be homogeneous in regard to level of intellectual disability and psychiatric diagnosis. Assessments should be relevant and normed to the ID population and psychotherapy outcome and process studies should be tied to a specific model or therapeutic approach (Nezu & Nezu, 1994).

A somewhat more current review of the literature on psychotherapy with persons who have ID was conducted by Prout and Nowak-Drabik (2003). The authors' original intention was to conduct a meta-analysis of the studies of psychotherapy with persons with ID over a 30-year period from 1968 to 1998; however, utilizing the standard criteria for inclusion in a meta-analysis, only nine out of 92 studies met these criteria. Prout and Nowak-Drabik used the expert consensus rating method to include information describing the nature of the studies, specifically regarding psychotherapy, outcome variables, and experimental design. Consensus ratings were also performed on overall effectiveness and benefits. Two licensed psychologists and a doctoral psychology student with strong backgrounds in methodology research and psychotherapy outcomes read and evaluated each study. The results indicated clinically based treatment had a high rating on the effectiveness variable, and individual treatment had a higher rating on both effectiveness and outcome. The consensus raters found the overall quality of research was dominated by case studies and single-subject designs, interventions were poorly described, treatment manuals or protocols were rarely used, and outcome data were vaguely described (Prout & Nowak-Drabik, 2003). The authors concluded that observable behavior was the most utilized outcome measure, due to the lack of standardized assessments specific to psychiatric symptoms for people with ID; the bulk of the research (49%) was conducted from 1979-1988, which seemed to correlate with the increased awareness of dual diagnosis issues. Finally, Prout and Nowak-Drabik noted the data-supported psychotherapy treatments to be more effective than behavioral interventions and supported an increased utilization of psychotherapy for people with ID.

Although the lack of empirical research on the effectiveness of psychotherapy for people with ID has continued to be a barrier for this population to access psychotherapy services, adaptations to recognized evidence-based therapy approaches such as cognitive-behavioral therapy and psychodynamic therapy have been the consistent recommendation from the research literature. Whitehouse, Tudway, Look, and Kroese (2006) reviewed studies that reported adaptations to cognitive-behavioral and psychodynamic therapies. Out of ten (CBT) studies and fifteen psychodynamic and analytical studies reviewed, several consistent adaptations were found. The most cited adaptation for psychotherapy for people with ID with both

CBT and psychodynamic therapy was flexibility in the length and structure of the sessions, followed by the simplification of verbal communications and using fewer words in discussions (Whitehouse et al., 2006). The use of pictures, drawings, and videotapes in relation to the developmental level of the person with ID was shown to be effective and using a directive approach to keep the client on task was effective. Finally, involving caregivers was effective at the beginning of sessions to gather information about weekly events and progress in between sessions and to discuss homework or self-regulation tools at the end of sessions (Whitehouse et al., 2006).

Whitehouse et al. (2006) concluded that further research on the specific adapted components of therapy interventions were needed, but also voiced the concern that without adapted treatment studies, people with ID would continue not to have access to treatment methods and psychotherapy services. Whitehouse et al. quoted Linington (2002), "It is psychotherapy that is handicapped. For this is a psychotherapy which is

undermining its own ability to understand and respond to individual subjectivity” (p. 413).

Pert et al. (2013) conducted a qualitative, interpretive, phenomenological study that explored the views and experiences of people with ID who participated in CBT. Fifteen participants attended one-hour, weekly therapy sessions for ten weeks were given semi-structured interviews between the fourth and fifth sessions and the ninth and tenth sessions. The topic guide for the interviews included the nature of the referral problem, the nature of the emotional problem for which they were in therapy, past experience of therapy or professional help for the problem they were experiencing, their knowledge and expectations of CBT, the perceived impact of therapy on their lives, and future help they thought they may require (Pert et al., 2013).

Three major themes emerged from Pert’s et al. (2013) research. The first being talking in therapy, for which participants found that talking about their problems was helpful and having a therapist to talk with was easier than talking to other people in their life. Participants also valued talking in private and the confidential process of therapy, but did acknowledge that it was difficult to talk about certain topics, but as they began to feel comfortable, it got easier. The second theme identified was the feeling of being valued and validated. Participants spoke of being treated like an equal and that their problems were taken seriously, and they felt cared for and understood. The third theme was in relation to changes influenced by therapy. Participants acknowledged specific treatment goals, but also spoke of broader life goals of feeling better about themselves and having better relationships. The results indicated an underlying theme of the participants wanting to show others how they had changed. A subtheme that came out of the study was that

participants were concerned about the changes they had made lasting and needing more time in therapy to maintain the changes they had made. Other results from the study were the importance of the therapeutic relationship formed and having the choice of how much information and involvement direct care providers had in the therapeutic process.

While the continuing theme of the lack of evidence-based treatment models for therapy for people with ID has remained the argument for not providing therapy to this population, Barol and Seubert (2010) explored the use of EMDR as a trauma treatment for people with ID. EMDR, until recently, has been viewed as a technique or an approach for trauma treatment and is now recognized by the World Health Organization (2013) as one of two psychotherapies recommended for children, adolescents, and adults with PTSD (Shapiro & Nickerson, personal communication, October 30, 2014). EMDR integrates thoughts, feelings, emotions, and body sensations and utilizes bilateral stimulation and spontaneous associations of traumatic memories during the processing phase (Shapiro, 2002). Shapiro's theory of EMDR was based on how the brain processed and stored memories (Shapiro, 2001; Shapiro, 2006; Solomon & Shapiro, 2008). The adaptive information processing (AIP) model provided the theoretical framework and principles which guided case conceptualization and treatment procedures. Shapiro's model suggested that most pathology was derived from earlier life experiences and developed into a continued pattern of affect, behaviors, cognitions, and identity structures (Shapiro & Maxfield, 2002).

EMDR therapy uses standardized protocols and procedures to process traumatic experiences; however, its procedures and protocols exceed the parameters of this study and will not be discussed in detail. The eight phases of EMDR therapy include 1) history

taking and treatment planning; 2) explaining the theory and developing positive resources to use before, during, and after processing; 3) assessing target memories, identifying the negative and positive beliefs, identifying the significant level of disturbance (SUDS), identifying the positive belief the client wants to adapt (VOC), identifying the emotions that are related to the target memory, and identifying where the client feels that emotion in the body; 4) desensitizing the target memory; 5) installing the positive belief; 6) using a body scan to identify any lingering negative sensations; 7) debriefing and closure; and 8) reevaluating and incorporating a positive template (Shapiro, 2001).

Barol and Seubert's (2010) purpose for exploring EMDR as a therapy for people with ID was to support the already documented studies recommending the need for evidence-based trauma treatment for this population. The authors also wanted to explore whether EMDR would be an effective treatment for individuals with PTSD and ID, especially since studies have shown that individuals do not need to be able to vocalize the source of the trauma as part of the therapy (Bedard, Burke, & Ludwig, 1998; Tinker & Wilson, 1999). Finally, the authors wanted to provide adaptations to the EMDR protocol as the research has recommended and promote EMDR therapy as a therapy clinicians can use with the ID population.

Barol and Seubert (2010) recruited six participants with mild ID to participate in EMDR therapy for six to twelve sessions. Data for the multiple single-case study design included researcher observations, client self-report, caregiver observations, on-going in-session response scaling, and pre-and post-evaluations. Prior to and following EMDR therapy, participants were given an assessment compiled by the authors to identify PTSD symptoms or behavioral equivalents, as well as the development of a timeline of events

for each participant (Barol and Seubert, 2010). Each participant received psychoeducation, skills training, and resource development as part of the preparation phase of the EMDR protocol. EMDR therapy has a three-pronged approach to process past, present, and future events; however, due to the limited number of sessions for the study, most participants focused on present issues.

Barol and Seubert (2010) employed caregivers in important roles to provide information for history taking and current information, on-going conversations on progress in between sessions, and applying bilateral tapping as needed outside of the sessions. Barol and Seubert (2010) used a variety of adaptations to the EMDR protocol to include more checks on the level of disturbance (SUDS), directing clients from traumatic processing to positive resourcing, breaking memories into smaller parts, and greater verbal participation during trauma processing. Other adaptations included modifying the SUDS and VOC scales from one to ten to one to five, or using pictures or physical gestures to make them more understandable. The authors found that some of the participants could use the complete protocol or an adapted form to resolve their traumas, and that, in all cases, there were no accounts of adverse effects (Barol & Seubert, 2010).

In the Netherlands, Mevissen, Lievegoed, and de Jongh (2011) used four cases to explore the applicability and efficacy of EMDR with four people with mild ID who suffered from PTSD-like symptoms. Mevissen provided all the weekly EMDR sessions of 60 minutes each, but the number of sessions was based on individual needs. Mevissen et al. (2011) had a parent or a professional caregiver in the sessions to help with communication issues and act as a co-therapist to observe changes in behaviors and functioning between sessions. Mevissen et al. (2011) used the standardized

desensitization protocol and made adaptations when necessary. If the developmental level of the client was three years or less, the parent or caregiver narrated the traumatic event. The story would have a positive start, then move to recognizing the traumatic parts of what was seen, heard, felt, thought or smelled, and end with the client's positive self-belief. When eye movements were not able to be performed by the participant, other forms of bilateral stimulation, such as bilateral sound or tapping stimulation, were used (Mevissen et al., 2011).

The results indicated that all four participants had a decrease in PTSD-like symptoms (Mevissen et al., 2011) Together, all four cases presented with PTSD-like symptoms for three to seventeen years prior to EMDR therapy, and these symptoms ceased after two to thirteen EMDR therapy sessions. Mevissen et al. (2011) also found that at three-month and two-and-a-half-year follow-ups, treatment effects remained positive. During follow-up, parents and caregivers reported that all four participants presented with excessive anger outbursts prior to the EMDR therapy, and these had since subsided. Mevissen et al. suggested that the improvements by all four persons and the preservation of the EMDR therapy at three months and two-and-a-half year follow-up demonstrated that EMDR therapy was applicable and effective for treating PTSD in clients with ID. The authors acknowledged the need for further and more rigorous investigation of EMDR therapy with people with ID.

Controversies Regarding Psychotherapy for People With ID

The controversy over the efficacy of psychotherapy became more heated after Lynch (2004) provided commentary on his experiences with and concepts of psychotherapy practice to include referral and theoretical, conceptual, and ethical issues

when providing psychotherapy to people with ID. His article referenced Prout and Nowak-Drabik's (2003) study to support his experiences with efficacy for psychotherapy. Sturmev (2005) rebutted Lynch's claims for the efficacy of psychotherapy for people with ID, claiming, "Behavioral approaches must remain the preferred treatment options for people with mental retardation" (p. 56). Sturmev also referenced Prout and Nowak-Drabik's (2003) study, claiming the scientific evidence provided solid support for the effectiveness of behavioral interventions. He noted that assertiveness training, relaxation training, social skills training, and problem-solving training were traditional behavioral interventions.

Sturmev's (2005) statement brought about many responses and critical commentary regarding the use of psychotherapy for people with ID. Beail (2005) acknowledged Sturmev's claim of the lack of evidence for nonbehavioral psychotherapeutic interventions, but also identified the limitations of the evidence for behavioral interventions. Beail noted that the average age of participants in the Prout and Nowak-Drabik (2003) study was 16 years and that adults with mental retardation were underrepresented (p. 442). Beail pointed out that the literature did not support the effectiveness of behavioral interventions for psychiatric problems and suggested that clinicians should continue to be creative in using psychotherapy interventions that have been effective with the general population. He stated, "The absence of evidence for efficacy is not evidence of ineffectiveness" (Beail, 2005, p. 471).

Hurley (2005) responded to Sturmev's (2005) claims by suggesting that Sturmev's definition of "traditional" behavioral interventions was not accurate and that under the cognitive-behavioral psychotherapeutic approach, social skills, assertiveness

skills, and stress-management skills required mental and directive actions. She went on to suggest that Sturme y ignored the number of abundant clinical case studies, papers, and books available on individual, group, and family psychotherapy for people with ID. She referenced her own case study of a woman who had presented with anxiety and panic attacks who successfully responded to CBT. Hurley (2005) acknowledged the lack of well-controlled studies on different psychotherapy approaches, but she suggested that a conclusion on effectiveness cannot be drawn without rigorous studies and that should not stop clinicians from using psychotherapy approaches to treat people with ID.

Taylor (2005) also responded in support of psychotherapy for people with ID. He suggested that Sturme y (2005) mislabeled cognitive interventions in the Prout and Nowak-Drabik (2003) meta-analysis, such as direct face-to-face contact between therapist and client and assisting clients in modifying their feelings, values, and attitudes, as behavioral interventions. Taylor (2005) claimed that cognitive and meta-cognitive skills such as self-monitoring, self-evaluation and self-reinforcement skills were not acknowledged by Sturme y (2005). Taylor referenced his own studies and a review of published studies that showed the effectiveness of CBT for anger management for people with mild ID. He suggested that the evidence of his literature review on anger dyscontrol indicated behavioral interventions were less effective when applied to adults with mild ID. Taylor advocated for the rights of people with ID to have access to psychological therapies (2005).

Sturme y (2012) continued his stance that behavioral therapies were the preferred treatment option for people with ID. He conducted a systematic review of studies that used applied behavior analysis (ABA) and psychopharmacology. The author found that

there was strong evidence for ABA for some forms of psychopathology, such as autism and obsessive compulsive disorder, but found that most studies were for externalized behaviors. He also found that there had been an increase of randomized, controlled trials (RCTs) for the medications Risperdal, Zyprexa, and Lithium; however, the results were again for externalized behaviors and not for psychotic symptoms.

Sturmey (2012) suggested that CBT was a package of behavioral interventions and has been used for depression and anger management, but lacked empirical support. The author suggested that the RCTs for CBT were of poor quality and lacked evidence of effectiveness. Sturmey also found that there were no controlled studies for the treatment of PTSD and found no evidence-based practices for PTSD. Although the question of the efficacy of psychotherapy approaches is still unanswered, there seems to be a consensus among the experts in the field of ID and mental health that more research is needed, but that people with ID should not be denied psychotherapy services.

The Lack of Trained Clinicians

Throughout the literature, a common theme of the lack of trained clinicians and direct care providers was a consistent barrier for people with ID who suffer from trauma and PTSD (Barol & Seubert, 2010; Bradley, Sinclair, & Greenbaum, 2012; Edwards, Lennox, & White, 2007; Esralew, 2006; Harvey, 2012; Hurley, 2005; Lynch, 2004; Mevissen, Lievegoed, & de Jongh, 2011; Werner & Stawski, 2012;). Werner and Stawski's (2012) review of the literature regarding the knowledge, attitudes, and training of professional groups such as psychiatrists, social workers, psychologists, and direct service workers found that knowledge regarding mental health issues was scattered and underdeveloped. Several studies reviewed found that professionals believed that mental

health issues were uncommon in adults with ID, and hospital staff acknowledged a lack of knowledge and experience to serve the ID population well (Werner & Stawski, 2012). Edwards, Lennox, and White (2007) found that psychiatrists in Australia believed that people with ID received a poor standard of psychiatric care, and that over half the psychiatrists surveyed reported that they preferred not to treat adults with ID. Edwards et al. (2012) also found that 80% of psychiatrists did not receive sufficient training to work with people with ID. In the United States and Canada, psychiatrists surveyed agreed that their training in ID was not adequate and agreed that training in the field of ID should be mandatory, but less than half of the residency programs surveyed listed mandatory ID clinical experience (Werner & Stawski, 2012).

The barrier of properly diagnosing PTSD also became a challenge when direct caregivers and other professionals working in ID services lack training or the knowledge and skills related to the mental health needs of people with ID. Although the staff working with individuals with ID may be asked to provide information to the psychiatrist or general practitioner, their input may be less positive and describe symptoms as challenging behaviors and, thus, contribute to further distress and trauma (Harvey, 2012; Bradley, Sinclair, & Greenbaum, 2012). The lack of training for mental health issues for people with ID for psychiatrists and psychologists led to poor treatment of individuals with ID, and continued down from professionals in the ID system, to the direct care providers (Werner & Stawski, 2012). This cycle continues to perpetuate negative attitudes and stigma for people with ID.

The lack of training for mental health professionals regarding trauma and PTSD is not limited just to the ID population. Studies have shown that people with severe mental

illness and others who sought treatment from community mental health centers were likely to have experienced at least one traumatic event (Cusack, Frueh, & Bradley, 2004; Fontana & Rosenheck, 1996). Frueh et al. (2001) suggested that the intake assessment was the most commonly used tool for assessing individuals' needs at community mental health centers, and this assessment did not systematically ask about a trauma history and focused more on presenting problems. Frueh et al. found that community mental health professionals in South Carolina were not trained to focus on trauma history during the initial assessment and that only 30 % of clinicians had more than 6 hours of training on trauma-related symptoms and treatment options.

Zanville and Cattaneo (2009) collected data from 140 charts at a community mental health center in Washington, D.C. which required intake coordinators to systematically inquire about trauma history. The authors found that, to be eligible for services at this community mental health center, the individual must meet the criteria for a primary diagnosis, for which PTSD was not included. A diagnosis of PTSD could be used as a secondary diagnosis, but 58% of the psychiatrists in this sample did not assign a secondary diagnosis. Zanville and Cattaneo (2009) found that, out of the 140 charts they reviewed, only two out of 72 individuals who had a trauma history were diagnosed with PTSD, 20 out of these 72 individuals were recommended for therapy; however, 75% of those individuals identified as having significant trauma histories did not receive therapy as a treatment recommendation. The study did not review the barriers for why clients did not receive trauma treatment, but speculated that the lack of resources of trained therapists could have been a possibility and the high rate of no-shows for appointments was also considered.

Training in trauma and PTSD was not an essential component of graduate-level education curriculums, and most clinicians had only a basic knowledge of diagnosing trauma and even a smaller base of knowledge of evidenced-based treatment for trauma and PTSD (Salyers, Evans, Bond, & Meyer, 2004; Courtois & Gold, 2009). This issue posed an even larger problem for people with ID who suffered from trauma and PTSD whose only access to mental health treatment was community mental health centers. The most viable solution was for the mental health system and the ID system to work together to rise above the issues of primary diagnosis of ID or mental health and the territorialism of funds to best meet the needs of people with ID who have suffered trauma and PTSD (Courtois & Gold, 2009).

Phenomenology History, Hermeneutics, and Controversies

The origins of phenomenology were rooted in the philosophical disciplines and have been described as a human science, a movement, a method, and an approach (Giorgi, 2009; Moustakas, 1994; Vagel, 2014; van Manen, 2014). Phenomenological research was part of the qualitative research paradigm and has been increasingly used in the schools of psychology, education, nursing, health care, and management (Moustakas, 1994; van Manen, 2014). Under the umbrella of phenomenology were diverse versions of phenomenological philosophies and alternative ways of understanding the meaning of “meaning;” prereflection of experiences passed, and the experience of our day-to-day “lifeworld.” Hermeneutics has several definitions based on historical stages to include the theory of biblical exegesis, a philosophical methodology, a science of linguistic understanding, a methodological foundation of human science, a phenomenology of existence and existential understanding, and a system of interpretation (Kakkori, 2009).

However, most of these definitions were beyond the scope of this study. It was also beyond the scope of this section of the literature review to delve into all the different philosophical theories and details of those theories of the different schools and scholars of phenomenology. However, a brief historical synopsis of the main themes of several of the phenomenologists as they relate to this study has been provided, which focused on both the descriptive and interpretive guidelines by van Manen (2014), who was influenced by many of the hermeneutic and phenomenological scholars before him (Dowling, 2007; van Manen, 2014).

Edmund Husserl (1859-1938) was considered the father of phenomenological research, which was born out of protest for the positivism principle that reality was independent of human interaction, his criticism of psychologism (Dowling, 2007; Ehrich, 2005; Reiners, 2012). Husserl's early work was influenced by his teacher, Franz Brentano, and embraced Brentano's principles of descriptive psychology, phenomenology, and intentionality as the fundamental practice for classifying conscious acts and experiential mental actions (Dowling, 2007; Moustakas, 1994; Zahavi, 2003). Husserl considered phenomenology as an a priori science of consciousness and believed that intentional relations made up consciousness, in that, every mental action was related to an object and that all perceptions had meaning (Moustakas, 1994; Zahavi, 2003). He defined experiences and perceptions as having characteristics of being "of" or "about" something, as being object-directed, and giving a person a sense of something in his/her world, thus as having intentionality (McGovern, 2007). The "first-person" knowledge of our experiences cannot be explained from an objective "third-person" account due to not

being able to take in the internal and subjective matter of personal experiences (McGovern; McIntyre & Woodruff-Smith, 1989; Zahavi, 2003).

Husserl then shifted to the development of his transcendental phenomenology, keeping with the Cartesian concept that mind and body were exclusive and that the mind was directed towards objects (McConnell-Henry, Chapman, & Francis, 2009; Zahavi, 2003). Husserl believed that every mental action was related to an object and that all perceptions had meaning (Moustakas, 1994; Zahavi, 2003). He developed a descriptive phenomenology which described conscious experiences and suspended or bracketed his presuppositions (Reiners, 2012; Zahavi, 2003).

Husserl criticized psychology for attempting to apply natural science methods to human issues such as ordinary communication and understanding (Dowling, 2007; Laverty, 2003; Zahavi, 2003). Husserl's goal was to make phenomenology the "new science," and he devised a rigorous method to study things as they appeared based on the concept that most experiences are prereflective (Zahavi, 2003). He believed that we should focus on the way in which reality was given to us in experience, and before being able to do phenomenology; one must apply "reduction" or go from a natural attitude to a reflective or phenomenological attitude. He developed a strategy called *bracketing* to look at and describe the essential features of conscious experiences and to suspend acceptance of the natural attitude (Kakkori, 2009; Smith, Flowers & Larkin, 2013, p.14). Husserl termed the process the *epoché*, which entailed the suspension of natural realistic inclinations, preconceptions, prejudices, and presuppositions (Zahavi, 2003).

Husserl used a series of reductions to provide rigorous science and included phenomenological reduction, eidetic reduction, and transcendental reduction. Husserl

claimed phenomenological reduction was that everything that is known and taken for granted became a phenomenon; eidetic reduction was the process of moving from consciousness to essences of the thing or being (Kakkori, 2009; Zahavi, 2003, p. 39). Husserl's later work continued his investigation on time, the body, intersubjectivity, and the lifeworld. He attempted to demonstrate that both the lifeworld and science were constituted in transcendental intersubjectivity (Zahavi, 2003, p. 132).

Martin Heidegger (1889-1976) was a student of Husserl and was considered his protégé. In 1927, Heidegger dedicated his book *Being in Time* to Husserl and announced his departure from his mentor's philosophical direction (McGovern, 2007). Heidegger moved away from Husserl's descriptive phenomenological approach and was the first to look at phenomenology through the hermeneutic lens (Smith, Flowers, & Larkin, 2013). Heidegger argued that understanding of lived experience needed to be explored from an ontological view, in that lived experience was an interpretive process (Dowling, 2007; Reiners, 2012). His focus was on "Being," or "Dasein," his preferred term, in that understanding involved becoming aware of the meaning of being, and he sought a method that would disclose life in terms of itself. He believed that "Dasein" was the essence that allowed humans to wonder about their existence and question the meaning of Being-in-the-world (Koch, 1995). Heidegger did not emphasize the idea of suspending preconceptions and presuppositions and, instead, highlighted that "relatedness to the world" was always already underway (Kafle, 2011; Vagel, 2014).

Both Husserl and Heidegger viewed the phenomenological method as giving access to being and beings, in that it allowed persons to distinguish different modes of being (McGovern, 2007). However, on the subject of intentionality, Heidegger believed it

was a feature of *Dasein*, not of consciousness, in that it was not just mental concepts that were dependent upon representations, and it was not just a mode of knowing; intentionality in his theory was the mode of the existing subject and was not separate from its objects (McGovern, 2007). Both Husserl and Heidegger provided analysis of persons' everyday experiencing instead of adopting the abstractions from the natural sciences. They also agreed that access to objects in the daily world was more than perceptual concepts and were perceived in terms of the values they have for persons (Nenon, 2013).

Some researchers believed that Heidegger fused hermeneutics and phenomenology together and moved away from the epistemological idea (to know) to the ontological (to be) way of being in the world (van Manen, 2014; Vagel, 2014). Vagel (2014) suggested that Heidegger believed hermeneutic research identified meanings as in being and language, and that "intended meanings come into being" (Vagel, 2014, p. 39).

Harvey (2012) suggested that Heidegger adopted the concept of the hermeneutic circle from Scheleirmacher, who established a dialectical relationship between "parts" and "whole" regarding information that is integrated into the interpretation of text and meaning. This was expanded upon by Dilthey (1833-1911), who incorporated a historical dimension and the relationship between past and present into the hermeneutic circle (Harvey, 2012). Heidegger used the hermeneutic circle to explain "how what is understood forms the basis for grasping that which still remains to be understood" (Bontekoe, 1996, p. 2), and to demonstrate the reciprocal activity of preunderstanding and understanding (Dowling, 2007). The hermeneutic circle was widely used by hermeneutic phenomenology research and looked at the relationship between the part and

the whole, at a series of levels (Smith, Flowers, & Larkin, 2013; Vagel, 2014; van Manen, 2014). The use of the hermeneutic circle is expanded upon in Chapter 3.

Gadamer (1900-2002) was a student and close friend of Heidegger and appropriated hermeneutic phenomenology by arguing that “human existence is not a methodical problem” (van Manen, 2014, p. 133). He argued that prejudgment, prejudices, and preconceptions were part of our linguistic experience, and made understanding possible, and were embedded in historical consciousness (Dowling, 2007; van Manen, 2014). Gadamer believed that human understanding occurred as a dialogue and that there was a reciprocal process between the researcher and participant. Thus, interpretation infused every activity (Dowling, 2007; van Manen, 2014). He also referred to a metaphor of “the fusion of horizons,” which suggested that the encounter between the researcher and topic was not fixed, but came together to expand vision and deepen understanding (van Manen, 2014, p. 133). Gadamer also embraced the hermeneutic circle’s circular movement of understanding and interpreting the topic by viewing the whole to part to whole.

Merleau-Ponty (1908-1961) was a follower of Husserl and Heidegger, and although he did not agree with Husserl’s Cartesian concept of the self as body, he did support Husserl’s position on bracketing. He also acknowledged the importance of Heidegger’s ontological features as he tried to develop a multi-dimensional description of *Lebenswelt - lifeworld* (Dowling, 2007; McConnell et al., 2009). For Merleau-Ponty, human relation to the world was a relation of perception; he believed “language cannot be separated from body and conscious thought” (1962, p. 215). In his efforts to develop a more existential phenomenology, he proposed that phenomenology was the study of

essence, and his goal was to put essences “back into existence” (1962, p. vii). His phenomenology involved direct description and methodological reduction to reach an original awareness (Dowling, 2007; van Manen, 2014).

Giorgi, born in 1931, was a psychologist who was influenced by Husserl’s descriptive phenomenology, especially with the notion of intentionality of consciousness (Giorgi, 2009; Smith, 2010). He is known for his phenomenological methodology for research in psychology, and for being part of the Duquesne Group, known for creating the original graduate program of phenomenology and psychology (Smith, 2010). He believed his descriptive phenomenological approach was more scientific and that “interpretation tries to clarify ambiguities and makes necessary the introduction of assumptions” (Giorgi, 2009, p. 127). He posited that “a descriptive analysis attempts to understand the meaning of the description based solely on what is presented in the data” (p. 127). Giorgi’s method involved description reduction on many levels from generalized consciousness to essence, with bracketing or ‘epoché’ of past knowledge and presumptions. Giorgi’s method then had the descriptions divided into units, which were transformed into meanings units to be described through the psychological aspect of lived-through experiences. Giorgi’s contributions to phenomenological research and methodology have influenced not only qualitative psychological research, but also other fields such as nursing. His contributions have also brought about controversies in phenomenological research, which are discussed later in this section.

Max van Manen (2014) is considered a modern hermeneutic phenomenologist and was influenced by “the Dutch School” of phenomenology. He considered the phenomenology of practice the Dutch contribution to phenomenology (van Manen,

2014). Van Manen used the term “phenomenon” and experience as the same thing (p. 106). He described that “the purpose of the phenomenological reflection is to try to grasp the essential meaning of something” (van Manen, 1990, p. 77). He defined his method thus: “The phenomenological method consists of the ability, or rather the art, of being sensitive – sensitive to the subtle undertones of language, in the way language speaks when it allows the things themselves to speak” (van Manen, 1990, p. 111). Van Manen’s hermeneutic phenomenology was based on everyday practice and the understanding of human beings in their lifeworlds. His method was a combination of descriptive and hermeneutic (interpretive) elements and is discussed further in Chapter 3.

Added to the controversies surrounding PTSD, and therapy for people with ID, are the debates regarding quantitative versus qualitative research methodology. Based on positivism and the ontological model of quantitative empirical research, there was only the objective truth (Sale, Lohfeld & Brazil, 2002). In contrast, the ontological model of qualitative research stated there are multiple truths based on a person’s experiences (Sale et al., 2002).

Quantitative researchers have suggested that phenomenological research lacks methodological rigor, generalizability, transferability, and validity (Denzin & Lincoln, 2000; Gerring, 2004). Quantitative researchers also suggested that sample sizes of qualitative studies did not ensure representativeness (Guba & Lincoln, 1994). However, qualitative researchers have suggested that quantitative studies cannot capture the lived experiences of important phenomena such as patient experiences with a disease, social interactions, and perceptions of specific populations of people (Sale, Lohfeld, & Brazil, 2002). Qualitative researchers argued that sample sizes were small and were not meant to

represent large populations, but provided the basis for thick, rich description and allowed the researcher to explore and investigate real-life phenomenon through detailed analysis of their relationships (Yin, 2001).

Stake (1995) suggested that the main distinction between quantitative and qualitative research was the inquiry for explanations versus the inquiry for promoting understanding. Miles and Huberman (1994) suggested that the banter between quantitative and qualitative researchers was not necessary and that both methodologies needed each other. Although there were clear differences between qualitative and quantitative approaches, some researchers maintained that the choice between using qualitative or quantitative approaches actually had less to do with methodologies than it did with positioning oneself within a particular discipline or research tradition (Denzin & Lincoln, 2000; Miles & Huberman, 1994).

The controversies regarding phenomenological research continue, especially among phenomenologists. The debate about what constitutes phenomenology and the different schools of phenomenological method can be very confusing. Finlay (2009) suggested that one of the main controversies was the difference between descriptive and interpretive or hermeneutic phenomenology by different scholars such as Giorgi, Heidegger, Gadamer, and other scholars who viewed phenomenology as description and interpretation which are on a continuum, similar to the view of van Manen. Another controversy regarded the issue of “epoché” (bracketing) or not to bracket. Husserl and Giorgi maintained the need to bracket past knowledge, understandings, and assumptions of the phenomenon to establish rigor and validity of the research (Finlay, 2009). Hermeneutic researchers, on the other hand, believed that bracketing was not possible or

desirable and that researchers needed to be aware of their beliefs and shift back and forth from the participants' experiences to their own, "continually reflecting on both interpretations to move beyond previous understandings" (Finlay, 2009, p. 13). Finally, Finlay (2009) suggested that "phenomenologists study human being in human terms," (p. 14) and phenomenological research was considered both a science and an art. The debate lay with how much weight was put on the science or the art, and van Manen suggested that "the balance of science-art considerations may shift according to the stage of research" (2007, p. 25). For this study, I believe that a hermeneutic phenomenological approach provided the best avenue to capture the lived experiences of clinicians and their perceptions of trauma treatment for people with ID. The specifics of establishing rigor for hermeneutic phenomenology for this study are discussed in Chapter 3.

Summary and Conclusions

Overall, the review of the literature has provided a historical look at the development and theories of PTSD, and the identification, separation, and the continuum of people with ID and mental health issues. Although leaders in the field of ID acknowledge that people with ID have a higher risk of psychiatric diagnoses, there continues to be bias and diagnostic overshadowing for treatment options (Barol & Seubert, 2010; Bradley, Sinclair, & Greenbaum, 2012; Edwards, Lennox, & White, 2007; Esralew, 2006; Harvey, 2012; Hurley, 2005; Lynch, 2004; Mevissen, Lievegoed, & de Jongh, 2011; Werner & Stawski, 2012). There are limited studies that provide information on diagnosing and treating trauma and PTSD for people with ID, and yet this population continues to be vulnerable to abuse, neglect, and exploitation (Esralew, 2006; Fletcher, Barnhill, & Cooper, 2016; Harvey, 2012; Hurley, 2005; Lynch, 2004). The

literature review discussed the lack of clinician training on trauma and PTSD for people with ID, as well as the issue of the lack of training for clinicians regarding PTSD in the general population. The literature review also discussed several controversies, including the different theories of PTSD, the effectiveness of psychotherapy for people with ID, and the debate over phenomenological differences in methodology. The history of phenomenology, hermeneutics, and different schools of phenomenological philosophy were also discussed in the literature review. This study enriched the literature regarding trauma and PTSD treatment for people with ID and added information regarding the gap in the research relating to clinicians' perceptions of trauma treatment for people with ID.

Chapter 3 expands on the qualitative design of this study to describe clinicians' perceptions of trauma treatment for people with ID. Specifically, the chapter includes an introduction to Chapter 3; the research design and rationale for the design; the role of the researcher; the methodology; participant selection logic; instrumentation; procedures for recruitment, participation, and data collection; and the data analysis plan. Issues of trustworthiness and ethical procedures are also discussed. Chapter 3 ends with a summary of the main points and highlights what is contained in Chapter 4.

Chapter 3: Research Method

Introduction

My purpose for conducting this qualitative phenomenological study was to describe and interpret the lived experiences of clinicians with and without experience with people with ID, and to capture their perceptions of trauma treatment for people with ID. In this chapter I present the research questions and guide the reader through the methodology, research design and rationale. I describe the participants and population of the study and ethical protection of participants. I describe the setting, data gathering procedures, the data analysis process, issues of trustworthiness, and conclude the chapter with a summary.

Research Design and Rationale

In this study, I sought to describe and interpret clinicians' lived experiences to capture the meaning of their perceptions of trauma treatment for people with ID. The research questions were as follows:

1. For clinicians who do not have experience working with people with ID, what were their perceptions of providing trauma treatment for people with ID?
2. For clinicians who have experience working with people with ID, what were their perceptions and experiences providing trauma treatment for people with ID?

In keeping with a phenomenological approach, it was important for this study to provide the everyday lived experiences of the clinicians that shaped their perceptions of trauma treatment for people with ID, and appeared or gave themselves to us, and were presented in a descriptive, interpretive, linguistic, and hermeneutic manner that showed

the lived quality or significance of the experiences in a fuller and deeper manner (van Manen, 2014, p. 26). A second component of this study was based on the concept that people with ID do experience trauma symptoms and PTSD (Bowman, 1999; McCarthy, 2001; Ryan, 1994). A third component for this study was guided by the principle that people with ID can engage in trauma treatment. The fourth component for this study regarded the participants' training in trauma and PTSD and their training regarding people with ID. These components are part of the conceptual framework, the lived experiences of the participants, and the phenomenon.

Phenomenology is a combination of the Greek words that implies the activity of giving an account of the various ways in which things can appear (Coleman, 2006). Merleau-Ponty (2002) believed that "phenomenology is the study of essences" (p. vii). It is, in other words, the study of "the meanings as we live them in our everyday existence, our lifeworld" (van Manen, 1990, p. 11). The terms *phenomenology* and *experience* from van Manen's (2014) perspective are the same thing; he defined *description* as a combination of description and interpretation to "show how our words, concepts, and theories shape and give structure to our experiences as we live them" (p. 58). Hermeneutics is the theory and practice of interpretation. The word is derived from the Greek god Hermes, who was responsible for communicating messages from the gods to ordinary mortals (Cole, 2006; van Manen, 1997). Hermeneutic phenomenology applies an ontological approach, in that it is concerned with reality, and the perceptions of the stories people tell of their experiences and their search for a deeper understanding of the meaning of that experience (Kafle, 2011).

Van Manen (1990) suggested six activities or structures for hermeneutic human science research, and provided the rationale for conducting this type of study. First, van Manen (1990) took from Gadamer (1975) the idea that to question something means to find ourselves deeply interested in that which makes the question possible in the first place. As further stated by van Manen, “to truly question something is to interrogate something from the heart of our existence, from the center of our being” (p. 43). Working with people with ID is my passion, and helping people with ID heal from trauma truly comes from the center of my being.

Second, van Manen (1990) suggested that phenomenological research requires investigating experiences as we live them rather than as we conceptualize them. In my study, this means describing and interpreting the clinicians’ lived experiences in relation to their perceptions of people with ID and their perceptions of trauma treatment for this population. It also means seeking out the meaning of lived experiences of shared situations of the clinicians and their perceptions.

Third, van Manen (1990) suggested that phenomenological research requires reflecting on the essential themes which characterize the phenomenon. This did not mean just identifying themes or providing introspection, but also the recollection of past or current lived experiences of the clinicians that brought meaning, nearness, and special significance which related to trauma treatment for people with ID.

Fourth, van Manen (1990) suggested that phenomenological research requires describing the phenomenon through the art of writing and rewriting. He believed that language and thinking cannot be separated, and the art of writing hermeneutically was thoughtfully “letting that which is being talked about be seen” (p. 33). My goal for the

text of the study was not just writing the results, but utilizing the text to show how the lived experiences of clinicians shaped their perceptions of trauma treatment for people with ID. I worked to embody and embed the meaning of their lived experiences and perceptions in the text (see van Manen, 2014).

Fifth, van Manen (1990) suggested that it is important for the researcher to maintain a strong and oriented relation to the phenomenon. He noted that to be oriented means to be cautious of temptations to get side-tracked or not to be cognizant of preconceived opinions, and to stay strong to the research question. Since my passion is working with people with ID and helping them heal from the traumatic experiences they have endured, and since I was curious about clinicians' perceptions of trauma treatment for people with ID, staying strong and oriented to the research project was one of my strengths as a researcher.

Finally, van Manen (1990) suggested that it was important to "balance the research context by considering parts and whole" (p. 31). Balancing the parts and whole of the text of the interview questions to identify the meaning of the "whatness" is the hallmark of hermeneutic phenomenological research (van Manen, 1990, p. 33). He suggested that it is important to look at all the text and identify how each part contributes to the overall research questions, which was my challenge as a novice human science researcher. But my inventive thoughtfulness, interpretive quest, and scholarly drive prompted me to balance the parts and whole of the clinicians' perceptions of trauma treatment for people with ID.

Addeo (2013) suggested that the researcher develop a concept map to organize the research concepts and show how different concepts are linked to each other and to the

original research questions. He suggested that a concept map can clarify the research framework, provide guidelines for the interviewing process, and assist with interpreting and analyzing the data. The concept map for this study can be found in Figure 1.

The methodological structures that van Manen (1990) suggested were just that— suggestions—and he noted that these structures are procedural dimensions and do not have to be completed in any order or that each step be completed. He did advocate for the researcher to have a strong spirit for hermeneutic inquiry. Although hermeneutic phenomenological scholars have different opinions on how to design and conduct a study, they agreed to approach the research with open-mindedness, flexibility, patience, empathy, and a willingness to delve into the participants' lived experiences to identify meaning (Dowling, 2007; Kafle, 2011; Smith, Flowers, & Larkin, 2013; Vagel, 2014; van Manen, 1990, 2014). These qualities are what drive my spirit for conducting hermeneutic phenomenological research and justified my reason for choosing this type of inquiry to identify the clinicians' perceptions of trauma treatment for people with ID.

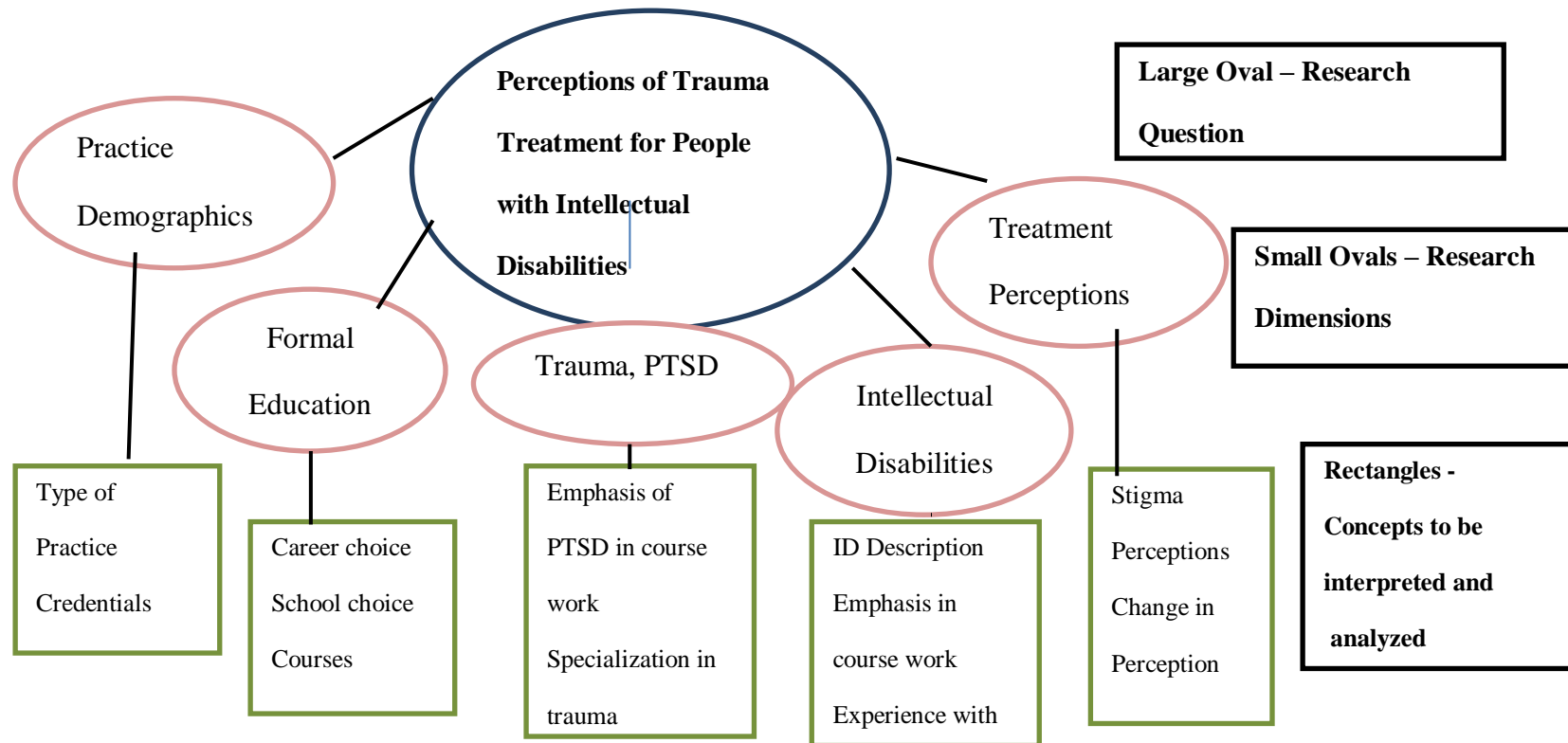


Figure 1. Concept map for clinicians' perceptions of trauma treatment for people with ID. Adapted from *Hermeneutic as a Research Method: How to do Research Using Hermeneutic Approach*, by F. Addeo, 2013, retrieved from <http://www.slideshare.net/FeliceAddeo/hermeneutic-as-aresearchmethoddraft>

The Role of the Researcher

My role as the researcher was to recruit and select the participants, interview participants, gather the data, and complete the analysis and interpretation of the data for this research project. Once the participants were selected, interviews were scheduled, and a face-to-face interview with each of the participants was completed. I was responsible for going over the informed consent form, and for answering any questions from the participants prior to doing the interview. There did not appear to have been any issues regarding personal or professional relationships because I did not know most of the participants selected and did not have a supervisory or instructor relationship with any of the participants. No power relationships appeared to have been developed or needed to be managed.

One of the hallmarks of hermeneutic phenomenological research is the process of *epoché* or *bracketing* one's biases, pre-understandings, assumptions, or beliefs to open oneself to the significance of the phenomenon. According to van Manen (1990), it is better to disclose these understandings "to deliberately hold them at bay" (p. 47), but to also provide personal experiences as relevant to the phenomenon. Vagel (2014) and van Manen (2014) suggested that researchers provide personal descriptions of lived experiences to create reflexivity and to remind themselves that they are historical beings and their experiences may have commonalities with the experiences of others. Vagel called this the "post-reflexion statement" (p. 133), which I used throughout the study and was revisited and made anew. Vagel suggested that the post-reflexion statement can provide underlying shifts and changes in knowledge and understandings as the meaning of the participants' experiences are explored.

To provide my biases, pre-understandings, assumptions, and beliefs, I am providing a description of my personal experience and perceptions of working with people with intellectual disabilities who have experienced trauma and PTSD. I acknowledge that I have my biases regarding trauma treatment and psychotherapy for people with ID and that controversy may have arisen, but I am confident that the hermeneutic methodology of reflection allowed me to identify those biases and document them as part of the results and discussion sections of Chapters 4 and 5. This description also provided an element of trustworthiness for the study.

My Life-World Experience

I have over 30 years working with people with ID. My first experience working with anyone with an intellectual disability was after I graduated with my Bachelor's degree in music, and I was a substitute teacher at an elementary school. I had to teach a class for children with special needs. I remember I felt I did not know what I was doing because I had not received any training in disabilities through my undergraduate training, but decided to give each child a percussion instrument and asked them to sing songs. Writing this, I can feel my chest open up and a smile on my face, because I remembered how much fun it was.

Throughout my career working with people with ID, I have held positions as a job club facilitator, a direct care provider in both residential and sheltered workshop settings, a community connector, a community participation supervisor, a residential coordinator and supervisor, a case manager, a trainer, and a licensed therapist specializing in mental health issues for people with ID. My educational journey includes receiving a master degree in psychology and obtaining my license as a professional counselor (LPC). I took outside courses and worked part-time for over five years working in the field of substance

abuse and domestic violence with adults and teens in the criminal population as a certified addictions counselor.

During my time as an addictions counselor, I realized that many of my clients had severe trauma backgrounds and redirected my focus to learning everything I could about trauma and PTSD. I took all the trainings I could get on trauma and PTSD, which included (CBT), (DBT), somatic experiencing, thought field therapy, attachment disorders, and personality disorders, because these topics were not focused on during my graduate studies. I learned about a therapy approach called EMDR. On the first night of the lecture part of the training, the facilitator started talking and I began to have goose bumps over my arms and an excitement came over me. I remember saying to myself, “I understand what he is talking about, and my graduate training and other courses have made the difference.”

I currently work in a small behavioral health clinic specializing in behavioral and psychiatric issues for people with ID. The clinic is comprised of a behavior analyst, a psychologist, a psychiatrist, and a licensed clinical social worker. Together, we have developed an interdisciplinary psychiatric evaluation process to diagnose, treat, and train caregivers and agencies to work with people with ID and psychiatric issues. For the last 12 years, I have been honing my skills to adapt therapy strategies to meet the needs of people with ID. I have developed trainings for people working in the ID field and others on how trauma and PTSD, personality disorders, substance abuse, aging, and mood disorders affect people with ID. On my doctoral journey, I have focused my attention on people with ID and psychiatric issues, especially trauma and PTSD. I believe I have become a true specialist with this population, and my biases for treatment and therapy are strong. My position for this study is that people with ID who have endured trauma and

PTSD can and do benefit from therapy and should be afforded the same access to treatment as is the average person.

Methodology

Van Manen (2014) suggested that many of the phenomenological scholars warned against using a methodological set of standard strategies or techniques, and stated that it was difficult to describe phenomenological research methods because there was not just one phenomenology (p. 41). Van Manen suggested that phenomenological interviewing, observing, reflecting, thematizing, and writing were ingredients for conducting hermeneutic phenomenological research. He quoted Gadamer, who pointed out, “There is no method to human truths” (p. 30).

Participants and Sample

The term “sample” in phenomenological research is usually selected purposively (Smith, Flowers, & Larkin, 2013; Vagel, 2014; van Manen, 2014). However, van Manen (2014) suggested that a better term to use was *examples*, because phenomenological inquiry would not deliver empirical generalizations. Instead, he suggested it was important to question how many examples would provide experientially rich descriptions and insight in order to explore the meanings of the phenomenon effectively (van Manen, 2014). The current emphasis was on richness and quality, rather than quantity and numbers. My objective for this research was to become inundated with the text to identify and interpret the meaning and understanding of clinicians’ perceptions of trauma treatment for people with ID. The criteria for selecting participants were based on their willingness to participate in the study, accessibility to the clinicians for interviews, and specific knowledge and experience in trauma treatment. For this study, the term “clinicians” included psychologists, clinical social workers, professional counselors, and

board-certified behavior analysts. Patton (1990) considered this type of sampling a combination or mixed purposeful sampling because this combined criterion sampling, convenience sampling, and purposive sampling.

The criteria for the clinicians to participate in the study included having a master's degree or higher in the field of psychology or human sciences, and being licensed or board certified to practice therapy in the state of Colorado. Clinicians were also required to have at least five years of experience as a practicing clinician, as well as being in good standing with the Department of Regulatory Agencies (DORA). Clinicians were selected according to their commitment to the study and their availability for further interviews, reviewing transcripts, or follow-up questions. The initial inclusion screening protocol and checklist is in Appendix C.

Participants were recruited in a variety of ways, which included online networks such as the Denver Therapists Network, the EMDRIA regional network, and the Department of Regulatory Agencies, and by *snowballing* referrals from personal contacts or by participants. The recruitment letter is in Appendix B. Potential participants were contacted by email or phone, were provided a brief synopsis of the research study, and were invited to contact me for further information and to set up a time to go over the study, obtain informed consent, and conduct the interview.

Many qualitative researchers agreed that sample size is a matter of judgment, and there are no real rules for sample sizing in qualitative research (Creswell, 2003; Denzin & Lincoln, 2002; Guba & Lincoln, 1994; Patton, 1990). It was not the amount of data gathered, but its richness and the detail (Mason, 2010; Tuckett, 2004). However, sample size was related to data saturation, which must generate enough data to learn in detail and in depth about the experience of the individuals (Mason, 2010). Data saturation or

redundancy is a term to describe when no new information of significance was provided by the data gathered or nothing new was heard in the case of interviewing (Lincoln & Guba, 1985; Patton, 1990). According to van Manen (2014), the quest to find meanings and lived experiences from the participants does not depend on data saturation but on seeking experientially rich descriptions unique to the study which provide reflective interpretation (p. 353). Vagel (2014) suggested there was no magic number of participants for a phenomenological research study, but for this study, eight participants were interviewed.

Instrumentation

Interviews are the heart of phenomenological research, and the interviewer is the primary research tool of the hermeneutic phenomenological inquiry (Kvale, 2007; Vagle, 2013; van Manen, 2014). Kvale (2007) viewed the interview as an inter-view, “an interchange of views between two persons conversing about a theme of common interest” (p. 1). The interview allowed the interviewer to enter into the participant’s lifeworld and allowed the participant to describe her lived experiences as they pertain to her perceptions of trauma treatment for people with ID. Vagel (2013, p. 79) posited that it was not always necessary that each interview was the same or that it was necessary to ask the same questions at each interview, but to treat the interview as an opportunity to learn something about the phenomenon.

A second research tool utilized in this research was suggested by Groenewald (2004) and is in the form of field notes or Memoing. Groenewald (p. 15) provided four different types of field notes: 1) observational notes using all the senses, 2) theoretical notes to identify possible meanings and to reflect on the experiences, 3) methodological notes to remind the researcher of the process, and 4) analytical notes for summary and

progress reviews (p. 15). Groenewald suggested that field notes were part of the analysis because they involved interpretation.

Researcher-Developed Instruments

I developed open-ended, semi-structured, in-depth questions to gather experiential material to develop a rich and deep understanding and meaning of the participants' experiences regarding their perception of trauma treatment for people with ID. The questions were developed on the basis of the literature review regarding trauma treatment for people with ID. Appendix D provided possible interview questions, keeping in mind that there was an openness to change the questions and follow-up depending on the stories told and answers given (Kvale, 2007, p. 65). All interviews were tape recorded and transcribed for accuracy and data analysis. Appendix E provided an interview protocol, and space was allowed to bracket my own feelings, emotions, and assumptions during the interviews, as well as to document observations during the interview.

Content validity in qualitative research involves communication with the research participants to capture their experiences and perspective relative to the research questions and the project as a whole (Brod, Tesler, & Christensen, 2009). A qualitative content analysis does not produce counts and statistical significance like the classical content analysis, but does provide the identification of patterns, themes, and categories of the project's reality, and coding is the fundamental analytic process used with a qualitative content analysis (Miles & Huberman, 1994; Patton, 1990; Richie and Spencer, 1994). However, van Manen (2014) believed that this was not the way of doing phenomenology (p. 319). He wrote that hermeneutic phenomenological tradition did not include abstracting, coding, and procedural approaches because these actions cannot produce phenomenological understanding and meanings of human experiences represented in text.

Instead, van Manen (2014) suggested completing a theme analysis to identify sources of meaning and structures of experience from the whole story, a selected paragraph, a specific sentence, phrase, expression, and/or a single word. He suggested taking a lived experience description and converting it into an anecdote, then utilizing a wholistic, selective, and line-by-line thematization and identifying themes for reflective writing driven by epoché and reduction, which was the direction I chose to take.

Procedures for Recruitment, Participation, and Data Gathering

The researcher was responsible for conducting all interviews and gathering all data. A note about the term “data gathering,” Vagel (2014) and van Manen (2014) both used this term instead of “data collection,” as it was more ontological in nature. Therefore, the term “data gathering” was used throughout this study to stay in the phenomenological spirit and attitude.

As the researcher, I was responsible for setting up the interviews with the participants at a location which was convenient to them and represented their life world, such as their office or work place. In-depth interviews can take a considerable amount of time (approximately one to two hours) and were part of the time criteria for participating in the study. Prior to the interview, I obtained informed consent and provided a brief overview of the purpose of the study, explained the use of the tape recorder, and allowed the participant to ask any questions. I reiterated the study’s purpose again and allowed time for questions prior to starting the interview. Because of the schedule of the participants and the researcher, data gathering took 6 weeks to complete. If more participants had been needed for data gathering purposes, purposive sampling and snowballing would have been used for their recruitment. I transcribed the tapes verbatim after each interview to ensure accuracy and confidentiality and to familiarize myself with

the data. Follow-up interviews with the participants were not needed. All participants received a transcribed copy of their interview and my interpretation of the interview; this gave the participants an opportunity to comment on the interpretation and elaborate on their original statements. All participants received a finished copy of the transcript of their interview and a summary of the results of the completed dissertation. A copy of the approved completed dissertation was available if requested.

Data Analysis Plan

Stake (1995) suggested that “there is no particular moment when data analysis begins” (p. 71), and like other qualitative research methodologies, it is difficult to separate the data gathering process from analysis in a phenomenological study (Vagel, 2014). As van Manen (1997) stated, “The aim of phenomenological data analysis is to transform lived experience into a textual expression of its essence—in such a way that the effect of the text is at once a reflexive re-living and a reflective appropriation of something meaningful” (p. 36). The data from the interview transcripts were used to identify the participants’ lived experiences and perceptions of trauma treatment for people with ID to provide textual reflexive and reflective expression and meaning. Utilizing guidelines from Hycner (1999), Vagel (2014), and van Manen (1990, 2014), the data analysis plan began with listening to the recordings, reading the verbatim transcriptions of the interviews, and becoming immersed with the text as a whole. At the same time, an attitude of openness or phenomenological reduction was applied to allow meanings to emerge. Any presuppositions, understanding, or meanings that I expected the participants to say were bracketed to just let the lifeworld of the participant speak (Hycner, 1999).

I then numbered and read line-by-line the transcribed text to delineate units of general meaning that might be important to describe and interpret, but did not yet address the research question. A second, third, and other line-by-line readings were completed to develop anecdotal narratives to then identify relevant units of meaning. Van Manen (2014) provided guidelines to create lived experience, descriptive anecdotes by using short and simple stories from the interviews to describe a single incident (p. 252). The anecdote began at the moment of the experience and included concrete details. The anecdote included several quotes and ended when the incident passed and had a point to make (van Manen). Vagel (2014) reminded me as the researcher that I was ‘crafting text—not merely coding, categorizing, making assertions and reporting’ (p. 98).

The units of relevant meanings were then transitioned into clusters of meanings that were then analyzed to determine if the clusters identified central themes of the essence of the clusters and the phenomenon. This was completed for each interview, and then the themes were reviewed across interviews to see if there were commonalities as well as individual variations. Throughout this process, the hermeneutic circle was incorporated. Bontekoe (1996) described the hermeneutic circle as a process where the researcher moved between the whole, the parts, and the whole for understanding and interpretation of the phenomenon, giving meaning that was circular and iterative. He further explained the process of “how what is understood forms the basis for grasping that which still remains to be understood” (p. 2). Van Manen (2014) cited Gadamer, who stated that a researcher brought her knowledge and experiences that merged (fusion of horizons) and created new knowledge and understanding.

Staying with van Manen’s (2014) approach to hermeneutic phenomenological inquiry, I decided not to code the data, but to number the text line-by-line for each

interview. I made lists of units of meaning, created anecdotes, and labeled clusters of meaning and themes for interpretation and understanding. I considered using the Nvivo10 software program as a database to keep information organized and safeguarded. The Nvivo10 software program is a qualitative research tool that can handle all types of data, including word documents, audio files, tables, spreadsheets and videos (QSR International, 2015). Electronic qualitative software programs such as Nvivo ease the arduous task of managing the large amount of data that hermeneutic phenomenological research compiles. The Nvivo software program provides researchers with rapid and supportive access to their data, but does not do the analysis. Each researcher is responsible for entering the data, deciding what to retrieve, creating clusters, determining queries, and applying knowledge and creativity to selective analytic strategies.

Miles and Huberman (1994) suggested “the outlier is our friend” (p. 270) and can take on a variety of forms, such as discrepant cases. These cases can provide opportunities to look at the data from different vantage points and possible representations of alternative meanings. Discrepant cases may also uncover assumptions that may alter the core understanding of what is being investigated (McPherson & Thorne, 2006). Therefore, if discrepant cases were identified, they would be included as part of the results and interpretation sections of this study. There were no discrepant cases.

Issues of Trustworthiness

Reliability and validity are interpreted differently in qualitative research (Creswell, 2003). Under the umbrella of the term “trustworthiness” lays the quality of qualitative research (Seale, 1999). Lincoln and Guba (1985) believed reliability and validity corresponded with the question: “How can the inquirer persuade his or her

audiences that the research findings of an inquiry are worth paying attention to?" (p. 290)

Lincoln and Guba (1985) developed their own set of criteria for reliability and validity in qualitative research to include credibility for internal validity, transferability for external validity, dependability for reliability, and confirmability for objectivity. Creswell and Miller (2000) suggested that a two-dimensional framework of the lens of the researcher and the researcher's paradigm assumptions be used when choosing the procedures for reliability and validity. They further suggested that the lens was the viewpoint of the researcher for establishing validity, and the researcher's worldviews or paradigm assumptions also shaped their selection of procedures used (p. 125).

Credibility is determined by how believable the study is (Patton, 1999). My goal was to provide rich, thick descriptions and interpretations of information provided by the data gathering and the process of analysis; giving the participants the opportunity to comment on the interpretation and elaborate on their original statements related to their perceptions of trauma treatment for people with ID promoted credibility. I was reflective in stating my own personal experiential presumptions, understandings, and biases related to the study, as well as compiling a journal of field notes documenting my self-awareness of the interactions during the research project and reactions to various events. Vagel (2014, p. 97) and van Manen (2014, p. 347) did not look at the qualitative procedure of triangulation as fitting for phenomenological research, as it may result in misinterpretations and misunderstandings. However, data gathering provided multiple data moments across participants' interviews, writings, and observations that could be used along with field notes and my position as the researcher as a form of triangulation in regard to using the hermeneutic circle and the whole, part, whole process to generate

understanding and meaning regarding the participants' perceptions of trauma treatment for people with ID.

Transferability is different in qualitative hermeneutic phenomenological research, in that it is a form of inquiry that does not produce generalizations (van Manen, 2014). However, this did not mean that the thick, rich descriptions and interpretations of the lived experiences of participants related to their perceptions of trauma treatment for people with ID cannot provide a greater in-depth understanding of the meanings that may apply to others. Koch (2006) acknowledged that the themes emerging from a hermeneutic experience may not be the same for the researcher and readers, nor be in agreement regarding the researcher's interpretation, but the reader should be able to track the way the researcher came to it. Stake (1995) called these "naturalistic generalizations," which the reader may form vicariously from the narrative and descriptions throughout the study. Lincoln and Guba (1985) suggested that transferability was not the burden of the researcher, but fell upon the reader, who is considering applying the findings to his or her own circumstances, which was the goal of this study.

Dependability is the qualitative counterpart to reliability and looks at the consistency of the data in regard to another researcher being able to follow the decision trail regarding the theoretical, methodological and analytical choices throughout the study and arrive at comparable, but not contradictory conclusions (Koch, 1994, Sandelowski, 1986). Baxter and Jack (2008) cited both Stake (1999) and Yin (2003) as having recognized the use of a research study database, which increased dependability. I approached the issue of dependability by identifying my biases, describing the design of the study, and outlining the data gathering and data analysis plan as a decision trail, indicating my choices for such decisions. While the use of an independent auditor was

desirable, my financial situation did not allow for this process. Dependability was also enhanced by having transcripts of tape-recorded sessions and semi-structured interviews that provided a record of naturally occurring interactions and contributed to accuracy and consistency.

Confirmability lies with the researcher's own biases, experience, and training (Patton, 1999). I have disclosed biases and experiences in the section identified as "My lifeworld experience." I acknowledged that my bias was in part, due to my passion for working with people with ID who have experienced trauma and PTSD and the successful results I have obtained adapting trauma therapy approaches for this population. Guba and Lincoln (1985) suggested that confirmability was established when credibility, transferability, and dependability were achieved.

Ethical Procedures

Prior to beginning the study, the researcher submitted a study proposal to the Walden University Institutional Review Board, which included a detailed explanation of how informed consent was to be obtained for client participants and therapists. The Walden IRB approval number (03-11-16-0114261) was placed on the consent forms for the participants.

The participants in this study were not from a vulnerable population, but were asked about their perceptions of a vulnerable population. Specific information discussed on informed consent form included (a) the project's goals and methods, (b) source of funding and if there were conflicts of interest, (c) the institutional affiliation of the researcher, (d) the benefits, risks, and the follow-up of the project, (e) discomfort the participant may endure during the project, and (f) the participant's right not to partake or to withdraw from the project at any time without repercussions. Other components on the

consent form included (a) risks, benefits, side effects or discomforts, and alternatives to the treatment, (b) how confidentiality will be protected, (c) a statement regarding the participant's opportunity to ask questions, (d) how to contact the researcher, (e) who to contact with concerns or complaints, and (f) a statement regarding that no sexual intimacy will happen and is against the law. The researcher also included a brief statement about the interviews being tape-recorded and how the identity and confidentiality of each participant will be maintained.

The anonymity and confidentiality of the participants were of great importance. Any identifying information and written transcriptions had the names omitted and were identified with a specific code. If any participant had decided to withdraw from the study prior to the initial interview, snowballing and purposive sampling would have been used to recruit another participant. If any participant withdrew from the study after the initial interview and was not able to review his or her transcribed interview or be available for a follow-up interview, the case would be deemed a discrepant case and interpreted accordingly. Although I did not believe any of the interview questions would have caused any adverse reactions, I would assist the participant with finding a therapist and provided each participant with a list of resources to contact if necessary.

According to Colorado Mental Health Statute (CRS, 2013), research records must be kept for seven years and then destroyed according to state and federal confidentiality statutes and regulations. The researcher will store all data related to the research project at her home office for seven years in a locked file cabinet, and all information stored on the researcher's home computer will be password protected.

Summary

Chapter 3 provides an overview of the research method, design, and procedures of the qualitative hermeneutic phenomenological research project. Information about the participants and population of the study, ethical protection for the participants, and the setting for the study were given. An overview of the data gathering procedures and data analysis plan was provided. I have also discussed issues of trustworthiness, how reliability and validity were assured, and I have disclosed my personal lifeworld experiences and biases.

Chapter 4 includes an introduction to the chapter and provides a brief review of the research questions as well as the setting of the project, the demographics of the participants, and the procedures for gathering and recording the data. The chapter includes a discussion of the data analysis plan, describes relevant units of meaning and themes, and discusses issues relevant to trustworthiness. Chapter 4 discusses the results and addresses each research question and presents data to support each finding. The chapter ends with a summary of the answers to the research questions and provides a transition to Chapter 5.

Chapter 4: Results

Introduction

My purpose for conducting this qualitative phenomenological study was to describe and interpret the lived experiences of clinicians with and without experience working with people with ID, and to capture their perceptions of trauma treatment for people with ID. The goal was to capture the essential meanings of the lived experiences of the participants and how those meanings were applied to their perceptions of people with ID and trauma treatment. The research questions were as follows:

1. For clinicians who do not have experience working with people with ID, what were their perceptions of providing trauma treatment for people with ID?
2. For clinicians who have experience working with people with ID, what were their perceptions and experiences providing trauma treatment for people with ID?

In the first two chapters, the focus of this study, along with the historical and current challenges faced by people with ID who have experienced trauma or PTSD, was described. Controversies of treatment approaches for people with ID and the significant responses from leaders in the field of ID were presented. Theories of PTSD and stigma were presented in Chapter 2, as was a conceptual framework which embodied interpretation and meaning utilizing a hermeneutic phenomenological approach.

Chapter 3 provided the research design and rationale for the design, the role of the researcher, and the methodology, including participant selection logic, instrumentation and procedures for recruitment, participation, data gathering, and the data analysis plan. Issues of trustworthiness and ethical procedures were also discussed. In Chapter 4, I discuss the recruitment and sampling method, the screening method, the setting for

gathering the data, the participants' demographics as they pertained to the study, and how the data were gathered and analyzed. I also discuss the evidence of trustworthiness and the results of the data. Chapter 4 concludes with a summary and a transition into Chapter 5.

Recruitment and Sampling Method

On March 11, 2016, I was granted approval from Walden's IRB (03-11-16-0114261) to begin my study. I began the recruitment process by utilizing three different online therapist databases, including the Psychology Today database, Therapy Tribe, and Good Therapy database. These databases narrowed my search by selecting treatment specialty types, type of insurance, age ranges served, and treatment orientation. The therapist's profiles were purposively reviewed for years in practice, location, and current licensure status. I carefully reviewed the therapist profiles for years of experience, location within a 25-mile radius of my home, and a specialty in trauma and PTSD. One or two therapists were randomly selected from each page. In total, I emailed 175 recruitment letters through these databases. I also emailed 25 therapists through the Denver EMDR regional database, although this database only includes the names and email addresses of therapists and no other information. I also recruited therapists while attending the Colorado Counseling Association (CCA) conference on April 22, 2016.

I then went to the Colorado Department of Developmental Disabilities (DDD) approved provider list to recruit therapists who had experience working with the ID population. This database was more challenging because many of the therapists were Board Certified Behavior Analysts (BCBA) specializing in children with autism, and others were working in large agencies. I was purposively looking for therapists in private practice who were not working with people served by the Community Centered Board

(CCB) where I am employed to make sure there was no conflict of interest. I emailed four licensed therapists and four BCBA's. The recruitment phase lasted 30 days. I received one interested response from the 175 emails through the online databases, two responses from the EMDR database, and one response from a therapist at the CCA conference. Three persons from the DDD approved provider list responded - one BCBA and two therapists in private practice.

Once an interested participant contacted me, I explained the study and my role, and went through the initial screening protocol (see Appendix C). I then checked the licensure status through the Colorado Department of Regulatory Agencies database. If the participant met the inclusion criteria, I then emailed the candidate the informed consent form. Once the participant returned the informed consent form, I contacted the participant to set a date and location for the interview that was convenient to her. At the end of one interview, I used snowball sampling to recruit another participant with experience working with people with ID who had trauma and PTSD experience. The participant introduced me to this person and I explained the study and completed the initial screening protocol. Overall, eight participants were recruited, four with experience working with people with ID and four participants who did not have experience working with people with ID.

Setting

The setting for the interviews with the participants was determined by what was most convenient for them. Three of the participants came to my office because they lived nearby, were meeting clients nearby, or because it was more convenient for them. I met with five of the participants at their offices, which were all within a 25-mile radius of my home. The five offices were similar in decor. They had a small waiting area separate

from the therapy office, and their offices had low lighting or natural light, a couch, desk, several cushiony chairs, and pictures on the walls. Three of the participants had their credentials framed and hung on a wall, and three of the participants had a portion of their office sectioned off with a little table and chairs, games, toys, and stuffed animals because they also worked with children. Two of the participants' offices were in the same house-like setting, and were upstairs from the waiting area, which was not accessible for a person in a wheelchair. When asked, these two participants were confident they could use an office on the main floor if they had a client in a wheelchair. There were no personal or organizational conditions that influenced the participants or their experience at this time that would have affected my interpretation of the study results.

Demographics

The first four questions of the interview with each of the participants involved demographic information regarding gender and experience or lack of experience providing therapy for people with ID. They were asked to describe their credentials and number of years in practice, the type of payment options they offered their clients, and their therapeutic orientation. Table 1 shows this demographic information.

Table 1

Demographics

Participant	Gender	Credentials	Years in Practice	Orientation	Billing Options
P1M1a	Female	LCSW BCBA	7	Behavioral analysis (acceptance and commitment theory)	Medicaid DD PAR Private insurance
P2K1a	Female	LPC	13	Adlerian	Medicaid DD PAR Private insurance Sliding scale Private pay
P3M2a	Female	LPC LAC	10	Cognitive behavioral (AIP/EMDR)	Medicaid Private insurance Private pay
P4M3b	Female	LCSW LAC	6	Cognitive behavioral (AIP/EMDR)	Private insurance Victims compensation
P5L1a	Female	LPC	18	Cognitive behavioral (reality theory)	DD PAR Private pay
P6L2b	Female	LPC	30 +	Cognitive behavioral(AIP/EMDR)	Department of Corrections contract
P7M4b	Male	LCSW	5	Attachment theory	Private pay Sliding scale/pro-bono
P8P1b	Female	LCSW	30 +	Cognitive behavioral (AIP/EMDR)	Private pay Sliding scale Victims compensation Vocational rehabilitation

Note. All participants are in private practice. a = participant with experience working with people with intellectual disabilities; b = participants without experience working with people with intellectual disabilities; LCSW = Licensed Clinical Social Worker; BCBA = Board Certified Behavior Analyst; LPC = Licensed Professional Counselor; LAC = Licensed Addiction Counselor; AIP = Adaptive Information Processing model; EMDR = Eye Movement Desensitization and Reprocessing therapy; DD PAR = Developmental Disability Prior Authorization Review, which identifies services paid for under the Developmental Disability Medicaid waiver of Colorado.

Several of the clinicians reported a foundation in cognitive behavioral theory, but noted that they use several approaches to meet the client's needs:

P6L2b: It has evolved through the years. I guess one of the things that I have found is that one approach does not fit all. I guess my basis has been a humanistic orientation. Um... you know the client centered, and attitude. Um... because I think that my success is primarily based on rapport and therapeutic relationship. And then once that is established, it's a lot easier applying CBT.

P5L1a: Reality therapy works wonders in my practice. I think that and at the end, it really aligns well with cognitive behavior therapy, but what I really like about the tenants of that therapy is that... you're looking at... you know, behaviors your trying to satisfy... four major psychological needs, i.e., the need to belong, the need for freedom, the need for fun, and the need for power. And you look at this population (ID)... Gosh, these are all the areas that they are really lacking.

P8P1b: When I was kind of sort of choosing and thinking about it, I guess it was eclectic. You know, it was kind of realizing that one size does not fit all and that people have a lot of moving parts, and so I felt like I had pretty good training in all different modalities and kind of saw what one felt comfortable with me, as well.

P4M3b: I usually describe it as...a strong foundation of CBT because I don't think... you know, when people here see... we tease sometimes, it's that old fashion, strict, compliance to the model and I don't... I'm not that, but I don't think that I'm different enough to say its eclectic, or it's... I mean... it's really and

truly... my orientation is truly grounded in CBT. I do use a lot of mindfulness; I do a lot DBT work, depending upon the appropriateness. I am EMDR trained, which I think is awesome and goes with CBT wonderfully.

Data Collection

Data gathering for this study consisted of face-to-face semi-structured interviews and my personal field notes. Four participants had experience working with people with ID who had trauma or PTSD, and four participants did not have experience working with people with ID, but had a specialty in treating trauma or PTSD. Prior to starting the interview, I gave each participant a copy of his or her signed informed consent form and went over the consent form to see if the participant had any questions. Participants were provided with a list of mental health resources (Appendix G) in case they had an adverse reaction from completing the interview. None did.

Each participant had one interview which lasted from 40 minutes to 1 hour and 16 minutes. The semi-structured interviews were recorded on a Sony digital recorder. Kvale (2007) viewed the interview as an inter-view, “an interchange of views between two persons conversing about a theme of common interest” (p. 1). Kvale’s view was evident throughout the data gathering process. Each participant was asked the same questions, although some of the participants answered the question prior to being asked as part of the conversation. Follow-up questions were based on what the participant was talking about and to clarify meaning. There was no variation in data collection as presented in Chapter 3.

There was one unusual circumstance that appeared while doing the interview with one of the participants. As she was describing her credentials and experiences, she reported that she had a Master’s in Education and was a special education teacher and a

school social worker. However, she reported she had never done trauma therapy with an adult with ID and felt she fit in with the group of participants who did not have experience working with people with ID. I classified her as a participant without experience working with people with ID. She stated, “But I have not had an adult with ID to do trauma therapy with.” She went on to report:

And then I have a Master's in Education. I was a special education teacher. And at the time when I was doing that, the label was more moderate developmentally disabled... was the label, and I had a lot of kids with Down syndrome, as well. Loved them all. Even though working as a school social worker... your goal is... you are kind of to triage the kid. Solution-based type of counseling and get them back to class. Provide any resources needed with the family. Heavily on getting therapy outside.

Data Analysis

The data analysis process started as soon as I arrived at the participant’s office or when the participant arrived at my office. Field notes were used to describe the office settings and observations throughout the interviews, and to document my thoughts after each interview. Staying with van Manen’s (2014) approach to hermeneutic phenomenological inquiry, coding was not used except for identifying each participant. Each participant’s code started with the letter P for participant. The participant’s code included a number for the order in which the interviews were conducted, the first initial of the first name, and a number for the order of when the interview was conducted.

Wholistic Reading Approach

During the transcription of the recorded interviews, I immersed myself in each, listening to it over and over, and I found myself stating “this is good,” “this is bad,” and

“this is ugly.” I then listened to each of the taped interviews, reading along with the typed transcriptions and keeping with van Manen’s (2014) approach to hermeneutic phenomenological inquiry. I explored insights and experiences while using a wholistic reading approach to identify general units of meaning and categorized them as the “good,” the “bad,” and the “ugly.” I also reviewed my field notes regarding the overall experience with each interview.

A theme that emerged with all participants in the “good” category of general units of meaning using the wholistic approach was their passion for the work they do. As each participant described his/her experiences, I could feel the passion, frustrations, disappointments, and gratifications illuminated throughout their interviews. Although not a theme, throughout each interview, there was a mutual exchange of information sharing about workshops, trainings, treatment approaches, job openings, and agency personnel changes.

A theme that emerged in the “bad” category of general units of meaning from a wholistic reading approach was that each participant had experienced frustration dealing with a community agency, entity, or system that denied his/her client with or without an intellectual disability, services or supports. From the “ugly” category; using a wholistic reading approach, each participant had a story of a client who had experienced trauma or PTSD or experienced stigma and stereotyping. Appendix F includes a sample of participants’ stories of clients who experienced trauma and PTSD. These samples also demonstrated some of the emotions I experienced while conducting the interviews and participant clinical interventions and outcomes.

Selective Reading Approach

I then read the transcripts using a selective reading approach to cluster interview questions together and highlight phrases and words that revealed lived experiences being described and identified relevant units and clusters of meaning and possible themes. This approach assisted with identifying demographic information and common words and phrases that led to the identification of what van Manen (2014) called essential and incidental themes. Table 2 provides an example of the selective reading approach.

Table 2

Example of Selective Reading Approach

Category	Key terms	Participant's lived experiences
Where did you go to school and why did you choose that school?	Lived there	I went to college in New York, I was living there.
	Location	I chose based on location, it was close to home.
	Family move	My husband and I made a move and moved to California.
	Convenience	That was the main reason, being a single parent. And I had 3 kids, so I choose it because it was a really convenient way for me to do it.
	Cost/ affordable	It's affordable. Because it was what I could afford.
	Quality of program	Offered Master's and also different credentials, but then in checking it, they weren't universal throughout the 50 states. They were rated highest in clinical training. An impressive program and I felt it would meet the needs of what I was looking for.

Note. All participants lived where they went to school, and none of the participants reported that they moved to a specific state to go to a specific school. Names of schools were omitted to protect the confidentiality of the participants.

Detailed Reading Approach

Finally, I numbered and read each transcribed interview line-by-line to capture expressions and experiences that let the meaning show or give itself to the text. For each sentence or phrase, I used van Manen's (2014, p. 320) suggestion to ask the question, "What may this sentence or sentence cluster reveal about the phenomenon or experience being described?" This approach brought out the essential themes to answer the research questions.

Throughout the data analysis process, the hermeneutic circle was incorporated. Bontekoe (1996) described the hermeneutic circle as a process where the researcher moved between the whole and the parts and the whole for understanding and interpretation of the phenomenon, giving meaning that was circular and iterative. The units of relevant meanings were then transitioned into clusters of meanings that were then analyzed to determine if the clusters of meaning identified essential themes of the phenomenon and research questions. This was completed for each interview, and then the themes were reviewed across interviews to identify essential themes as well as individual variations. Figure 2 illustrates the data analysis process incorporating the hermeneutic circle.

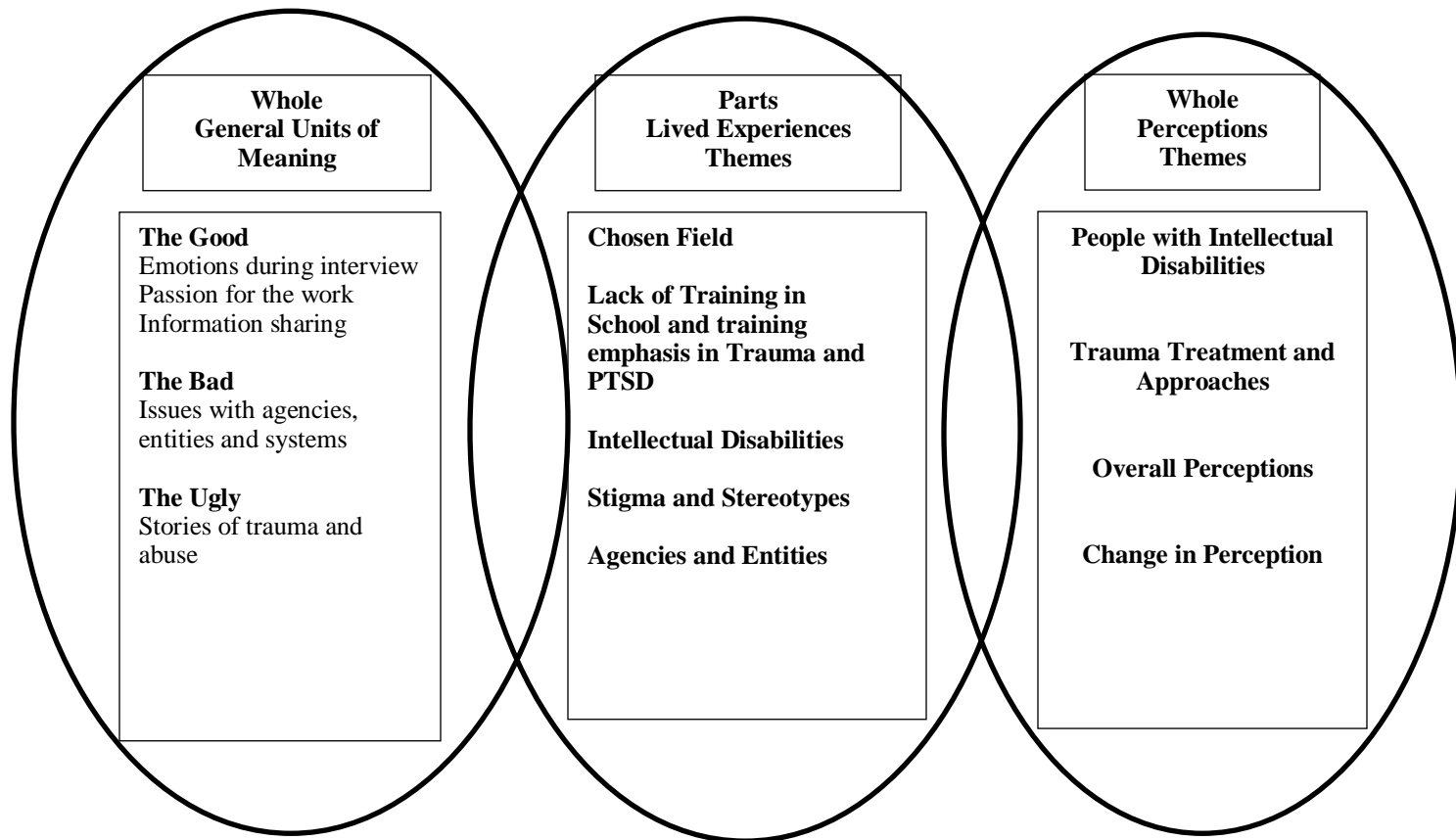


Figure 2. Data analysis process—hermeneutic circle. Reduction and self-awareness were present during the whole process.

Incidental and Essential Themes

Van Manen (1990) described incidental themes as themes that were related to the phenomenon being studied and essential themes as “aspects or qualities that make a phenomenon what it is, and without it the phenomenon could not be what it is” (p. 107). Incidental themes included choice of school, types of courses, orientation, and funding options for their clients. Essential themes identified were chosen field, lack of training, stigma and stereotypes, they’re just folks, likes us; preying on their vulnerabilities, PTSD and trauma symptoms are the same with people with ID, EMDR and the adaptive information processing theory, mindfulness interventions. There were no discrepant cases.

Theme 1: Chosen Field of Psychology

The first theme that came to light was exploring what brought the participants to choose the field of psychology and to specialize in working with people with trauma and PTSD. Other themes will be presented throughout the Results section and to support the interpretation of the findings.

P1M1: When I was in undergrad in Minnesota, I began working in respite with a child with autism, and so then I started really enjoying my work with kids with autism and so decided to pursue more experience with autism. So then I expanded to developmental disabilities in general. And during graduate school, I started to work for a company that did applied behavior analysis discrete trial training with kids with autism and learned from this, was basically like a tutor. And so I tutored kids with autism doing the discrete trial training, teaching response training, and all those types of behavioral therapies. At that time, I then decided to continue my education and ended up getting a certificate in applied behavior

analysis in addition to my social work graduate degree, clinical social work degree. um.. and then became a board certified behavior analyst.

P2K1: Yeah and a... and then working there, I really saw how many people with disabilities needed therapy services, and there was just no one who knew both mental health and DD. And so that was kind of... I felt like that was a calling for me, and so I decided to go back to school and specialize in working with people with developmental disabilities who have trauma and PTSD. It's been my calling since. I love it, absolutely love it.”

P3M2: I guess... I kind of always, um... I've always wanted to be in the field of psychology. Um... there's a huge incidence of mental illness in my family. We grew up... My great aunt had schizophrenia, she lived, and it's a... New York, in a multi-family house, and so we grew up... she lived next door, in the same building, in the next apartment. And um... so I kind of grew up first hand with what this is. You know, because a huge family has instances of it besides her as well. It's always been... what I felt was my calling in my career choice. I've flipped-flopped around inside of it for quite a while. You know...psychology, Ph.D., clinical work, research; you know and landed in this.

P4M3: Oh, gosh... I don't know if I have a story. I'm kind of like that. I had a therapist when I was a teenager who just helped me through a lot of stuff, it was kind of on and off for 10 years, and I knew when I was sixteen I wanted to be a therapist. So it was always something that I kind of knew I was going to do. I studied trauma, that was kind of my focus in grad school, and it became really apparent to me, the connection and the link between addiction and trauma.

P5L1: Well, I have a brother with intellectual disabilities and um... got involved in the field in the early 70s because of him I think. Um... and after my third child was born, I decided I wanted to try something different. So I went back to school to become a counselor. I really was not intending to do it with this population, and as I was going through school, Wow! This is a really neglected area with the people I have worked with for many years, and it was also a... an easy way to get clients cause I knew so many people, so many agencies that I had worked with privately, so I went to a local community centered board and said, "can I talk with your case managers to see if there was a need for this?" and, of course everyone said, "Oh... We don't have any therapists." So it kind of evolved from that. My passion has been people with intellectual disabilities since I was twenty.

P6L2: And, then, unfortunately... fortunately, and unfortunately, that's one of those... situations where I got pregnant as a teenager and had to start working. So ... I got a job with federal, what it is... the Government Center, doing lab work, and they had a stay-in-school kind of program. They were willing to pay for my college education to get a chemistry degree. So I could continue and have to work so many years and not ... to not pay them back. Took my first chemistry class, passed the classroom stuff, you know... flying colors, but my math sucked. And they wouldn't pay for tutoring. So they recommended that I go talk to people in human resources because I had a very psychological way of understanding thermodynamics.

P7M4: I started to look at what were the pieces that, ah... What were the trends, and what were the things that connected all of the different things that I liked, that didn't have the pieces I didn't like. And I sat with my mom and my stepfather and chatted with them about it for a long time. And one of the things I had remembered that my parents have taught me, when I asked them... What does Judaism say about heaven? They said, "Heaven is the legacy we leave behind and the way we are remembered by our loved ones and community. And we create legacy through the pursuit of justice and repairing the world." Oh, okay, so having been in therapy for years, off and on since I was eight, um... And remembering the impact that had for me...Um... I thought, well, maybe there are ways to do that and bring justice and repair to the world. And my stepfather is a social worker. He's a much different social worker than I am. He's not clinical at all, he had been administrative and ED for a nonprofit for 30 some years. So... um... he and I discussed how social work might fit for me, and um... and what were the different aspects and attributes of social work? And I decided to go into social work from a clinical lens.

P8P1: I had had EMDR as a client back in 1999 for childhood trauma. That was kind of... a whole core shift... that... yeah, probably... my own experience influenced that, but heavily, what I saw and what was needed, also these kids in school that was I working with had tons of traumas and, um... They were extremely and still are a vulnerable population. A lot of the females I saw had been raped. And then also the third piece was... I really kind of like doing this

work. I really liked kind of doing it. You can see real thoughts here. Wow. With brain based stuff.

Evidence of Trustworthiness

Guba and Lincoln (1994) developed their own criteria for trustworthiness to include credibility, transferability, dependability, and confirmability (p. 280). I used various strategies and approaches to heighten rigor and trustworthiness, including member checking, thick rich descriptions, triangulation, and reflexivity. Prior to starting the interviews, each participant was asked to answer the following question to promote trustworthiness. Each participant answered “true” to the question:

For the purpose of trustworthiness, validity, and possible conflict of interest, please answer the following question before the interview takes place. As the researcher, I have no affiliation with you or your business; between us, we have no clients or business affiliations in common. True or false?

Credibility is determined by how believable the study is (Patton, 1999).

Throughout Chapter 4, I have provided rich, thick descriptions of the participants’ lived experiences by the data gathering and process of analysis. Each participant was provided a copy of the transcribed verbatim interview and given the opportunity to comment and elaborate on his/her original statements related to his/her perceptions of trauma treatment for people with ID. None of the participants made any changes to their transcribed interviews. I was also reflective in stating my own personal experiential presumptions, understandings, and biases related to the study in Chapter 3. Multiple data moments were used across participants’ interviews along with my field notes and my position as the researcher as a form of triangulation in regard to using the hermeneutic circle and the

whole, part, whole process to generate themes, understanding, and meaning regarding the participants' perceptions of trauma treatment for people with ID.

Transferability is different in qualitative hermeneutic phenomenological research, in that it is a form of inquiry that does not produce generalizations (van Manen, 2014). However, the rich, thick descriptions of the lived experiences of participants may provide what Stake (1995) described as naturalistic generalizations. I found this to be true when interviewing participants who had experience providing substance abuse therapy or working with the criminal population and my own experience providing substance abuse therapy and working with the criminal population. Koch (2006) acknowledged that the themes emerging from a hermeneutic experience may not be the same for the researcher and readers, nor be in agreement regarding the researcher's findings, but the reader should be able to track the way the researcher came to it. I used an interview protocol, and each participant was given the same interview questions. I have provided rich, thick descriptions of the lived experiences of the participants so that the reader could consider applying these experiences to his or her own circumstances.

Dependability is the qualitative counterpart to reliability and looks at the consistency of the data in regard to another researcher being able to follow the decision trail regarding the theoretical, methodological and analytical choices throughout the study and arrive at comparable, but not contradictory conclusions (Koch, 1994; Sandelowski, 1986). While the use of an independent auditor was desirable, my financial situation did not allow for this process. However, I approached the issue of dependability with identifying my biases and staying true to van Manen's hermeneutic phenomenological traditions. I described and followed the design of the study, the data gathering, and data analysis plan as outlined in Chapter 3 as a decision trail and indicated my choices for

such decisions. In Chapter 3 I stated I had planned to use the Nvivo10 software program as a project database. However, in staying with van Manen's traditional hermeneutic phenomenological inquiry, I decided to use the wholistic, selective, and detailed reading approach and used my computer highlighter function to identify themes. I enhanced dependability by keeping a password protected file as the project database which included all transcripts of tape recorded sessions. I followed the semi-structured interview protocol that provided a record of naturally occurring interactions and contributed to accuracy and consistency in the study's findings.

Confirmability lies with the researcher's own biases, experience, and training (Patton, 1999). I have disclosed my biases and experiences in the section identified as "My lifeworld experience" in Chapter 3. Lincoln (1985) suggested that confirmability was established when credibility, transferability, and dependability were achieved. I do believe that I have established credibility, transferability, and dependability.

Results

In this study, both incidental themes and essential themes emerged from the data. Some of the incidental themes of the participants' lived experiences did not shape their perception of trauma treatment for people with ID, but they were relevant to the phenomenon itself. Other incidental themes were related to essential themes. Overall, the participants' perceptions of trauma treatment for people with intellectual disabilities who have experienced trauma or PTSD were that this population does experience trauma and PTSD, and that trauma and PTSD are under recognized and underdiagnosed. All the participants agreed that there was a lack of training identifying and treating trauma and PTSD in the ID population.

Incidental Themes

The first incidental theme was illustrated in Table 2, and was identified as choice of school. The second incidental theme identified was about the type of courses the participants took for their graduate degree. This theme was relevant to the phenomenon because the data showed that only one participant had specific training and courses in trauma and PTSD in graduate school. Participant P4M3 stated, “Um... and then they also had certificate programs, so I did the trauma certificate program.” Of note, participants who were LCSW’s noted a strong emphasis in child and family courses, and participants who were LPC’s noted a strong emphasis in counseling courses such as basic counseling, group counseling, and career counseling.

Examples of incidental theme 3-participant’s therapeutic orientation are given in the demographic section of this chapter and in Table 1 and are relevant for how the participants apply trauma treatment to people who have experienced trauma and PTSD. The fourth incidental theme of type of funding options for the participant’s clients is in Table 1. This theme was relevant to the phenomenon because all four participants who had experience working with people with ID were approved behavioral providers through the Colorado Department of Developmental Disabilities, which is the only option available for therapy services other than private pay if the individual does not have Medicaid and a targeted mental health diagnosis.

Essential Themes

Essential themes are “aspects or qualities that make a phenomenon what it is and without it the phenomenon could not be what it is” (van Manen, 2014, p. 107). Essential themes that emerged from the data were chosen field of psychology, lack of training, stigma and stereotypes, they’re folks, like us, preying on their vulnerabilities, PTSD and

trauma symptoms are the same with people with ID, EMDR and the adaptive information processing theory, mindfulness interventions, and overall perceptions of trauma treatment for people with ID who have experienced trauma and PTSD.

Theme 1: Chosen Field of Psychology

The first theme of chosen field of psychology has already been presented in the data analysis section and is essential because it showed how the participants' lived experiences guided them to specialize in treating trauma and PTSD. One participant had her own childhood trauma; two participants experienced therapy when they were young; two participants had a family member with either a mental illness or an intellectual disability; another participant saw a need and had a calling; another enjoyed her work with children with autism; and another used his faith and parental guidance to choose his path in psychology.

Theme 2: Lack of Training

Theme two evolved through several of the interview questions related to the participants' training during graduate school in intellectual disabilities and training in trauma and PTSD, and other avenues the participants took to obtain their specialization in treating trauma and PTSD. All participants were asked how much emphasis was placed on people with intellectual disabilities during their graduate studies, and all but one participant stated, "None, not much, a mention, very little, or limited." The one participant (P1M1) who did state she had a lot of training in intellectual disabilities clarified her response by stating,

"I guess in applied behavior analysis, a lot, because it was mostly, mostly autism. I would say, and then, in my graduate degree work, in my clinical social work. Not a lot. It was more mental health. This was not as interesting to me."

When asked about how much emphasis was placed on people with ID who had mental health issues, all the participants stated none. Participant P8P1 stated, “Oh, none, no, those were seen as two separate things. You couldn't have both.” Participant P2K1 stated, “Oh none, none, because they are retarded. I mean... you know... because that is the disability, so they don't have mental health issues.” When the participants were asked why they thought there was no emphasis on ID during their studies, several of the responses by both participants with and without experience with ID were essential to the theme.

P2K1a: You know... I think it is a lack of knowledge. I also think its society not recognizing the needs of people with disabilities. I mean...I think we've come a long ways with the deinstitutionalization, but I also think that there still is a mindset, everything is with their disability. That there's no... They can't have a dual diagnosis with anything. Which is completely untrue.

P3M2a: I do not think people really recognize that the two are combined and can be, sometimes in my experience, interchangeable and very confusing. So I don't think a lot of people recognize that there could be a combination. At least in the general public. Not obvious to some of the people I work with.

P4M3b: You know... I don't know, it's... may...you know... Maybe it is a difficult subject for people. I don't understand why they... it's like the stigma in... In the everyday world also permeates, you would think mental health professionals are clinical and are above that, but we're not.

P6L2b: The instructors didn't have the expertise, the comprehensive understanding of dual diagnosis back there... that didn't even exist. Um...And there were very few instructors that seemed to really care about us being, becoming comprehensive clinicians.

P7M4b: I think the social work program; my impression is that the social work programs try to jam in way too much information in the time they have. And so, too many essential things go by the way side. And that was one of them.

All the participants were also asked how much emphasis was placed on trauma and PTSD during their graduate school training. Some participants had more training than others. All the participants' responses were essential to the theme. Participant P8P1b stated, "Not much, not much. Although, in the play therapy, quite a bit. But again, that was dealing with kids that were in the system... foster care, that kind of thing." Participant P1M1a stated, "Not much, very little, I mean a little, but it's not a lot, we did learn a little about empathizing and starting where the client is., but that's about it. Just in the beginning. Symptoms of it." Participants P7M4b and P6L2b stated, "Very little." Participant P5L1a stated, "Boy... I just don't remember much at all. I really don't. And that was early 90s so, you know, when we heard about it, very little, very little was mentioned." The participants who had more training in trauma and PTSD during their graduate studies discussed their lived experiences.

P2K1a: You know, I would say that it wasn't necessarily the classes that were trauma focused, but the professors that I had, who would guide us towards that specific issue. Um...but I don't think it was a primary focus in, in all the education. I think the most effect of trauma was from my group therapy teacher,

who had a private practice and was, and taught as well, and she dealt with a lot with trauma, and so she brought that into that classroom. This actually is very interesting now that I think about that. I don't think there was really, and we didn't really have any specific trauma courses. Which is huge. That's very interesting actually now that I am thinking about it.

P3M2a: Actually, a great deal. I think it was really kind of highlighted and you have to, you have to keep trauma in mind in like everyone. You know, in every category in every client, you know, that should be... that was really stressed that it needs to be part of your conceptualization of them. You know, what kind of trauma background they have and what role does it play in their symptoms now. Yeah. I feel like it was new. It was kind of, you know, the theory... the understanding from school was, this is not how we have always looked at it, but this is the new way to go and this is how... you know, you should think of it going forward. I didn't get the feeling that they've always done it that way.

P4M3b: Because I was on the trauma certificate program, I had more than... than most people. Since I left school, I've done a lot of work supervising a lot of interns from that school. And they've completely changed it. They don't have the certificate on trauma anymore. All of their classes are trauma informed. Which is very cool to me. That was not how it was when I was there.

The participants were then asked how they obtained their knowledge in trauma and PTSD, and all the participants reported they took workshops, attended conferences, read books, and watched videos and webinars on their own. Some of the participants added understanding and meaning to why they attended trainings to specialize in trauma and PTSD.

P2K1a: Great question. So I started in my internship. I worked at a Family Center, providing therapy to kids and families that were victims of domestic violence. And again, saw a ton of trauma from these kiddos who didn't understand what they were witnessing, and how and nor did the parents understand how it was affecting them. So I started doing trainings with my internship, and then I went to work at a community mental health center, and I would say 50% of the people that I was working with there were trauma, strict, just straight trauma. And so throughout that I started to take individual courses in trauma and PTSD and mindfulness.

P3M2a: Actually one of my instructors in... I think it was in my trauma class or practicum... One of the last few classes, she said, you know... graduate work is just your foundations and this is not the end of your learning and this does not prepare you to specialize and this gives you a broad base. And so go out and do the specialization. You know... training, certificates, and workshops and whatever you need to do. And I think that really hit home with the suicide risk assessment and you don't get too much of that.”

P4M3b: Well, and then my EMDR training, too, I just... the couple of classes I had specific to trauma and then it being intertwined in the addiction world and... With most of my background being co-occurring... my internship was at a halfway house which is chronic mental illness plus severe addiction and 99.9 % of those guys have huge histories of trauma. So I just... I saw the practical application of it. Most of my clients in my whole career have had serious, you know, child abuse, sexual abuse, all kinds of things, not to mention, you know,

when working with the prison system, if they weren't traumatized before, they are when they get in there.

L5L1a: Well it just sort of came up, a need realizing... when I first started my practice, I had read an article that 80% of people with ID had experienced some kind of abuse. And I didn't believe it. So the first three years I tracked it and it came out 90% of the people I served. So it made me start thinking about, this is posttraumatic stress that we were seeing, and I then... was sort of would... like..., Wow, this is the same thing that is happening to our vets, and I started reading about it. I went to some workshops on it. I never really changed the way I had planned to see clients.

Theme 3: Stigma and Stereotypes

Theme three evolved through the interview question of what kind of stigma or stereotypes do people with ID experience and then the follow-up question regarded stigma and stereotypes with accessing mental health services. Diagnostic overshadowing and community mental health systems not being able to meet the needs of people with ID were central to this theme. Another area that identified lived experiences of stigma and stereotyping by the participants was when they were asked to tell a story of an experience they had with a person with ID. The results indicated that participants who had experience working with people with ID had lived the stigma and stereotyping with their clients, and the participants who did not have experience working with people with ID discussed their assumptions. My field notes noted that some of the participants without experience working with people with ID seemed hesitant to say certain words that defined stigma and stereotyping. The following examples described the participants' lived experiences.

P1M1a: I would say they... they... in the community... probably discrimination with people in public that don't understand that they have a disability. Especially my higher functioning ones, that don't physically look like they have a disability, but definitely have a cognitive disability, they seem to be probably discriminated against the most, in my experience, just because they're not physically looking like they have a disability. In my experience, the mental health system does not meet their needs.

P2K1a: Oh, honey... You know... I feel that... probably the biggest stigma is that there's something wrong with them and people don't want to be around them. Or... they treat them like children. I think those are probably the two biggest things. They don't know how to react, and so they either like, "Oh, my god, Stay away", or they're like, "Oh, hi, little baby," and they kind of baby talk and do the child thing. And neither of those things is correct. In the mental health system... Oh, they can't... And so... someone will go in a community mental health center, and they will need meds. And they will determine they can't get therapy, so they will refuse to do meds. And so then they call me... Ah... no! They are a Medicaid provider; they cannot refuse to provide psychotropic medication. So this is who you call, and this is how you do a grievance, and this is how you get back in. So then they will end up going there and come to me for therapy because they will deny them therapy.

P3M2a: You know... even from the clients themselves, that stigma that they are dumb, stupid, they're just not smart, they're just not as good as everyone else. In the mental health system ... I think a huge amount of therapists think that... especially CBT is too cognitive... to ... you know... too intense... can't possibly

work... or there's no point because you... this is as good as it gets kind of thing...

Um... which I think is awful.

P4M3b: I think... I mean, I think there's a lot of uneducated around people with ID. Not saying that I... I myself don't know a lot, but... I think people can look at them... I'm sure they get awful judgment, and people think they are stupid or, you know... it's even though it's surely a different way of understanding information. I can't imagine what kind of... some of the things that population goes through. In the mental health system, I would imagine that it is a very undertreated population. They think it would be easy to go right to the ID and focus on that and not focus on other things as well.

P5L1a: Where do I start? That's a barrier that we are having trouble with. Um ... I think the biggest barrier is that they cannot live normal lives, and I...I think family members still carry, promote that stigma for their own family members. In the mental health system ... Yeah, I think there is a huge stigma that it doesn't help this population. Um... that it's not available for them because of their disability.

P6L2b: Misfits... loneliness... Maybe not full-blown hopelessness, but discouraged. Well, if they're into criminal behavior... low life's, which a lot of them... make... a lot of mine, you know... some of the lower functioning, resort to crime. Um...stupid, damaged, this is kind of, sort of related, not direct, nimby, not in my back yard, go away, you know. We don't want to know anything about you. In the mental health system... no, probably not served.

P7M4b: Across the board, the greatest is on... I think the fear of the unknown, that just for the child who walks to see a child with crutches, or canes, or in a wheelchair. Any kind of assisted device, the fear of, "why is that person using

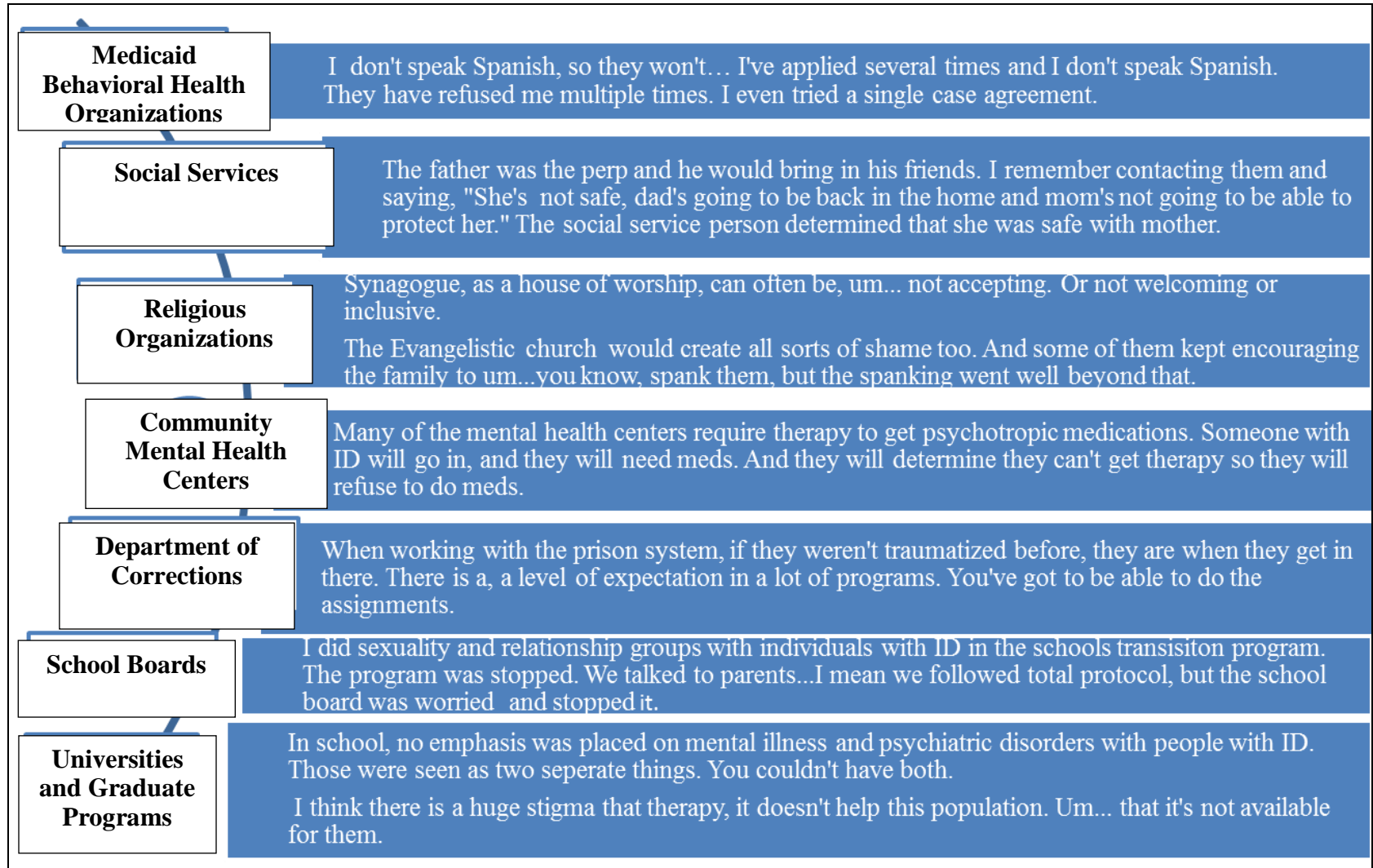
something I've never seen." Right ... is limiting and distancing. One in particular... synagogue, as a house of worship, can often be, um... not accepting. Or not welcoming... inclusive of a lot of young children who don't behave as the very serious adult would want them to. In the mental health system.... Well, that's interesting. I think one of them is that I've experienced myself, and I've discussed with colleagues. Who am I to treat somebody with a cognitive difference, intellectual disability, and delay... whatever? Do I have the capacity to serve them in the way that I want to? Do they have the capacity to get out of this what I would otherwise want them to, or otherwise neurotypical clients might? So it kind of shuts off the prospect of healing, but causes a notion that... that person may not have the cognitive capacity to deeply engage in the work.

P8P1b: Well, I can speak from my observation, but if it seems obvious that they're impaired by... let's say in a supermarket, and maybe the social skills are of... or they bumped into... you know... something that is away from whatever we call the norm from it. I think they can get a lot of looks and stares and with that comes a lot of judgment. Um ... I have certainly observed where they are not helped, maybe by a clerk right away. What I have experienced was everything as I said, from bullying or beaten by their parents. If they were the family... was ruined by the scales of the evangelistic church. The church would create all sorts of shame, too. And some of them kept encouraging the family to um...you know, spank them, but the spanking went well beyond that. In the mental health system, no, I don't think their needs would be met. Now they may have experienced a lot of stigma, during the intake process. They may have been put in the back line and that kind of thing. However, I did find... I did find that, unless they were with the

right therapist that really did understand the dual diagnosis, their needs weren't met.

All the participants noted some type of stigma or stereotyped experience with people with ID when working with government or nongovernment entities. Figure 3 describes these lived experiences.

Figure 3 - Stigma and stereotypes for people with ID – Participants' lived experiences of agencies and other entities



Theme 4 –They’re Just Folks, Like us.

Theme four evolved from asking all the participants to describe a person with intellectual disabilities, including where they live and what they do. Three participants, two with experience working with people with ID and one without, used the word folks when describing people with ID. Two participants used words such as wide range or spectrum of abilities. Two participants reported that people with ID were born with it or that ID was genetic, and one participant did not like the word disability and used the word neurotypical to differentiate an average person to a person with ID. Other words used to describe a person with ID were, “a different way of processing,” or “taking more time to for things.” Only one participant identified psychometric measures to describe a person with ID, but in the next sentence described people with ID as folks. I was surprised that only one participant without experience working with people with ID used the term psychometric measures, as one of my assumptions was that those participants without experience would describe people with ID with psychometric or in clinical terms. The participants with experience working with people with ID knew the terminology of the intellectual disability system, the agencies that provided residential and day program service, and the interdisciplinary team model that the Colorado DDD system uses.

All participants were also asked to describe an experience they had with a person with ID. The participants with experience working with people with ID described stories of their therapy clients, and the participants who did not have experience working with people with ID seemed surprised (according to my field notes) that they had an experience with a person with ID. One participant had a best friend with a brother with Down syndrome, another experienced several children with autism at a summer camp,

another had a neighbor who had a child with intellectual disabilities, and another believed she was working with an individual with ID now but did not have formal documentation. Due to the rich, thick descriptions of the participants' stories, I have put them in Appendix F. Participants were also asked to describe a person with ID.

P1M1a: I would say that, it's just, it's a range of different abilities and sometimes there's a lot of splinter skills, which means that, a lot of individuals can be extremely well versed and be able to communicate their thoughts and feelings and emotions and participate in therapy, and some are nonverbal, some are able to function pretty independently, live on their own. Some need full assistance. I would say just, I mean, intellectual disability is generally a cognitive deficit, but I think there are so many different ranges of individuals, I have some on my caseload, I wouldn't believe how they have a cognitive disability. Others, I like, I get very confused on how much they are reciprocating, you know... receptively understand what I am saying. So it's just... every individual varies.

P2K1a: You know, I think everyone could be considered to have a disability because we all have struggles, you know, none of us are 100% at everything. And so that is kind of how I go about doing it, is that we all have disabilities, in the fact that, whether they are medical, behavioral, or mental. We all struggle with things in our lives. And I think making it more like kind of normalized helps folks see that. Good questions. Well, they can live in many different arenas, they can do a host home, they can do independent living in an apartment, they can have roommates, they can live with families... they can live in a group home... 3bed PCAs. Um...and I think it is really just based on their needs of how much support

they require. They go to day program or work. Yeah, although that has been an interesting turn of events with the state, as far as deciding that they are closing down workshops, and they must... after 5 years, get a job in the community. And I think that is difficult for some of our folks. You know, some of our folks... they enjoy doing the little bit of work they have, in kind of a work shop center, and they do not want anything more. And they are functioning enough that they can make that decision. But then, it is going to be taken away from them eventually.

P3M2a: They might just take an extra couple of minutes for things, you know.

They might have a little bit different way of understanding or looking at the world. They live everywhere. They are everywhere. And I think there is a wide range... I've had quite a few clients that are very highly functioning, and they are on that, I guess the borderline level, you would call it. Um... but they are employed, and they are self-sufficient and... Those that are not going to be employed, you know, 40 hours a week, they will have to have accommodations at work, and it will have to be a short day. Um... and they will need supplemental income.

P4L1Lb: It could be, I guess, organic in terms of genetic or injury. It could be organic in terms of um...tissue damage from substance abuse. There's such a large spectrum, that I'll have to answer that... they... they are all of us, and they are everywhere, and we are everywhere.

P5L1a: Individuals who have challenges cognitively. Um... and, sometimes, behaviorally, ah... but folks who are very capable of working through some of those challenges. They live in host homes, they live in their own homes, and they

live with family. Um...sometimes they are married and live independently, and they go to work, they go to day program, they go to dances, they go to church, they...um... go in their community, coffee shops.

P6M3b: Gosh, I don't know. I... you know, my concept of... you know... ID is somebody that has been born or had it... or born with it or had a... you know a TBI or something like that. Where it is a different way of processing information. I mean, I think it's... I would... I assume... there's a spectrum. I mean... sure, some live on their own...you know, can be very high functioning. I'm sure some with families and other live in... in centers, treatment centers.

P7M4b: I inherently struggle with the word disability. And, at the same time, other languages like differently abled. Too clunky, you know, it isn't pragmatic. It's as much about seeing and operating in the world differently. Right... where you're uniquely, than, neurotypical individuals might learn to function in the world.

P8P1b: Well... I would say that they are human beings like the rest of us. They learn differently. Certainly when measured, psychometrically, they look different. And many depending on their level of intellectual disability are much more concrete than others. But, they're folks, you know, they're just folks, like us, and um... we're just lucky to have them in the world.

A series of questions about what types of trauma people with ID experience, trauma and PTSD symptomology, theories of PTSD, and treatment interventions were discussed. Several themes emerged from these conversations.

Theme 5: Preying on Their Vulnerabilities

All the participants were asked what types of traumas do people with ID experience, and the most mentioned trauma was sexual abuse, followed by physical and emotional abuse. Participants with experience with people with ID mentioned situations that some might not think of being traumatic such as, being taking advantage of, being vulnerable in the community, bullying, and loss.

P3M2a: Oh, goodness... I think a lot of... like the story I was telling you before... a lot of being taken advantage of...being manipulated...being probably sexually abused. I've seen that... a great deal... and just used... I mean like, for crimes or for this or for that. Stealing their checks... you know what I mean... preying on their innocence.

P7M4b: Well, I think there are the...micro traumas and little “t” traumas and the everyday experience of um... limited access, um... limited engagement with community and... Blatant exclusion. Um... and also, the higher rate of severe, intense chronic big “T” traumas. You know, ah... a nonverbal child is more likely to be a target of a perpetrator or a predator because he/she is less likely to report verbally.

P5L1a: Yeah, the change in staff is huge. It's huge. The loss ... that... that whole... the trauma around loss, because they are continually experiencing that. Continually... because of staff turnover. That is what happens. And they get very attached to those... the van drivers. I can't tell you how many of my clients love that person who picks them up every morning and takes them home every day.

Theme 6: PTSD and Trauma Symptoms are the Same with People with ID

All eight participants stated that trauma symptoms would look the same or be similar in a person with ID, but the participants who had experience working with people with ID who had trauma and PTSD elaborated more on what the symptoms could look like. Three participants mentioned how hallucinations could be misdiagnosed as psychotic symptoms and could be flashbacks or dissociation related to PTSD.

P1M1a: I think like, if persons have experienced a lot of trauma, they could potentially lash out if they are put in a situation that feels the same as when they were bullied, or if they were sexually abused, then they would lash out and kind of, kind of think about that experience. They have a lot of difficulty verbalizing what happened, or verbalizing that it even is trauma. And kind of acknowledging that, but I am sure that they have physical symptoms if they are placed in situations that are uncomfortable or difficult, I sure the physical symptoms come right back.

P2K1a: Well, I think they are similar to anyone, but I think... you know ... isolation, I think um...I think they have the same physical symptoms around, they can wet the bed, no matter what age. Well something is triggering that trauma... um... I think they can tell us... I think they can say, "Hey, this happened to me." We see behaviors from it. We see... anger, we see... physical aggression. We see... um...Yeah, I mean... yeah... I think the flashbacks sometimes may look... I don't know that someone who doesn't know the population may see them more as hallucinations versus flashbacks. I've run into that because that is just how

they're... they're sure how to describe what is going on for them, but absolutely I've seen flashbacks.

P3M2a: Um... you know I think... what I've seen... and I don't know... and this is based on my clients. They kind of look similar, but... it's not as much that it's intellectualizing... it's more of... I've seen a lot of that feeling symptoms... and the anxiety where the out-of-control emotions... and not a lot of hope that they can... handle it... or get a handle on it or control it... or um... a lot, you know... this happened... you know... that's my fault because I'm stupid and just kind of internalizing it that way... and not seeing it.

P4M3b: I would imagine they would look the same, but I would also imagine that they would go unnoticed because they would be attributed to the ID and not PTSD. For some... I would think... I mean, I don't know. I would imagine they would look the same.

P5L1b: The same kind as anybody else, and that includes all the above, anything and all the above. Every now and then, even these 30 some years, I hate this... but there may be... you know... twist and turns that are new, you know, that it's like... Wow! I wish I didn't hear that. You know... And even a lot of the psychotic stuff that I've... you know... the clients that have opened up a little bit more about their auditory hallucinations and then... as well as some of the visual ones, are so theme based. Um... and so connected with these early trauma things... this makes all the sense in the world. You know... maybe it's not a psychotic disorder at all. It could be PTSD with dissociation or flashbacks.

P6L2a: Oh... Sleep disorders, eating disorders, anxiety, anger, aggressions, depressions are huge...depression is a big one. I'm not sure about what you want. Oh... Physical illness, clearly somatic... somatic complaints...I have not seen the dissociation kind of part, but clearly dreams, nightmares.

P7M4b: In some ways, I think they would show up similarly. I think it is important, you know... look for the common, and... And a lot of ways, they are going to be much more subtle. They may be more hidden where somebody with an intellectual disability... might feel more shame and want to hide.

P8P1b: Um... Sometimes they looked a little like anyone else. Other times... let's say, like that hyperarousal piece of PTSD would be more exaggerated. The jumpiness would, you know... it would be in yelps, and screams, and upset, maybe they would try to hit somebody that was behind them, it was just an innocent kind of thing. Um...I remember one kid whose flashbacks were just a nightmare and happening kind of all the time, nonstop throughout the day. So he had the PTSD. I suspect there was more comorbidity. There was something else because he couldn't turn and walk. So maybe that was the piece of psychosis, and maybe some PTSD symptoms can be so big and hard that they can look like a psychosis and feel like one ... to that.

Theme 7: EMDR and the Adaptive Information Processing Theory

All four of the participants who were trained in EMDR mentioned Shapiro's adaptive information processing theory as part of their orientation to treat trauma and PTSD. All the participants were aware of EMDR therapy and agreed that EMDR therapy would benefit people with ID who have experienced trauma and PTSD.

P8P1b: The EMDR piece that attracted me was that you drill them deep... it can get hard, and you're processing this stuff... but you have plenty of opportunity to bring it back to resourcing and back to the safe place. But at the end of the day, they end up with a positive cognition about themselves. And they have created this new neuro network, and I guess... I'm grateful that years and years ago, that I had it because, otherwise I might... kind of be left with wondering, well they're looking good... but is it really gone? And is it really not going to come back? I don't know about you, but I get those kinds of questions.

P4M3b: When there's, like for me, EMDR is a very kind of... I love it because it is a very tangible thing to do. Um... and we can adapt the EMDR protocol to anything, and so... you know, it makes sense to have EMDR... would be... be a good. I think it would be a very good intervention as long as you had the right language with it.”

One participant with experience working with people with ID stated, “I don't do EMDR, but, I... you know. I will send my clients off to people who do. Because I think it can be really helpful.” One participant mentioned schema theory as part of her orientation to treat trauma, and another participant mentioned Foa's fear network and flooding approach.

P5L1b: Um... I... I'm not so sure... you know... where to put myself in any of those things, but what I believe is that... as we are going up, and the limited cognition that we have, we do the best with what we have. And in the process, we have incomplete conclusions in the life span sense. But at the time, that stuff

works, but if it becomes habituated, and a lot of the schemas that seem to be enduring, become habituated.

P1M1a: To work on those types of therapies and kind of like bring the client back into that traumatic experience and trying to, basically, almost like force them to acceptance... of like this did happen and kind of reliving it and talking about those kind of feelings and thought and everything, physiologically what is happening to them, physically, and trying to relive the trauma, almost like the flooding perspective, but just flooding in terms, in the therapeutic session, flooding and trying to say like, okay this is what you experienced, what are you seeing, tell me in your mind, like what was going on in your head, what are you talking about, what are you feeling, seeing, what are you smelling and trying to relive and then place a different emphasis on, okay, so how can you change your physiological response now when you think about this traumatic experience?

Theme 8: Mindfulness Interventions

The participants were asked what approaches they use to treat trauma and PTSD and how they would modify these approaches. All the participants mentioned using some kind of grounding, self-soothing, stabilization, resourcing, or coping tools before they start processing traumatic memories. All the participants mentioned mindfulness interventions as a coping strategy. Three of the participants discussed establishing the relationship and developing trust before starting the trauma work.

P1M1a: It's basically trying to accept thought processes. Like that's okay, you're supposed to kind of simplify yourself and look at yourself and say, okay, in that situation, what I was feeling anxious. What was I feeling anxious about? What did

that feel like, what did that look like, and what is that related to? So it's almost like taking a step back and look at yourself from the external perspective and say, you know. Hey, what is really going on?

P2K1a: Um... you know, depending on the level of trauma, I go with; I'll even start out with play. I'll do a lot of play or art because a lot of times, no matter what age someone is, or their disability, talking is very difficult. Um... and so I'll start out with either play or art or seeing under... It's hard for our folks to...be in that movement of the trauma, and so... you have to do it step-by-step. You know, you get them to express it through something else, and so I think it's just their level of understanding and what can I use with this particular... type of... and using with them. I think mindfulness is a great technique to work with our folks.

P3M2a: I think, you know, modified CBT would probably be the best way to call it. Depending on their symptoms. I... like I've had clients where they really do need to do some mindfulness, do some grounding work, basic, basic, um...you know anxiety, coping skills before they can even... you know....they need to have symptom reduction. Yeah, like the resourcing. Um...and then I think... once they get into it more, once they have that down, or if they're further along on their path. Um... a lot of DBT, I think it works great with it because it truly is that they have these beliefs you know about themselves, about this trauma. And then, I think, my own practice has been when, when that has taken them as far as they can go... or that's just not cutting it for that client, I will use EMDR.

P4M3b: DBT kind of informed, I don't do the traditional DBT. Um ... A lot of... I just say trauma informed treatment, so a lot of kind of... stuff to calm the brain down. Which... which could fall under EMDR. A lot of mindfulness, a lot of kind of grounding work.

P5L1b: Because I think that my success has been primarily based on rapport and therapeutic relationship. And then once that is established, it's a lot easier applying CBT. And in terms of maybe...strengthening the client, um... with some skills and strategies and tools to cope... and that kind of minimizing... some of the daily on-going stress interferes with life functioning, mostly on an emotional basis. And then, the rapport's strong, clients have got... you know... an adequate skill base that they've practiced for a while. And then the core issues can be addressed.

P6L2b: First, we look at stabilizing; build the trust and stabilizing and doing some soft stabilizing stuff. You know, I do tracking. Let's talk about how you physically feel when you're feeling the affect from this trauma. And let's talk about how you feel when you're not, you know, and let's compare those. What does it feel like when you're tense versus when you're relaxed and not thinking about the trauma? Looking at the sensory. We talk a lot about sensory. You know, are there smells that set things off? How do you feel about touch? Doing narratives. And then talking about really good positive experiences and what that feels like and how can you get to that place. We do a lot of that framework before we actually really get into that, you know, talking more about what happened. Mindfulness, all the mindfulness.

P7M4b: I think that, for me, most of, it shows up as helping people recognize and access, and then, regulate, stay grounded, through the emergence of the trauma in our work and then also through the attachment work.

P8P1b: I would stick to the protocol, but modifying it according to the disability and where they're at within it. And knowing that, the modification isn't just because of the disability, but how that trauma has affected it. I mean, we know a lot of kids that have learning disabilities that have, you know, normal full scales, and miss a whole lot along the lines because of trauma.

The four participants who did not have ID experience working were asked if they would treat people with ID who had trauma and PTSD. One participant stated he would not treat a person with ID who had trauma and PTSD and elaborated on his decision. Another participant explained that she would work with people with ID, but her current contract has expectations and she did not feel she had the resources to work with a person with ID. The other two participants would work with people with ID, but wanted to know more and have more training.

P1M1a: Yeah, I would say that if I felt like cognitively they were able to work through some of those and they were able to, you know... depending on their cognitive abilities, I would definitely, I mean, if then if something surfaced, I would probably refer them to someone that had more experience in trauma.

P2K1a: You know... I find... I feel gratified in helping people grow and learn about themselves. And I think that there's even more gratification seeing someone with a disability work through issues, that people pushed them to the side for

years, and years, and years. And so I'd... and so ... just the little steps forward that they make... I think is awesome.

P3M2a: I don't know... I mean...it's just one of those things... why not work with someone who needs it and can benefit... you know... Yeah... I don't...I don't understand how some therapists... I'm mean... I get the idea of specializing, but there's a difference between specializing and excluding... you know.

P4M4b: I would want to, but I would also not want to practice outside of my scope. I wouldn't know.... thinking there's so much I didn't know. I don't know. Um...Now I want to know more.

P5L1b: Absolutely, yeah... I get a lot of those.

P6L2b: I wouldn't be able to do it because I don't have the resources. Um... and there is a... a level of expectation in a lot of programs. You've got to read this stuff. You've got to be able to comprehend it. You know... and you've got to be able to do the assignments. Write them. You've got to be able to share. You know these kinds of things in the group exercise.

P7M4b: I probably would not, because I have to ask myself, is the client going to be able to get out of this what they are looking for in the way I do therapy? And am I going to be able to be the therapist I want to be for this client?

P8P1b: Yes, yes I would. Um ... first take lots and lots of good history. I wouldn't just get it through them alone. I would find a parent, a caregiver... looking for one that might be as objective as we could. Um ... so I would try and get that history and find out when the traumas happened. I would look at... okay, this possibly happened at this age or earlier on, then I know it's going to be bigger. I know that

there might be a chance that there's even splits in their... as well. Because certainly they can split.

Clinicians' Perceptions of Trauma Treatment for People with ID

To close the interviews, each participant was asked his/her overall perception of trauma treatment for people with ID. All of them voiced that people with ID can do trauma therapy, that it is under recognized, and that therapists are not trained to serve this population. One participant stated, "I think it is a responsibility of the community that is not being met." Another participant stated, "I think it is very limited. I think that the people who do it and know the systems are great, but I don't think there are a lot of resources for people to access to receive the treatment they need." The participants were also asked if their perception had changed since the start of the interview. The four participants who had experience working with people with ID reported that it did not change because they were already aware of trauma in this population, and they do trauma treatment with people with ID, but one participant stated, "I think, also knowing that there is not a lot of research out there, and, you know, I think there needs to be more." The four participants who did not have experience working with people with ID had a change in perception, and all but one participant stated that they would work with the ID population, and one of them commented:

I'm so proud of being a social worker. I love that title, and so much of that is recognizing marginalized populations, and we talk, you know... in school with colleagues... we talk about minorities of race and religion and... economic status... all these groups, and ID is never... is not one of those that we talk about,

and that's a little shameful to us... to us, I think. I think that it's something that...needs to be talked about more.

Another participant summed up his experience with the interview by stating:

It's interesting that I noticed that I have had several moments of guilt or shame for not being, um... a direct provider. Um...I've also um... had, as I have had very often, recurring anger that I no longer can see Medicaid clients, unless I'm a Medicaid provider. Even pro bono. I would gladly... but it... through this conversation it occurs to me, um... the injustice of the lack of access, the poor access, the poor needs assessment. Um... the failure of the community to provide.

The Phenomenon

Van Manen's hermeneutic phenomenology was based on everyday practice and the understanding of human beings in their life worlds. For this study, the phenomenon was based on the participants' lived experiences and their everyday work as private practice clinicians' treating people with trauma and PTSD. Four of the participants had experience working with people with ID who have experienced trauma and PTSD and four participants who did not have this experience. This study generated incidental themes and essential themes. Van Manen (1990) described incidental themes as themes that were related to the phenomenon being studied and essential themes as "aspects or qualities that make a phenomenon what it is, and without it the phenomenon could not be what it is" (p. 107).

The incidental themes of school choice, courses taken in their graduate studies, their therapeutic orientation, and the funding options they provide for their clients, set the stage and described who these participants were as private-practice clinicians. The terms

phenomenology and experience from van Manen's perspective are the same thing; he defined description as a combination of description and interpretation to "show how our words, concepts, and theories shape and give structure to our experiences as we live them" (van Manen, 2014, p. 58).

Eight essential themes emerged from the semi-structured interviews with the participants. The first theme of chosen field explored how the experiences of the participants guided them to specialize in treating people with trauma and PTSD, whether it was due to previous childhood trauma, being in therapy when young, having a sibling with an ID or mental illness, having a calling and seeing a need, or using their faith and parental guidance to choose the field of psychology.

All the participants acknowledged no or very little exposure to training in intellectual disabilities or PTSD in their graduate studies and the need for this discussion at the graduate level, which led to the emergence of theme two – lack of training. All the participants sought advanced training in trauma and PTSD, but only one participant sought behavior analysis for advanced training in autism and intellectual disabilities. Three of the participants without experience working with ID stated they would take advanced training on people with ID and mental health issues. Theme three (stigma and stereotypes) emerged from the participants' experiences with government and non-government entities and getting access to services for their clients. The participants expressed true emotion and passion when discussing stigma and stereotyping. All the participants acknowledged that people with ID who have experience with trauma and PTSD were underserved and diagnostically overshadowed by their ID.

None of the participants used psychometric or clinical terms to describe a person with ID, thus, emerged the fourth theme – they're just folks, like us. To the surprise of the participants who did not have experience working with people with ID, they were able to identify encounters and lived experiences with a person with ID, whether this was at a summer camp with children with autism, a best friend's brother, a neighbor, or the possibility of a current client having ID.

The final four themes emerged through a series of questions that highlighted the participants' clinical lived experiences treating people with trauma and PTSD. Theme five (preying on their vulnerabilities) emerged when all of the participants identified sexual abuse as the most common type of trauma they encountered in their work, followed by physical abuse and emotional abuse. Participants who worked with people with ID noted other situations that some might not consider traumatic such as being taken advantage of, being vulnerable in the community, bullying, and loss.

All the participants agreed that trauma and PTSD symptoms would be the same or similar to people of the average population, although participants with ID experience noted subtle differences that could be misdiagnosed as challenging behaviors or psychosis. The only theory of PTSD that was prevalent was Shapiro's adaptive information processing theory and EMDR. All the participants, whether trained in EMDR or not, agreed that EMDR would be beneficial for people with ID who have experienced trauma and PTSD. Finally, all the participants stated they taught mindfulness exercises to trauma clients as a self-soothing and regulating intervention.

Overall, the incidental and essential themes generated awareness and opportunity. Perceptions of the participants who had ID experience did not change, but they

acknowledged more work needs to be done and there is a need for more resources for people with ID to access for their treatment needs and to heal from trauma and PTSD. The perceptions of the participants without ID experience did change, recognizing that they could provide therapy for people with ID, and just having the conversation about their perceptions of trauma treatment with people with ID gave them a better understanding of their needs and new meaning to their own abilities as clinicians. Three out of four of the participants stated they would work with people with ID, and the one participant who noted he would not work with the ID population also acknowledge that the conversation did bring up some feelings of guilt and shame for this decision.

Summary

Semi-structured interview questions have provided rich, thick descriptions of participants' lived experiences that have shaped their perception of trauma treatment for people with ID. The eight participants were recruited from on-line therapists' data bases, the EMDR regional data base, and the approved provider list from the Colorado Department of Developmental Disabilities. The participants were sampled purposively and by snowball sampling. The interviews were recorded digitally and transcribed verbatim and provided demographic information about the participants that was relevant to the study.

The data analysis method stayed true to van Manen's (2014) hermeneutic phenomenological tradition of inquiry utilizing a wholistic, selective, and detailed reading approach. Throughout the data analysis process, the hermeneutic circle of whole, part, whole process was used and included the identification of my own understanding and presuppositions along with my field notes. Incidental and essential themes were

identified. Essential themes were identified and included: chosen field of psychology, lack of training, stigma and stereotypes, they're just folks, like us, preying on their vulnerabilities, PTSD and trauma symptoms are the same with people with ID, EMDR and the adaptive information processing theory, and mindfulness interventions.

Overall perceptions of trauma treatment for people with ID who have experienced trauma and PTSD were identified. Samples of full transcripts are provided in Appendices I, J, K, and L. Chapter 5 provides an introduction and review of the purpose and nature of the study, the interpretation of the findings, the limitations of the study, and recommendations for further research. I have provided the implications for social change, and my reflections of the research project.

Chapter 5: Discussion, Conclusions, and Recommendations

Introduction

Researchers in the field of ID have suggested that trauma and PTSD affect people with ID similarly to people in the general population, but there is a need to keep in mind the individual's developmental level (Bradley, Sinclair, & Greenbaum, 2012; Esralew, 2006; McCarthy, 2001; Mevissen & de Jongh, 2011). In this chapter, I provide an overview of the findings and interpretations of clinicians and their perceptions of trauma treatment for people with ID. Four clinicians had experience working with people with ID, and four participants had not had such experience. In this chapter, I also discuss the limitations of the study, recommendations for further research, implications for social change, and then offer a conclusion.

The purpose of this qualitative phenomenological study was to describe and interpret the lived experiences of clinicians with and without experience working with people with ID, and to capture their perceptions of trauma treatment for people with ID. A hermeneutic approach and an ontological focus were used to describe how the participants' presence in the world and life experiences shaped their perceptions of people with ID and with trauma treatment. I have provided rich, thick descriptions of the participants' stories and experiences that have shaped their perceptions and meaning in a fuller and deeper manner. I have also used an epistemological approach (how we know what we know) and believe that this research study contributes to knowledge itself (Kafle, 2011). I have also incorporated an axiological approach, in that I involved my own values and experiences in the process to generate knowledge (Mingers, 2003). Van

Manen (2014) suggested that forgetting one's pre-understandings is not possible and that various assumptions and interests are part of the phenomenological reflection.

My goal was to capture the essential meanings of the participants' lived experiences and how those meanings were applied to their perceptions of people with ID and trauma treatment. I used a hermeneutic phenomenological approach to interpret the meaning of the lived experiences of the clinicians in relation to their perceptions of trauma treatment for people with ID. Through purposive and snowball sampling, eight private-practice clinicians were recruited through several on-line databases. Four of the clinicians had experience providing therapy to people with ID and four of the clinicians did not. All eight participants had experience providing trauma treatment to their clients.

Through open-ended semi-structured interview questions (Appendix C), the participants shared their lived experiences and complex client situations that shaped their perceptions of trauma treatment for people with ID. Once the data were gathered and transcribed, I completed the analysis using traditional van Manen (2014) thematic analysis of wholistic reading, selective reading, and detailed reading to identify sources of meaning. Throughout the data analysis process, I used the hermeneutic circle, moving between the whole, the parts, and the whole for understanding and interpreting the participants' lived experiences, giving meaning that was circular and iterative.

In Chapter 2, I discuss a large body of literature discussing, understanding, describing, and promoting models of treatment for trauma and PTSD for people in the general population, veterans, and victims of abuse survivors (Foa et al., 2004; van der Kolk, 1996), but note that the body of literature that acknowledges and speaks to the diagnosis and treatment of trauma and PTSD for people with ID is in its infancy

(Newman, Christopher, & Berry, 2000; Razza & Sosbey, 2011). This study adds to the body of literature promoting trauma and PTSD treatment for people with ID. Incidental and essential themes formed through the hermeneutic conversations with the participants were used to answer the research questions:

1. For clinicians who do not have experience working with people with ID, what were their perceptions of providing trauma treatment for people with ID?
2. For clinicians who have experience working with people with ID, what were their perceptions and experiences providing trauma treatment for people with ID?

Incidental themes included choice of school, types of courses, orientation, and funding options for their clients. Essential themes identified were (a) chosen field, (b) lack of training, (c) stigma and stereotypes, (d) they're just folks like us, (e) preying on their vulnerabilities, (f) PTSD and trauma symptoms are the same with people with ID, (g) EMDR and the adaptive information processing theory, and (h) mindfulness interventions.

Interpretation of the Findings

In this study, participants shared their lived experiences in relation to their perceptions of trauma treatment for people with intellectual disabilities. They shared their credentials, years of experience, therapeutic orientation, and funding options. The demographic information is shown in Table 1. The participants' therapeutic orientations were not ideologically pure, and several of the participants recognized that one approach does not fit all, and other participants had blended orientations with foundations in cognitive behavioral theory and therapy.

The participants shared their funding options for their clients, and most of them recognized the need to provide a sliding scale or to do pro bono work. The therapists who were credentialed as approved Medicaid providers shared their frustration with the approval process, paperwork requirements, and denial of services for people with ID who had Medicaid at community mental health centers. Clinicians who had chosen not to be approved Medicaid providers also voiced their frustrations with the approval process, paperwork requirements, and low reimbursement rates. Participant P7M4b stated:

Ah... I have ethical quandaries with the basic nature of insurance, and I have, um..... pragmatic concerns about the way Medicaid and Medicare function. It is a major hole in the system. It is not enough to give somebody Medicaid and then hand them a list of providers.

Clinicians who were LPC's acknowledged and shared their frustrations about only LCSW's being able to bill Medicare, and clinicians who worked with people with ID and were ID approved providers voiced their frustration with the separation of behavioral funding and mental health funding. Participant P2K1a stated:

You know, I don't know. I just think we are more clinical. The one thing that drives me crazy about our DD system is... is that, oh, let's separate the person out and let's do... okay, this is the DD part, and this is the mental health part. And it's crazy because the DD challenges and the mental health issues intertwine, so I've just gotten to the point where I'm treating the whole person.

Several incidental themes evolved while interviewing the participants. All the participants went to school where they lived, and several participants commented on how their choice of school was based on financial considerations and convenience for what

was going on in their lives. Only one participant mentioned school accreditation. Two of the participants who went to school in New York commented on being able to study at a leading school for social work or having professors from a leading school in social work. Table 2 shows the participants' comments.

Four of the participants were LPCs and four were LCSWs. There was a difference with the description of the types of classes taken for the different master's degrees. LCSWs described a strong emphasis on child development, family systems, community organizing, and clinical practice. LPCs described a strong emphasis in theories of counseling, group counseling, abnormal psychology, and theories of personality. All the participants highlighted their internship experiences as providing them with real-world experiences and readiness training, and as the most rewarding part of their educational experiences.

Only three participants mentioned that an emphasis on trauma-informed care was part of their educational training. Trauma-informed care is an evolving paradigm led by the Substance Abuse and Mental Health Services Administration (SAMHSA) to promote a universal awareness and practice for serving trauma survivors (DeCandia & Guarino, 2015; SAMHSA, 2014). Its original purpose was to integrate evidence-based interventions into behavioral health treatment care delivery systems, but it has now expanded to other organizations and service systems such as the criminal justice system, school systems, and primary care systems at the local, state, and federal level (SAMHSA, 2014). The participants who had and had not received trauma-informed care as part of their educational training agreed that trauma-informed care should be included in the ID system.

Findings and Interpretation Consistent with Literature Review

The responses from the semi-structured interviews for all the participants were consistent with the ID literature provided in Chapter 2, in that all the participants agreed that people with ID were more vulnerable for trauma and PTSD due to their ID (Baladerian, Coleman, & Stream, 2012; Feldman, Vengrober, & Ebstein, 2014; Sobsey, 1994). The participants suggested the ID population's vulnerabilities for trauma and PTSD were due to factors such as being institutionalized, being more isolated from friends and family, being dependent on caregivers, having multiple caregivers, lacking access to sex education and sexual health programs, having limited communication skills, and feeling disempowered to make complaints or be taken seriously if they do complain, which was also consistent with the literature. Participants seemed surprised when I quoted from the literature that people with ID experience mental health issues at rates 20-40% higher than the general population (Cooper, Smiley, Morrison, Williamson, & Allan, 2007; Eaton & Menolascino, 1982; Einfeld, Piccinin, Mackinnon, Hofer, Taffe, Gray, Bontempo, Hoffman, Parmenter, & Tonge, 2006; Emerson, 2003; Fletcher, Loschen, Stavrakaki & First, 2007; Mevissen & de Jongh, 2011; Reiss, Levitan & Szyszko, 1982). New information from the National Core Indicators (2016) in the United States showed a psychiatric diagnosis rate of 55% for people with ID. This information was based on a review of patient charts from 30 states, with a sample of 13,466 people. The participants in this study were not surprised to hear that the literature on trauma and PTSD for people with ID is in its infancy.

Participants who had experience working with people with ID shared their clients' stories of trauma and PTSD (Appendix F) and acknowledged that most of their clients

had several traumatic experiences, which was consistent with Ryan's (1994) study. Sobey (2008) found that children and adults with ID are three to four times more likely to experience abuse than those without ID. He went on to state that if a person experiences abuse once, it is likely that that person has or will experience other incidents of abuse. Several participants noted that 50%-90% of their caseloads presented with symptoms of trauma and PTSD. Participant P512a stated:

Well, it just sort of came up, a need realizing... when I first started my practice, I had read an article that 80% of people with ID had experienced some kind of abuse. And I didn't believe it. So the first three years I tracked it and it came out 90% of the people I served. So it made me start thinking about, this is posttraumatic stress that we were seeing and I then... was sort of would... like..., Wow! This is the same thing that is happening to our vets and I started reading about it. I went to some workshops on it.

In Chapter 2, I presented the term *diagnostic overshadowing*, which was a term first introduced by Reiss, Levitan, and Szyszko (1982) to describe the process of clinicians overlooking symptoms of mental health problems in people with ID and attributing them to being part of "having an intellectual disability." Although the participants did not use the term "diagnostic overshadowing," it was clear by their responses that diagnostic overshadowing continues to be a barrier for people with ID when accessing mental health services. Most of the participants with and without experience working with people with ID reported that they did not feel that community mental health services would be able to meet the needs of people with ID and trauma and PTSD, and felt that, diagnostically, the mental health centers would revert to the person's

ID instead of looking at the symptoms of trauma and PTSD. Participant P4M3b stated, “I would imagine that it is a very under-treated population. They think it would be easy to go right to the ID and focus on that and not focus on other things as well.”

Three of the participants (two with ID experience and one without) talked about misdiagnoses and focused on how PTSD flashbacks and dissociation was misdiagnosed for hallucinations and schizophrenia, which was consistent with studies by Ryan (1994), Esralew (2006), and Wigham, Halton, and Taylor (2011). None of the participants stated that people with ID could not participate in trauma therapy, and acknowledged that adapting therapy approaches such as simplifying language, using pictures, and modifying therapeutic techniques would be the best way to implement trauma therapy to people with ID, which was consistent with Whitehouse et al. (2006). Only one participant reported that he would not provide therapy for people with ID, and another participant reported that she would need more resources and flexibility to provide therapy for people with ID, which was not part of her payment contract.

Theoretical and Conceptual Framework Findings

Several different theories of PTSD were presented in Chapter 2 along with stigma theory as the theoretical foundation for the study. The conceptual framework for this study included the concept that people with ID do experience trauma and PTSD. Other components of the conceptual framework included the principle that people with ID can engage in trauma treatment; however, the treatment approach may need to be adapted to meet their needs. Finally, the framework included the lack of training for clinicians regarding their awareness of trauma and PTSD in people with ID and specific knowledge about symptoms needed to diagnose trauma and PTSD in the ID population.

Although most of the research that I reviewed on training professionals to work with people with ID who have co-occurring mental health issues involved psychiatrists who came from the United Kingdom (UK) and Australia, the UK seems to be taking the lead on training professionals. There is the beginning of a shift in the UK of mainstreaming mental health services for people with intellectual disabilities. A study by Jess et. al. (2008) compared the UK's specialty services for people with ID who had mental health issues and Australia's generic mental health model. In the UK, psychiatrists are required to participate in six months of clinical training with people with ID. Compared to the Australian generic model, psychiatrists' in the UK had greater flexibility and worked with people with ID in a variety of settings to include their home, day program, school, social work setting and prison setting. The UK participants self-selected to work with people with ID, which suggested that exposure to the population shape attitudes and knowledge in a more positive and inclusive manner.

Another study from the UK (Harwood & Hassiotis, 2014) used organizational change theories to redesign the undergraduate medical curriculum to provide a self-directed e-learning package as well as face-to-face interaction with people with intellectual disabilities. The e-learning package included conversations with people with ID discussing their challenges with having a mental illness, their abilities, and day-to-day activities. The results of their study suggested that the most watched module was on stigma and ID social status and that the overall experience of the students was positive towards people with ID and recommended the training for all doctors.

Eight essential themes emerged in my study from exploring theories of PTSD, stigma, and the components of the conceptual framework to discover the participants'

lived experiences with or without experience working with people with ID, which shaped their perceptions of trauma treatment for this population. The first theme generated was the participants' choice to go into the mental health field. The participants' varied lived experiences shaped their choice to go into the field of mental health and included participating in therapy when younger, experiencing a traumatic event, having a family member with an ID or mental health issue, or following their religious teachings. None of the participants who had experience working with people with ID purposely went into the mental health field to work with people with ID, but as their career evolved, they found a calling or a passion to work with the ID population. The participants who did not have experience working with people with ID expanded their perception with an understanding that people with ID who suffer with trauma and PTSD are an under recognized and an underserved population. This change in perception was brought about just having a conversation with the participants about people with ID.

The second theme of the lack of training about people with ID was universal with all the participants, as well as training on trauma and PTSD and other mental health issues with the ID population. The participants were asked why the subject of people with ID was not included in their training, and the majority expressed the lack of knowledge by professors. Training on trauma and PTSD with the general population was also lacking according to the participants except for three participants, who either had a professor who included trauma training in their course work or who received a certificated training in trauma and PTSD. Only one participant reported that trauma-informed care was central in all her courses. She stated:

I feel like it was new. It was kind of, you know, the theory... the understanding from school was, this is not how we have always looked at it, but this is the new way to go, and this is how... you know, you should think of it going forward. I didn't get the feeling that they've always done it that way.

When asked about training on trauma and PTSD and other mental health issues with the ID population, all the participants acknowledged that it was not discussed. Several participants expressed the lack of understanding by clinicians and society that people with ID can have trauma and PTSD, or other mental health issues and that most clinicians would default to the ID diagnosis as the reason for their symptoms and behaviors.

All the participants obtained advanced training in trauma and PTSD on their own by going to specific trauma trainings and conferences, and by reading research articles and books. Participants who had experience working with people with ID expressed a desire for more trauma and PTSD trainings and specific adaptations to meet their clients' needs. Participants who did not have experience working with people with ID welcomed advanced training on people with ID with trauma and PTSD and other mental health issues, but they did not know where to find those trainings.

The third theme generated was based on the theory of stigma, and all the participants acknowledged that stigma and stereotyping continued to be a barrier for people with ID, whether it was in a grocery store, at school, or with trying to get a job. The participants used words such as "not normal," "damaged," "dumb," "stupid," "looks different," "childlike," and "not as good as everyone else" when describing how others may stigmatize people with ID. All the participants expressed that stigma plays a major

role with accessing mental health services for people with ID. The participants expressed that the lack of knowledge of people with ID, society not recognizing the needs of people with ID, and the fear of the unknown fuel the continued stigma and stereotyping for the ID population.

Participants were asked to describe a person with ID and where they lived and what they did during the day, which generated theme four. Three of the participants described people with ID as “folks,” “They’re just folks, like us.” Other participants described people with ID as on a large spectrum or with a wide range of abilities. Several participants expressed that people with ID take longer to process information, have a different way of understanding and looking at the world, or have struggles in different areas, “just like we all do.” My favorite description was, “They are all of us, and they are everywhere, and we are everywhere.”

The participants were also asked where people with ID live and what they do during the day. The participants who had experience working with people with ID were very familiar with the ID service system and knew the different types of residential services, such as independent living, the host home model, and the family caregiver model. They were familiar with the ID service system terminology, funding hierarchy, and the interdisciplinary team model. One participant stated,

They live everywhere, and, hopefully, they do anything and everything they want to do, and have the capacity to make that happen. Often I think people with intellectual disabilities, cognitive differences, are limited more by the environment around them than by their own curiosity and desire.

These participants were familiar with what people with ID did during the day and the different levels of day program services to include supported employment, community access services, and specialized habilitation.

Several of these participants voiced their frustration with the closing of sheltered workshops, suggesting that their clients enjoyed that service setting and that it met the needs of some people with ID. These participants were very aware of the rules and regulations regarding behavioral services through the ID services system and the lack of access to the mental health service system. Several of these participants voiced their frustration with the division of services and how that did not meet the needs of many of their clients.

Participants who did not have ID experience voiced their assumptions that there were residential services, but did not know the different service options available. These participants acknowledged that some people with ID could live independently, but most other people with ID lived with their families. One participant assumed that some people with ID lived in “treatment centers.” These participants acknowledged that some people with ID could have jobs in the community, but they were not sure of what else people with ID would do during the day, but knew that they would need support.

Four themes emerged from a series of questions related to the types of traumas people with ID experience, trauma and PTSD symptomology, theories of PTSD, and treatment interventions. All the participants mentioned sexual abuse, physical abuse, and emotional abuse, but the participants who worked with people with ID brought up situations that could cause traumatic experiences that some would not think of, such as being taking advantage of, being vulnerable in the community, bullying, and loss.

The participants considered people with ID more vulnerable for trauma and PTSD and acknowledged that people with ID do suffer trauma and PTSD and that the symptoms are the same or similar to those of people in the general population. All four participants with ID experience dispelled the myths that persons with ID have limited verbal capacities and cannot be treated in individual psychotherapy; persons with ID do not really suffer after trauma; persons with ID “forget” trauma; or persons with ID are not capable of emotional insight. The participants who had no ID experience quickly recognized that these myths were not true. Participants with experience working with people with ID could describe how symptoms might look differently such as aggressiveness, self-injurious behavior, and flashbacks looking more like hallucinations.

All the participants were asked what theory of PTSD was the foundation of their treatment approaches. Four of the participants did not mention a specific scholar’s theory and went on to describe their treatment approaches. All four participants who were trained in EMDR cited Francine Shapiro’s adaptive information processing theory as the foundation for implementing EMDR therapy. Only one participant with ID experience was trained in EMDR, but she stated that she had not had the opportunity to provide EMDR with a person with ID. All the participants were aware of EMDR therapy and felt that people with ID who suffered from trauma and PTSD could benefit from that therapy, but acknowledged some adaptations would be necessary. One participant mentioned schemas, one participant mentioned fear networks and exposure theory, and two participants mentioned attachment theory. Several of the participants mentioned the brain-based theories of PTSD, which were out of the scope of this study.

All the participants discussed their treatment approaches. Several of the participants with and without ID experience stated that building trust and the therapeutic relationship were key to progressing in therapy. Several of the participants with experience working with people with ID expressed that building the therapeutic relationship and trust took more time to establish. All mentioned that self-soothing and emotional regulation needed to be established with the client before processing traumatic experiences. All the participants stated they utilized mindfulness with their clients as a therapeutic strategy for emotional regulation.

Mindfulness interventions with people with ID are fairly new to the research with people with ID. Hwang and Kearney (2012) completed a systematic review of twelve studies that directly implemented mindfulness strategies for individuals with ID. The primary objective of these studies was to reduce aggressive behaviors. The elements of mindfulness that were analyzed were awareness of breathing, body sensations, actions, thought and feelings, and shifting of attention. Training in mindfulness was given in two stages; the first stage included daily intervention sessions, and the second stage included self-practice using audio recordings. The results of the review indicated that all studies reported positive results; in seven of the studies, aggressive behavior was reduced to zero. Follow-up with seven studies indicated that the effects of mindfulness interventions lasted for a year or longer (Hwang & Kearney, 2012). Although none of the mindfulness studies were specifically used for emotional regulation of trauma and PTSD symptoms, all the participants agreed the intervention would work with people with ID.

As for their overall perception of trauma and PTSD treatment for people with ID, all agreed it was important. Several of the participants with and without experience

working with trauma and PTSD expressed a new awareness of how people with ID are underserved. One participant stated, “I get the idea of specializing, but there's a difference between specializing and excluding.” Another participant stated, “I think it is a responsibility of the community that is not being met.”

The participants were then asked if their perception of trauma and PTSD treatment for people with ID had changed. The perceptions of participants who had experience working with people with ID did not change, but they acknowledged a need for mental health clinicians to have more training with the ID system and population. The perceptions of participants without experience working with people with ID did change; one participant acknowledged she had never put the two together, and another participant thanked me for letting her clarify her thoughts and perceptions. One participant expressed experiencing moments of guilt for not being a provider and summed his experience with the interview as:

Through this conversation, it occurs to me; um... the injustice of the lack of access, the poor access, the poor needs assessment. Um... the failure of the community to provide. That's part of the social justice piece, bringing justice, bringing repair to the world, bringing healing to the world. And it's not happening.

Limitations of the Study

This hermeneutic phenomenological study was limited to eight private-practice clinicians practicing in the Denver, Colorado metropolitan area. Four clinicians had experience providing therapy to people with intellectual disabilities, and four clinicians did not have such experience. All the clinicians had experience providing trauma therapy

in their practice. The purpose of the study was not to compare the participants' experience and knowledge of trauma, PTSD, or with people with ID, but rather, to highlight the lived experiences of the participants so as to better understand their perceptions of trauma treatment for people with ID.

Qualitative phenomenological research inquiry does not usually produce generalizations (van Manen, 2014, Stake, 1995), but naturalistic generalizations may emerge. I do believe that the readers of this study will be able to relate to something one of the participants described or can apply the findings to their own lived experience. The participants' lived experiences are unique to the individual and their responses to the questions and the method of analysis may have a different outcome with a different researcher.

Although rich, thick descriptions of the participants' lived experiences were provided, the sample was small, purposive, and convenient. A larger sample that included participants from community mental health centers may have provided discrepant themes and established saturation. However, the in-depth nature of the interviews and the amount of data produced made it unfeasible to use a larger sample. The use of a digital tape recorder did not interfere with the natural dialogue of the interview. However, audiotaping the interview did not capture the nonverbal cues or the emotional expressions of the participants' responses.

One of the hallmarks of phenomenological research is the process of 'epoché' or bracketing one's biases, pre-understandings, assumptions, or beliefs to open oneself to the significance of the phenomenon. Hermeneutic researchers, on the other hand, believe that bracketing is not possible or desirable and that researchers need to be aware of their

beliefs and shift back and forth from the participants' experiences to their own, "continually reflecting on both interpretations to move beyond previous understandings" (Finlay, 2009, p. 13). I acknowledge that I am a novice when it came to hermeneutic phenomenological research and that my interpretation of hermeneutics may not be as in-depth as a more experienced phenomenological researcher. I have tried to minimize my bias, pre-understandings, and assumptions by providing a description of my personal experience and perceptions of working with people with ID, utilizing a personal journal and member checking.

Recommendations for Further Research

Research investigating trauma and PTSD with people with ID is limited and is in its infancy (Doyle & Mitchell, 2003; McCarthy, 2001; Newman et al., 2011). Therefore, researchers interested in adding to the body of literature of trauma treatment for people with ID are welcomed and greatly needed to promote and advocate access to trauma treatment for people with ID. This study inquiring into clinicians' perceptions of trauma treatment for people with ID was limited to eight private-practice participants, four who had experience providing trauma treatment for people with ID and four who had not. Future research can expand the sample to include community mental health centers and larger agencies that provide trauma treatment for the general population and the ID population.

The literature review provided in Chapter 2 and the participants in the study agreed that people with ID suffer symptoms of trauma and PTSD qualitatively similar to symptoms found in the average population (McCarthy, 2000). However, due to developmental levels and language and communication deficits, the presentation of

trauma and PTSD present differently in some people with ID. Future research can qualitatively and quantitatively identify symptom presentations to be considered in the diagnosis of PTSD in people with ID. To date, Ryan's (1994) study on diagnosing PTSD for people with ID is still the only large scale quantitative study cited in the literature on trauma and PTSD with the ID population. A more recent case-control study of 54 participants in each group was conducted by Sequeira, Howlin, and Hollins (2003). The researchers evaluated a group of known sexual abuse survivors and a control group. They compared the different level of mental disturbance. Of the group of sexual abuse survivors, 19 out of the 54 participants met the criteria for PTSD and the demonstrated more severe behavioral problems than the control group. The survivor group also demonstrated social withdrawal symptoms more significantly. The authors recommended further research to compare level of disturbance and types of PTSD symptoms that may be similar across studies (2003).

Although the question of the efficacy of psychotherapy approaches for trauma and PTSD is still unanswered, there seems to be a consensus among the experts in the field of ID and mental health that more research is needed, but that people with ID should not be denied psychotherapy services (Beail, 2005; Barol and Seubert, 2010; Hurley, 2005; Lynch, 2004; Mevissen, Lievegoed, and de Jongh, 2011; Taylor, 2005). None of the participants in this study suggested that people with ID who have suffered from trauma and PTSD would not benefit from psychotherapy, but adaptations would be needed. Several of the participants stated that one therapy approach did not fit all. Further research could include a compilation of adaptations and creative approaches that have been successful for trauma treatment for people with ID.

Several of the participants with experience providing therapy with people with ID stated they would refer their clients for adjunct therapies such as music therapy, art therapy, and EMDR. Those participants who were trained in EMDR therapy suggested EMDR would work well with the ID population. Only two qualitative studies (Barol and Seubert, 2010; Mevissen, Lievegoed, and de Jongh, 2011) have been conducted using EMDR therapy for people with ID, and further research on how the EMDR protocol can be adapted for people with ID would be beneficial.

Stigma, lack of training, and diagnostic overshadowing continue to be barriers for people with ID to access psychotherapy services for trauma and PTSD treatment. All the participants in the study voiced awareness of these barriers. Further research on how to incorporate clinical training on trauma and PTSD treatment for people with ID and how to decrease stigma and stereotyping of people with ID is important to help people with ID heal, grow, and be successful in their communities.

Implications

People with ID who have suffered trauma and PTSD are very diverse, and their support needs change over their lifetimes. Many of the recommendations to impact positive social change, such as blended government funding, psychopharmacology, inter-system service coordination, support to develop models of care and treatment, and required qualifications and training expectations for staff members require changes in federal, state, and local policies and are outside the boundaries and scope of this study. However, as qualified mental health clinicians who do have experience with working with people with trauma, PTSD, and other mental health issues, we can continue to

educate our clients, families, direct providers, and agencies on the awareness and symptomology of trauma and PTSD.

The information from this study provides the awareness and knowledge of the barriers and lack of access to appropriate treatment for trauma and PTSD for people with ID from the clinician's perspective and can be used to facilitate more conversations with clinicians on ways to advocate and improve access to appropriate treatment. Mental health professionals need to be aware of the continued stigma and stereotyping people with ID experience having trauma and PTSD, and this study provided information about that. Clinicians who have experience working with the ID population need to continue to build relationships with community mental health centers and to provide consultation for people accessing these centers.

The data from this research has emphasized the lack of training of clinicians in treating people with ID and trauma and PTSD. Although changing college and university curricula to include this type of training is outside the scope of this study, clinicians who have experience working with ID can volunteer to provide presentations to university psychology classes. Clinicians with experience working with people with ID who have suffered trauma and PTSD can present at conferences and workshops to reach clinicians who do not have experience working with the ID population.

Future applications of this study can expand to community mental health centers. Assessing their perceptions of trauma and PTSD treatment for people with ID may influence their abilities to provide trauma and PTSD treatment. This may also expand adaptations and creative approaches to meet the treatment needs of people with ID.

Access to treatment and quality treatment approaches for people with ID who have suffered trauma and PTSD will improve with this awareness and knowledge.

Personal Reflection

Looking back and reflecting on the journey of completing this dissertation, I found it was not always a nice paved road. I ran into road blocks, pot holes, and traffic delays, but I also had times of smooth traffic and cruising. The winding road of hermeneutic phenomenology was the map I followed, which provided several different avenues and roundabouts to choose from to get to my destination. The research design, the development of the semi-structured interview questions, recruiting the participants, interviewing the participants, gathering the data, and interpreting it, seemed like speed bumps where I would speed up, only to slow down to go over the bump.

Throughout the research process, I was reminded to yield to my biases, presuppositions, and understanding to open lanes of new knowledge and meaning. One of my assumptions was that participants who did not have experience with people with ID would describe them in psychometric or clinical terms, but I was pleasantly surprised that they described people with ID in human terms. One of my biases was with behavior analysis and Sturmey's (2012) view that behavioral therapies were the preferred treatment option for people with ID. Participant P1M1 and I had a discussion on behavior versus symptoms of mental health, and although we agreed to disagree that our theoretical approaches were a divided highway, our path to help people with ID heal from trauma and PTSD was the same. After further reflection, I reminded myself how many times I have worked with a behavior analyst, and how we merged ideas and concepts to identify targeted mental health symptoms of trauma and PTSD, develop behavioral plans

to shape behavior, and decrease trauma and PTSD symptoms. I agree with several of the participants who stated, “One size does not fit all.”

The participants who did have experience providing trauma treatment for people with ID seemed to follow the interview interchange smoothly, with true emotion and passionate lived experiences of healing the stigma and stereotypes of their clients with ID. They advocated for people with ID who had trauma and PTSD to gain access to services. They knew the Developmental Disability system, the acronyms, and funding structures. They seemed to have shared lanes of frustrations and passion for the work they do with people with ID.

The participants who did not have experience working with people with ID also had shared lanes of frustration and passion. They shared their frustration about Medicaid and Medicare billing procedures and reimbursement, and their passion for doing trauma work. Several of the participants had difficulty with the ID terminology and making sure they were stating things in a politically correct manner. Three of the participants were EMDR trained and we shared our knowledge and experiences using EMDR therapy. Three of the participants were also trained and worked in the addiction and criminal population field. These issues provided common interchanges of knowledge and lived-experiences with which I could relate. I also learned a new theory of addiction from one of the participants. Three out of the four participants agreed they would take advanced training in trauma treatment for people with ID if it were offered, and their perception for working with the ID population changed. Only one participant said he would not work with the ID population, but commented that the interview instilled some guilt for not being a direct provider.

Overall, I have finally come to my destination from this dissertation journey. I found that all the participants had commonalities in their role of being a clinician and each of them were driven by their passion to help people heal from trauma and PTSD. I found that I had something in common or could relate to a lived experience with each of the participants, from one clinician to another. My hope is that those that read this dissertation can also find commonalities or lived experiences they can relate to and that they will also change their perception of trauma and PTSD treatment for people with ID.

Conclusion

People with ID are more vulnerable to experiencing trauma and PTSD. Their risk is 55% higher than people in the general population. They experience PTSD symptoms similarly to people in the general population and have the right to access and receive quality trauma and PTSD treatment just as anyone else.

The goal of this study was to capture and interpret the essential meanings of the participants' lived experiences and to examine how they applied these meanings to their perceptions of people with ID and trauma treatment.

The research questions asked were:

1. For clinicians who do not have experience working with people with ID, what were their perceptions of providing trauma treatment for people with ID?
2. For clinicians who have experience working with people with ID, what were their perceptions and experiences providing trauma treatment for people with ID?

A hermeneutic phenomenological approach was used to provide interpretation of and meaning to the clinicians' lived experiences in relation to their perceptions of trauma

treatment for people with ID. Through purposive and snowball sampling, eight private-practice clinicians were recruited through several on-line databases. Four of the clinicians had experience providing therapy to people with ID, and four of the clinicians did not have such experience. All eight participants had experience providing trauma treatment with their clients.

Through open-ended, semi-structured interview questions, the participants identified incidental themes of choice of school, types of courses, orientation, and funding options for their clients. Essential themes identified were: (a) chosen field, (b) lack of training, (c) stigma and stereotypes, (d) they're just folks like us, (e) preying on their vulnerabilities, (f) PTSD and trauma symptoms are the same with people with ID, (g) EMDR, and (h) the adaptive information processing theory, and mindfulness interventions. The primary perception of trauma and PTSD treatment for people with ID from all the participants was that people with ID can benefit from trauma therapy, that trauma and PTSD are under-recognized and under-treated in the ID population, and that therapists are not trained to serve this population. Without direct social change at the federal, state, and local levels and by clinician practices, people with ID who experience trauma and PTSD will continue to suffer. This suffering will only increase expensive health care, repeated hospitalizations, multiple residential placements, and re-traumatization. It is time to stop the suffering and provide the quality of care and treatment people with ID deserve in order to heal, to become whole again, and to be successful in their community.

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Appendix A: Permission to Adapt the Concept Map

From: feliceaddeo@libero.it [mailto:feliceaddeo@libero.it]

Sent: Sunday, June 14, 2015 3:11 AM

To: Kathy Schoech

Subject: R: Permission to adapt concept map

Importance: High

Dear Katherine,
 thank you very much for your email: it is always great to hear that your work is being appreciated :-)
 I give you my permission to adapt the concept map for your study.
 If you have any doubt about Hermeneutics or if you want just to discuss about it, please feel free to contact me.

Felice Addeo

 Ricamatore SPS07- Dipartimento di Scienze Politiche, Sociali e della Comunicazione
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---Messaggio originale---
 Da: KSchoech@rmhumanservices.org
 Data: 13/06/2015 23.20
 A: "feliceaddeo@libero.it" <feliceaddeo@libero.it>
 Ogg: Permission to adapt concept map

June 11, 2015

Hello Dr. Addeo,

My name is Katherine Schoech and I am from Denver, Colorado, USA. I am a doctoral student with Walden University and came across your training paper on hermeneutics as a research method. Thank you for providing such an informative paper on how to do hermeneutic research. I especially took note of the concept map to help me design my

research and develop my interview questions. I am completing a hermeneutic study on clinicians' perceptions of trauma treatment for people with intellectual disabilities, and hope to describe and seek meaning from the clinicians' experiences and everyday life that shape their perceptions of trauma treatment for this special population.

I am required by my university to ask for your permission to adapt your concept map for my study and receive permission in writing. I hope you will consider giving me permission to adapt the concept map and thank you for your time and consideration.

Sincerely,

Katherine Schoech

This message is intended only for the use of the intended recipient and may contain information that is **PRIVILEGED** and **CONFIDENTIAL**. If you are not the intended recipient, you are hereby notified that any use, dissemination, disclosure or copying of this communication is strictly prohibited. If you have received this communication in error, please destroy all copies of the message and its attachments and notify the sender immediately.

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Appendix B: Recruitment Letter

Dear clinicians and colleagues,

My name is Katherine Schoech, and I am a doctoral student through Walden University. I am currently working on my dissertation of clinicians' perceptions of trauma treatment for people with ID. I am seeking three to five clinicians who do not have any experience with people with ID to participate in an interview regarding their perceptions of people with ID. The interview should last about an hour and a half, and may require a follow-up interview and a review of the transcribed interview. I will come to your office or a place that is convenient for you to do the interview. Although I truly understand how valuable your time is, I do not have funds for compensation, but your input is valuable for the future of trauma treatment for people with ID.

If you are interested in participating in my study, I can be contacted through phone or email. Thank you for your time and consideration for participating in my study.

Sincerely,

Katherine Schoech, MA, LPC

Appendix C: Initial Inclusion Screening Protocol and Checklist

Protocol Tasks	Date	Status/Completed
Check Department of Regulatory Agency for licensure and/or registration status.		
Inquire about years as a practicing clinician.		
Inquire about trauma or PTSD experience.		
Inquire about experience working with or without people with ID.		
Inquire about age range.		
For female participants: Ask about pregnancy and if they feel they can participate in the research project.		
Obtain or confirm email address to send informed consent.		

Appendix D: Interview Questions

For the purpose of trustworthiness, validity, and possible conflict of interest, please answer the following question before the interview takes place. As the researcher, I have no affiliation with you or your business, and between us, we have no clients or business affiliations in common. True or False.

1. Describe your practice and the type of clients you see.
2. Describe your credentials and the number of years in practice.
3. Describe the types of payment/funding options you provide for your clients.

Follow up: If no insurance or Medicaid/Medicare: Describe your reasoning for not taking certain types of payment options.

4. Tell me a story about what made you choose the field of psychology/ human sciences.
5. Where did you go to school and why did you choose that school?
6. Describe the types of courses you took for your degrees.
7. What is your therapeutic orientation and describe how you came to choose that orientation.
8. During your schooling, how much emphasis was placed on trauma and PTSD.

Follow up: Describe what experiences made you specialize in trauma and PTSD?

How did you obtain your knowledge, training, and experience in trauma and PTSD?

What theories and approaches do you use to treat trauma and PTSD?

9. How would you describe a person with intellectual disabilities?

Follow up: Where do they live, and what do they do?

10. What kind of stigma or stereotypes do you feel people with ID experience?

Follow up: Tell me a story about your experiences with a person with intellectual disabilities.

11. During your schooling, how much emphasis was placed on people with intellectual disabilities?

Follow up: How much emphasis was put on mental illness/ psychiatric disorders with people with ID?

Describe why you think that is.

12. Describe what kind of traumas do people with ID experience.

13. Describe how the symptoms of PTSD might look like in a person with ID.

14. Would you work with a person with ID who had trauma or PTSD?

Follow up: Why or why not?

15. Describe what kind of training you would need to work with people with ID who had trauma or PTSD.

16. Describe how you might modify or adapt your treatment approaches for PTSD for people with ID.

17. Describe your overall perception of trauma treatment for people with ID.

18. Has your perception changed since the start of this interview?

Appendix E: Interview Protocol

Observations, thoughts, feelings, emotions	Questions	Body language and non-verbal communications
	<p>1. Describe your practice and the type of clients you see.</p> <p>2. Describe your credentials and the number of years in practice.</p> <p>3. Describe the types of payment/funding options you provide for your clients.</p> <p>Follow up: If no insurance or Medicaid/Medicare: Describe your reasoning for not taking certain types of payment options.</p>	

	<p>4. Tell me a story about what made you choose the field of psychology/ human sciences.</p> <p>5. Where did you go to school, and why did you choose that school?</p>	
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Observations, thoughts, feelings, emotions	Questions	Body language and non- verbal communications
	<p>6. Describe the types of courses you took for your degrees.</p> <p>7. What is your therapeutic orientation and describe how you came to choose that orientation.</p> <p>8. During your schooling, how much emphasis was placed on trauma and PTSD?</p> <p>Follow up: Describe what experiences made you specialize in trauma and PTSD?</p>	

	<p>How did you obtain your knowledge, training and experience in trauma and PTSD?</p> <p>What theories and approaches do you use to treat trauma and PTSD?</p>	
Observations, thoughts, feelings, emotions	Questions	Body language and non-verbal communications
	9. How would you describe a person with	

	<p>intellectual disabilities?</p> <p>10. What kind of stigma or stereotypes do you feel people with ID experience?</p> <p>Follow up: Tell me a story about your experiences with a person with intellectual disabilities.</p> <p>11. During your schooling, how much emphasis was placed on people with intellectual disabilities?</p>	
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	<p>Follow up: How much emphasis was put on mental illness/ psychiatric disorders with people with ID?</p> <p>Describe why you think that is.</p> <p>12. Describe what kind of traumas do people with ID experience.</p>	
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Observations, thoughts, feelings, emotions	Questions	Body language and non-verbal communications
	<p>13. Describe how the symptoms of PTSD might look like in a person with ID.</p>	

	<p>14. Would you work with a person with ID who had trauma or PTSD?</p> <p>Follow up: Why or why not?</p> <p>15. Describe what kind of training you would need to work with people with ID who had trauma or PTSD.</p> <p>16. Describe how you might modify or adapt your treatment approaches for PTSD for people with ID.</p> <p>17. Describe your overall perception of trauma treatment for people with ID.</p> <p>18. Has your perception changed since the start of this interview?</p>	
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Appendix F: Participants Lived Experiences with People with ID

P1M1a: M: I mean I guess, my work, I don't work as much with children anymore, but my work with children was very rewarding. It would be, it was very awesome to see them progress and to see them like grow into and developing skills. And I would say the one that I, I can think of a couple that once they started to develop language it was amazing. There's one that I still somewhat keep in touch with that I worked with in Centennial a long time ago. and she, she was pretty high functioning, but more like, kind of aspergerish, She socially did not have any interest in socializing. We used to go to the playground all the time and I would force her to say hello and force her to say will you play with me, .and just give her that language, and she just did not have a lot of interest. So now I still kind of keep in touch with this family from years ago. And she is now mainstreamed, she in all these social clubs, she's getting straight A's, and so those experiences stick with me. Just their ability and how they grow.

P2K1a: Well it is interesting because I had a particular case. She was actually one of the worst abused cases in the... my count, and ... I got her, in fact I got her straight from the hospital and um... When I first started seeing her, she was almost comatose. She walked in, wouldn't talk, wouldn't give me eye contact, wouldn't do anything. And I worked with her for a long time and her dad was so abusive to her in every manner and to her mother, and they kind of shared the abuse and so when mom would have a mental break down then she would endure all it, or if she had a mental break down, mom would endure all of it so they would try not to end up in the hospital. And so social services were involved because she was a person with disabilities. I think of that case... it just touched my heart. This girl is an amazing young lady and just to see her kind of come through this trauma. I learned so much, I think about working with trauma because of her. You know, because you read it, you do the research, you can be told, but when you are in the moment and really sitting and feeling, with her, it was, she is just an amazing and I love her and I still see her today actually. And so I saw her grow and work through so much that she actually could forgive her father and chose not to take him to court. And so that was pretty miraculous for me to watch that transformation... cause I know how I feel about the trauma and you know and how she was treated. And so to keep that personal piece of it out of it... because I wanted to kill him. You know, if I could, I wanted to kill this guy, but she, you know watching her provide forgiveness was amazing. I don't know... it gives me chills. Like, she just an amazing person, and I think that's a lot of what led me to also want to get into trauma and really learn and help people through that.

P3M2a Um... Sure... I'm trying to think, which one. I do have um... there's one client that sticks out... that was a probation... actually parole. Young... um... had taken advantage of by local gang's neighborhood. Ended up serving a few years in prison at a very young age. Very, very violent crime... and the sweetest individual, this was so incongruent with the crime. And the heart of it was... we did some CBT work... and the heart of it was beliefs about what people wanted from him and expected from him... and ... you know...

what kind of... those people are happy so what he had to do to be happy was to be like them. And he understood... you know... the hurtfulness against the victims and his family and things like that. Um... but he didn't place enough emphasis... because his...you know... so it was really a lot of working around that. And it was severe, severe, depression, severe suicidal ideations. Huge, you know... lack of self-esteem and very, very sad. Very sad... and family that didn't comprehend... you know... they were loving and great, but they didn't... you know... he didn't have any services set up... didn't have any disability income... didn't have any official assessments... you know, giving him a label that would make... you know make him eligible for services because the family was afraid of that. So it was a lot of work with that and getting him tested, let's get this formalized. And with him... let's find your talents... okay so this is harder for you... you know... what's easier, what do you do better... a lot of strength based work too.

P4M3b: Um... I honestly have not worked with anybody with ID. That's something I know I'm not school in and so I would refer out. So I don't have any really professional experience with that. Um ... I... My best friend, you know... he..., for my whole life... her step brother... was diagnosed with down syndrome, so it was something I was around a lot and... His family... They were a fabulous family. My friend's father worked a..., like the... he used to be... he's retired now. He was the head of a hospital and his wife... So, I mean... they provided a great home for him. I mean they worked really hard to do anything to help him... integrate him. To the state where he was pretty high functioning. Yeah

P5L1a: Okay... a woman who was in her 30's who um... she had severe cerebral palsy. So... very difficult for her to communicate with people. Speech was very difficult to understand, so she hesitated getting help, but she really needed someone to talk to. She had been in a relationship with a man and felt she couldn't talk to him about. So I started seeing her and we worked really hard... um...on understanding her speech. Um... 10 years later, I'm still seeing her. Um... she had become involved with a staff member at an agency that she worked at. I think he was a van driver. And it ended up being a very loving relationship. It wasn't an exploitive relationship that everyone thought it was. He ended up being a very important person in her life. But we did a lot of work with staff and family and helping other understand. And then this man got brain cancer. So we went through the whole trauma of losing him and mom and sister died within a five year period after that. So the loss issues with her, but most importantly, being someone she could... she never talked to anyone... she had spent, um...8 years in the institution, with... she saw some horrible stuff, but because she was nonverbal, they thought. She didn't talk to anybody and was in a wheel chair, staff would talk things in front of her... that were going on with other clients. She... just for 8 years. She was treated like a vegetable, having no idea that cognitively she was a very bright woman. I think she is one of my favorite stories because we have done lots and lots of work.

P6L2b: Shew... I got somebody now that I have been working with several months and I... I don't have any kind of clinical documentation, as to level of functioning, it's just... the interactions are so difficult that something... is... there are challenges there. Um ... very concrete. I've learned to not, um... present abstract challenges, to be very, very black and white, very basic. Um ... And very little feedback in order for this person to stay open to me ... not get defensive. Um ... And consider different points of view. So rigid, so... you know, on a one track. Um... and so it is my job... is trying to... what about this...what about that... what about different lifestyles so you don't keep going back to prison. Um...increasing support ... encouraging a better self-image. You don't have to deal drugs; you can do something else in your life. What would you like to do? Um ... Not feeling like an odd ball, you know there's that... that thing that goes along... and it's difficult.

P7M4b: My experience in the... at NYU around the delays and disabilities came through the internship at the school. So a lot of work with IEP's... That was filling out IEP's based on reports I was given. So I didn't even learn about the reports or the assessments. I was just told... these numbers, next to these letters, go in these boxes. And that was about it. But it was also so hands off and unethical, where at times I was told, just copy what is written in the IEP that has already been done, into this IEP. They're virtually the same kid, so just copy/paste. The way I was trained to treat those children at the school, whether it was children with educational challenges, developmental delays/disabilities, cognitive differences, and or the ones with mental illness, and... was through the lens of a woman who was a Neo-Freudian psychoanalyst. So she encouraged me to practice her version of Neo-Freudian psychoanalysis with young children with developmental and educational delays and disabilities, some of them with mental illness. What could you possibly do?

P8P1b: Um... what I have experienced was everything as I said, from bullying, that leave all the scars on the inside. They, many times ID kids that also had, you know... big rage issues... you know... that dual diagnosis thing. Were abused, or beaten by their parents. Um... Or whom ever. Um... If they were the family, was ruin scalps of evangelistic church. The church would create all sorts of shame too. And some of them kept encouraging the family to um...you know, spank them, but the spanking went well beyond that. Um ... Many had deep sense of shame and a lot that did come from the bullying. Um ... That they weren't okay. Sometimes to, that the bullying... I remember one particular incident; ah... the kid was tied up and put in his locker.

Appendix G: Full Transcript Sample of Participant with Experience Working with People with ID

Title: P2K1a interview
 Record date: 3/30/2016 11:06:23 AM
 Record time: 45:17
 Recording file name: P2K1a interview

 K: Okay, Alright, Today is... I hope it is March 29,

P2K1a: 30th

K: Oh it's the 30th, March 30th; see I don't even know where I'm at, 2016. And I'm interviewing Katina Lewis Ryan. Okay, and to start off with, I'm just want to read this and you can answer true or false. For the purpose of trustworthiness, validity and possible conflict of interest, please answer the following question before the interview takes place. As the researcher I have no affiliation with you or your business and between us, we have no clients or business affiliations in common. True or false?

P2K1a: True

K: Okay, got it. Alright ... so um...

Describe your practice and the type of clients you see.

P2K1a: Um... So I do clients between of ages of 5 and up. I serve people that are typical people and I also specialize in working with developmental disabilities. I do play therapy, sand therapy, um...talk therapy, I do some art, kind of do a vast range depending on the persons level of functioning. Is what you need?

K: Yep... Your fine... okay

Describe your credentials and the number of years in practice.

P2K1A: Oh... so I am a licensed professional counselor, um... I've been licensed since 2007. And I've had my practice since 2004. December of 2004, I think... 2005, sorry, 2005. Um ... yeah...

K: How would you say, like um... your credentials or years in private practice, but what about your overall experience.

P2K1a: Good question... So I've been working in the DD field, developmental disability field for... ID, what they call it. For 20 years. And I've been doing therapy for, since, well, including internship, 2003, I've been doing therapy, so 13 years, om my gosh...

K: Yeah, we're old.

P2K1a: WOW, we are old... (Ha-ha)

Describe the type of payment, funding options you provide for your clients.

P2K1a: I do a sliding fee scale, I also take Medicaid, and I take private insurance.

K: Private... what kind of private insurance?

P2K1a: So I do Blue Cross Blue Shield, Anthem, Cigna, Aetna, um... Mines and Associates... am I forgetting, those are probably my big ones. And then I also contract with the State of Colorado, to do the PAR. To do behavioral services.

K: Medicaid Waiver?

P2K1a: Yeah, Medicaid Waiver. Yep and I take every county Medicaid except one county.

K: Oh, you're not doing that county? So you take a different county?

P2K1a: Yes, that county.

K: And another county?

P2K1a: that county too, yep

K: But not... How come, not that one county?

P2K1a: I don't speak Spanish, so they won't... I've applied several times and I don't speak Spanish.

K: Oh wow

P2K1a: Yeah

K: I didn't know that.

P2K1a: Yep, they want people that speak Spanish, so...

K: For right now. Okay

The other thing is that... um... with Medicaid and some of our DD clients um... a lot of them have primary Medicare and Medicaid is secondary and because LPC's can't bill Medicare, how do you, do you take those clients, or how do you work that?

P2K1a: Great question. I do, and I'll do a sliding fee scale if their able to afford it. I go as low as \$30 an hour, depending on the situation, um... I've not run into very many with Medicaid/Medicare, as Medicare primary, typically. If I'm doing therapy, Medicaid will cover it. I would say 90% of the time, for therapy, so...

K: Ours won't. So what I have to do is, with my Medicare clients, it's so ridiculous, the psychiatrist or psychologist has to sign off on my note and one of them has to be in the building.

P2K1a: Yeah, That is how community mental health center was. So I don't know if it is different because I am private practice. I don't know because I have clients with Medicaid/Medicare and Medicaid... I bill Medicaid and they pay.

K: Wow

P2K1a: And I don't bill Medicare, because Medicare... never, it is, as far as private practice. They don't... they don't identify us as being able to be... as LPC's.

K: Yeah, I think because, because you're not a provider.

P2K1a: Yeah, exactly

K: We are

P2K1a: Right

K: We're Medicare/Medicaid provider.

P2K1a: Yeah, so I can just bill their Medicaid, and yeah, I've only ran into... I want to say... maybe 3 times, and then we just negotiated, like \$20 an hour, \$20-\$30 an hour, whatever, we have to negotiate so I can still see them.

K: Right.

P2K1a: Interesting, the difference.

K: Well, I don't have to answer that question, if no insurance, Medicaid/ Medicare insurance, we described that.

P2K1a: Yeah

K: Tell me a story about what made you chose the field of psychology and human services.

P2K1a: Oh my god, I love you. Um... so in my career I did case management and then I went into residential services and then working in residential services.

K Where did you do residential services?

P2K1a: That residential agency.

K: Oh that's right.

P2K1a: Yeah and a... and then working there, I really saw how many people with disabilities needed therapy services and there were just no one knew both mental health and DD. And so that was kind of... I felt like that was a calling for me and so I decided to go back to school and specialize in working with people with developmental disabilities. It's been my calling since. I love it, absolutely love it.

Where did you go to school and why did you choose that school?

P2K1a: I went to a private university.

Where did you go for your undergraduate?

P2K1a: In Nebraska

K: Nebraska College

K: What did you get there?

P2K1a: So my undergraduate, I got a... BA in Human Services, and the private university was a Masters in counseling Psychology. And I chose the college in Nebraska... it was a smaller private college. Um ... This is funny, but because I needed to be held accountable for the class. I mean really, they, they... If we missed a class we actually got downgraded, and so I really had to go, which I thought was really good for me. Regis I chose based on location, it was close to home and I felt like it was the very... it an impressive program and I felt it would meet the needs of what I was looking for, more than some of what the other universities around. Yeah.

K: Yeah, I started in a LCSW program and it' was like, this is not that clinical enough for me.

P2K1a: Well it's interesting, because I see social work very different than counseling. I mean, we, I think are, the education is very similar, but the mindset that you have and how you work with people, I think is very different, in that, social workers are very... I

don't know how to describe it... I mean I feel like LPC's are more of a humanistic approach. We looking at the whole picture of the person and I think social workers more kind of pin point specific issues that they deal with.

K: Wow

P2K1a: You know, I don't know. I just think we are more clinical. The one thing that drives me crazy about our DD system is... is that, Oh, let's separate the person out and let's do, okay, this is the DD part and this is the mental health part. And I've just gotten to the point where I'm just treating the whole person

K: The whole person, exactly. And I think social workers do that differently. Yeah, I agree.

P2K1a: Yeah, it just drives me crazy.

Describe the types of courses you took for your degree.

P2K1a: Oh... I took community counseling... I actually took a play therapy class. I took... oh your making me think Kathy. Um... I did career counseling, I did abnormal psych, um... trying to think of more of the elective ones I did. Play therapy was the best. I did group therapy...

K: A lot of those were required.

P2K1a: Yeah, yeah, the play therapy one was probably one of my electives because I wanted to work with kids. And that was a great experience. We actually went down to the um... Oh my gosh, I forget the name of the clinic, the center, the...

K: The autism center?

P2K1a: No, it was the children's center down by a children's hospital, and we, and I can't think of the name, but there was a two way mirror and we got to actually watch and then they let us go in and do some therapy with the kiddo's... it was awesome. I'll have to think of the name of it. So that was probably my favorite class. And then I took research and all the typical classes.

What is your therapeutic orientation and describe how you came to choose that orientation?

P2K1a: I knew you were going to ask me that. I think that my orientation, I don't know, I think I go between Adlerian and ... and, I'm probably very Adlerian, I just, I ... I guess when I approach someone, I'm very in the here and now, in the moment, and trying to... I keep everything that I know of the past in the back of my mind, but sometimes that isn't always the issue that comes into you, and I so I really try to focus on what do they need

now and then once we get that then we kind of go back and deal with other things that may be still lingering from our previous sessions.

K: That makes sense.

During your schooling, how much emphasis was placed on trauma and PTSD?

P2K1a: You know, I would say that it wasn't necessarily the classes that were trauma focused, but the professors that I had, who would guide us towards that specific issue. Um...but I don't think it was a primary focus in, in all the education. I think the most effect of trauma, was from my group therapy teacher who had a private practice and was, and taught as well, and she dealt with a lot with trauma and so she brought that into that classroom. This actually is very interesting now that I think about that. I don't think there was really, and we didn't really have any specific trauma courses. Which is huge. That's very interesting actually now that I am thinking about it.

K: Yeah, there weren't in mine either.

P2K1a: That's interesting

K: The only way I got into it was, in my Master's internship, I did domestic violence and substance abuse.

P2K1a: That's what I did.

K: And um... with the criminal population, what I kept finding, even with the domestic guys and women was that these people had layers of trauma and because the system, the DV system that we have is so containment focused, no wonder they don't get better.

P2K1a: Right

K: And my whole thing is, okay, I have got to get some real education in trauma, so that's when I went on ahead and took my own personal trainings and everything.

P2K1a: Interesting

K: Yeah, and then went through into EMDR, brain spotting, mindfulness, and you know, just all those courses to beef up that and then I did, and then all my course work in my PhD was all about trauma or PTSD and ID, which there is hardly anything there and stuff... but really the brain functioning of trauma and that kind of thing, and so, yeah and just really, you know, my courses didn't have any of that.

P2K1a: I know because that is really interesting. My group therapy teacher, only because she did trauma, and so she would bring that into the conversations that we were having about group therapy. Which is awesome. She was amazing.

K: So, for you, just knowing.

How did you obtain your knowledge and any training in trauma and PTSD?

P2K1a: Great question. So I started in my internship. I worked at a Family Center, providing therapy to kids and families that were victims of domestic violence. And again, saw a ton of trauma for these kiddos who didn't understand what they were witnessing, and how and nor did the parents understand how it was affecting them. So I started doing trainings, with my internship and then I went to work at a community mental health center, and I would say 50% of the people that I was working with there were trauma, strict, just straight trauma. And so throughout that I started to take individual courses in trauma and PTSD and mindfulness.

What kind of courses or what kind of trainings did you take?

P2K1a: You know... I actually, so I did them through PESI.

K: Yeah

P2K1a: And I kind of... you know, I kind of inundated myself, just anything that was trauma related, or even just how the brain manifested trauma. And so I don't even, I can't even tell you how many I have done but I... and that is still so much of what I work with that I continue that.

K: Right

P2K1a: Anytime a new one comes out, I sign up and go to that. Well it is interesting because I had a particular case. She was actually one of the worst abused cases in the... my county, and ... I got her, in fact I got her straight from the hospital and um... When I first started seeing her, she was almost comatose. She walked in, wouldn't talk, wouldn't give me eye contact, wouldn't do anything. And I worked with her for a long time and her dad was so abusive to her in every manner and to her mother, and they kind of shared the abuse and so when mom would have a mental break down then she would endure all it, or if she had a mental break down, mom would endure all of it so they would try not to end up in the hospital. And so social services were involved because she was a person with disabilities. I think of that case... it just touched my heart. This girl is an amazing young lady and just to see her kind of come through this trauma. I learned so much, I think about working with trauma because of her. You know, because you read it, you do the research, you can be told, but when you are in the moment and really sitting and feeling, with her, it was, she is just an amazing and I love her and I still see her today actually. And so I saw her grow and work through so much that she actually could forgive her father and chose not to take him to court. And so that was pretty miraculous for me to watch that transformation... cause I know how I feel about the trauma and you know and

how she was treated. And so to keep that personal piece of it out of it... because I wanted to kill him. You know, if I could, I wanted to kill this guy, but she, you know watching her provide forgiveness was amazing. I don't know... it gives me chills. Like, she just an amazing person, and I think that's a lot of what led me to also want to get into trauma and really learn and help people through that.

K: Right, I see that too.

P2K1a: God love them.

What theories and approaches do you use to treat trauma and PTSD? (17:32)

P2K1a: Um... You know, depending on the level of trauma, I go with... I'll even start out with play. I'll do a lot of play or art because a lot of times, no matter what age someone is, or their disability, talking is very difficult. Um... and so I'll start out with either play or art or seeing under...

K: *So what's the theory behind that?*

P2K1a: I don't know.

K: Right

P2K1a: Help me Kathy! You're the...

K: Well, you know... it's more... I think... and I don't know much about play or art, but it seems like as their inundated in that then... and their doing something, expressing...

P2K1a: Expressing, Yeah, right

K: They can express it that way and it's easier. "Tell me about this."

P2K1a: Yes, yes, exactly.

K: You know... I think even like... when we do some of those ...tests that are not, they're..., you know, there like association, even like the Rorschach, or that kind of thing, like House, Tree Person. You notice the house and it doesn't have a foundation.

P2K1a: Yes, yes, exactly.

K: You know, so you look at those kinds of things.

P2K1a: And you can start questioning... Oh, "Tell me more about"... and as you're making it about the house verses their trauma, and they can express their trauma through something else.

K: Right, right. In my trauma training... I have a person... we... I did some art therapy with and as with she started, it was just... her rooms, they were just terrible, she even put it, the person, and where the abuse and everything was.

P2K1a: Oh....

K: Three different times, then the house started to have some shape to it. And by the end, it was... there were flowers, there were trees...

P2K1a: Ah...nice.

K: And the new me, because we were always talking about new me behaviors and old me behaviors.

P2K1a: Perfect

K: So yeah... so I put that in my trauma training, where I actually even have those pictures in the succession.

P2K1a: Nice

K: So again, you can see... just using that.

P2K1a: Yes

K: And I'm not trained in any of that. It's like, jut draw me a picture. You know, so...

P2K1a: Right, but its expression. I mean you're using expressive art, Yeah, and I think that is so amazing for people with trauma. Again it doesn't matter what age or disability, because I think it just opens that door.

K: Right, right, Okay, So...

How would you describe a person with an intellectual disability?

P2K1a: Um... okay, I guess I've never thought of that or how I would describe someone. Um... You know, I think they're a person and they struggle with certain areas, just like anyone does. And they're... I guess, I... I try... the first thing I try to do is to figure out their level of understanding so I can make sure and... Explain things in a way they are going to understand it. But I think they are like everyone, they just don't understand things... they understand things in a different way than some of us.

K: Do you ever.... and this is sort of a side bar.

P2K1a: Yeah

K: But... like...So many times, the people we see don't even know why they are in our system.

P2K1a: ah ha

K: And...

Do you ever talk to them about their intellectual disability?

P2K1a: I do

K: You know... and

How do you go about explaining it?

P2K1a: Great question, you know, I do... because...and it's interesting because I've had... I have kind of done some joint therapy with sex offenders, with a sex offender therapist and then I've done some trauma training in conjunction with that. And a lot of these guys are pretty high functioning. Um...In fact, a couple of them absolutely refuse to say they had a disability. Which is kind of trying because I think folks who get that they have differences, are easier to explain ... like easier to have that conversation about what is your disability. But folks who don't want to admit that they have a disability is very difficult. And with one gentleman, he actually left services after his treatment. Um... because, he, and he swore up and down he didn't have a disability. And so we had long conversations around what disability means and what that looks like, and how that's different from everyone and... You know, I think everyone could be considered to be have a disability because we all have struggles, you know, none of us are 100 % at everything. And so that is kind of how I go about doing it, is that we how we all have disabilities, in the fact that, whether they are medical, behavioral or mental. We all struggle with things in our lives. And I think making it more like kind of normalized, helps folks see that.

K: Yeah

P2K1a: Like for him... In fact, he still checks in with me. I love this guy. He... he did leave services. And we talked a lot about preparing him. "Okay you've had all this support and services and this is why you've had this because of your disability, and now you're going and you're not going to have anything, and how are you going to survive that and still manage your disability." So he was able to come around and realize that he did need assistance and pin-pointed some family members that could assist him in those areas that he needed, so he could leave services, but it was very trying. I mean, it's very trying with the high functioning people.

K: Yeah, "I don't want to be around people... don't call me that."

P2K1A: Yeah... "I'm not disabled."

K: Right, right. I'm pretty straight forward. You know, I'm more reality, I don't foo-foo things around like some.... some team members do and I just say, "you know what, the thing is, your brain can't take in as much information and it's hard to hold on to that, and so... sometimes there's words that are too big that you don't understand, so... I really put it through, if I want them to advocate for themselves, is say, "I don't understand what you're saying."

P2K1a: Yes

K: "Explain that to me," you know... and go over it. "I still don't understand." So I put it back on them. Sometimes, you know, people are going so fast in these meetings.

P2K1a: I know

K: That I always take time... you know... the next session to go over that. That kind of thing.

P2K1a: Right

K: But it's so... you know, I don't foo-foo around and I'll even just say, "I'm going to college." Okay, here's a college text book. Read this page for me.

P2K1a: I've actually done that too.

K: You know

P2K1A: And they can't.

K: Right, so then I get the children's book out and say read this page for me, and they can get some of the words.

P2K1a: Yeah, yeah

K: And I say, "This is where you are at" and this...

P2K1a: Right

K: Is because your brain doesn't work as fast.

P2K1a: Right

K: And that doesn't mean that...

P2K1a: You're a bad person

K: Right, I said, "look at it, you have a job, you have an apartment, you have your friends you have a girlfriend, you have an account, you know, you know the bus system better than I do."

P2K1a: Right, ah ha

K: I can't do that and so... and there are some things that you are good at that I am not.

P2K1a: Exactly

K: And so, you know, that's how I put it at them.

P2K1a: Yeah... I like that. Yeah... I like that. Very good.

K: So, we kind of lost a question there, but um... well... we'll see. Okay is that number 9 or number 10, okay, it is.

What kind of stigma or stereotypes do you feel people with ID experience? (24:39)

P2K1a: Oh honey... You know... I feel that... probably the biggest stigma is that there's something wrong with them and people don't want to be around them.

K: Okay

P2K1a: And... Or... they treat them like a child. I think those are probably the two biggest two things. They don't know how to react and so they either like, "Oh my god, Stay away", or they're like, "Oh Hi, little baby," and they kind of baby talk and do the child thing. And neither of those things is correct.

K: Right.

What about ... or ... in regards to getting mental health treatment or therapy or trauma therapy.

P2K1a: Oh they can't. I mean... and it's interesting that you say that. I... when I was working at the community mental health center, you know.... I was kind of the go to person because of my experience. And I would decide whether or not they could receive therapy, and I would say 97% of the time... absolutely, and I didn't care if they were nonverbal or not. If they... If they were able to engage with me, we had therapy. It didn't matter how they engaged, just as long as they could engaged. Once I left... I get referrals constantly because... they will, or... and, and they are having issues getting medications

because they... the community mental health center... at least... and I think a lot of the mental health centers require therapy to get medications.

K: Oh wow.

P2K1a: And so... someone will go in, and they will need meds. And they will determine they can't get therapy so they will refuse to do meds.

K: Oh

P2K1a: Ah ha and so then they call me... Ah... NO! They are a Medicaid provider; they cannot refuse to provide psychotropic medication. So this is who you call, and this is how you do a grievance, and this is how you get back in. So then they will end up going there and come to me for therapy because they will deny them therapy.

K; Oh wow

P2K1A: And that happens a lot. Like, I would say... I mean, that's why I have a private practice.

K: Right

P2K1A: I mean, really!!

K: I know that another community mental health center is a little different. Only because I have a couple people go there, and they are meds only.

P2K1A: See, that they will do that if you do a grievance.

K: But they also know that I provide the therapy.

P2K1A: Ah ha

K: And we've had a lot of people come over from, to from a different community mental health center. I mean... so

P2K1A: And they have a whole DD program.

K: Yeah

P2K1A: I mean that's... and isn't that interesting that... I know, I know. And... Yeah... and the community mental health center are horrible. I would say they're probably one of the worst ones. They...I mean, It blows me away, because I'll call, or... or they will know

that they are in therapy with me and then they will refuse meds because they have to do both...

K: There

P2K1A: At their office. And so I've had people file grievances. Okay, that's not good mental health... Like, I'm not going to give up my therapist.

K: So is the community mental health center... are they through the Behavioral Health office or that Behavioral Health office. I thought...

P2K1A: They're that Behavioral house because of the county they are in.

K: Oh okay, I thought they were different.

KAY: No,

K: So that's who you go back to. You go back to the Medicaid Behavioral health office, and say they are refusing to do meds.

P2K1A: Yes, this is really funny because the person who is now over that behavioral health office is a person I know... Do you know her?

K: No

P2K1A: She was on HRC at that agency for years.

K: I think so.

P2K1A: Yes... She used to be the CEO at a community mental health center.

K: Oh

P2K1A: When I was there. She actually hired me. And so... I'm like, call that person, and she'll take care of you.

K: Right

P2K1A: Because she knows. I mean, you cannot deny someone services.

K: Right

P2K1A: But they will try.

K: Yeah

P2K1A: It's like, they're Medicaid, and you cannot deny Medicaid services for this person just because they do not want to see your therapist. You can't do that.

K: Right, yeah

P2K1A: But they do it all the time.

K: Yeah

P2K1A: And unless you bitch, they won't do it.

K: Yeah

P2K1A: You know...

K: Just checking to see if it's still running.

P2K1A: Time, Anyway

K: Okay, that's great No...That's great. No... This is more of the interview that feels good to me.

P2K1A: Oh good... good, Oh honey good

K: Just having a ...

P2K1A: a conversation, yeah... yeah

K: Tell me a story about.... You told about a person but,

Tell me a story about your experiences with a person with intellectual disabilities.

P2K1A: You know... I actually have a good one, a good one. I have a guy...who is bipolar, and... I would say he is mild MR... And he is a big guy. He's...god, 6'1' probably, 300 pounds... big guy. Ad has anger issues. And when I first. .. it was difficult for anyone to work with him because they were afraid of him. Even though this guy had never struck anyone, had never attacked his staff, but just because of his look, which I found very interesting. So I started to see him, and... He is a giant teddy bear. Like his... He's got so many emotions going on in him and didn't know how to express them except with anger, and that why people were afraid of him. And so it is interesting because he didn't know how to express that hurt and that sadness and that disappointment that he had. And um

...and so I think ... so he lives in his own apartment now. He moved from a host home to his own apartment. And... Has grown and learned so much about himself and his relationship with his family, because his mother takes full advantage of him and takes all his money when he works.

K: Oh.

P2K1A: And so I have been working with him on, "Its, your money." "Your mom can't take your money." "You need not feel guilty..."

K: Right

P2K1A: When your mom takes wants money...

K: Yeah

P2K1A: And so... I think that has been an interesting experience on how... you know... a lot of our folks don't have families and then when they do, they manipulate them.

K: Right

P2K1A: And so it's this catch 22, Do you really want family involved with them or not?

K: You almost put that as.... I'm wondering if that's part of the stigma and stereotypes.

P2K1A: Because they can be taken advantage of.

K: Yeah

P2K1A: Absolutely, you're right, absolutely.

K: Yeah, So... Just a follow up of...

Where do people with intellectual disabilities live and what do they do.

P2K1A: Good. Well they can live in many different arenas. They can do a host home, they can do independent living in an apartment, and they can have roommates. They can live with families, they can live in a group home, 3 bed PCA's. Um...and I think it is really just based on their needs of how much support they require.

K: And what do they do, during the day.

P2K1A: Oh, they go to day program or work. Yeah, although that has been an interesting turn of events with the state, as far as deciding that they are closing down workshops and they that they must... after 5 years, get a job in the community. And I think that is

difficult for some of our folks. You know... some of our folks... they enjoy doing the little bit of work they have, and kind of... the work shop centers and they do not want anything more. And they are functioning enough that they can make that decision. But then, it is going to be taken away from them eventually.

K; Well some of our agencies have also gone to the work crews.

P2K1A: Oh good,

K: Yeah, out in the community.

P2K1A: Good, good

K: So... Yeah... there are a couple that um... actually clean, like over at the college.

P2K1A: Oh nice, okay

K: Yeah, So they start real early in the morning or late in the afternoon. They have two shifts.

P2K1A: Oh good, good

K: Yeah, so there are some... some enclave work, or you know that is a small enclave in a business.

P2K1A: Which is nice.

K: Right... so they are considering that as supported employment.

P2K1A: Oh good.

K: In the community, but they have a supervisor there. So we've seen some of that.

P2K1A: Good, yeah

K: Alright, so...

During your schooling how much emphasis was placed on people with intellectual disabilities?

P2K1A: I would say none. I mean... I don't think... I don't think there's any... now there is... I think it's gotten better since I graduated. But at the time there was no... There was no class to take that would teach you about someone with an intellectual disability.

K: But even in the other classes. Even in research or even in some of those testing, any...

P2K1A: Not really... I mean, well...maybe testing, no... I mean no... I don't think that was ever... I mean we talked about MR because it was in the DSM, but other than that... I don't think... I don't think... I don't think any of my classes specified, not even in career counseling, like nothing. Yeah, just wasn't talked about.

K: Yeah

So how much emphasis was put on mental illness and psychiatric disorders with people with ID?

K: Oh none... none because they are retarded. I mean... you know... because that is the disability, so they don't have mental health issues.

K: Right, Right.

P2K1A: Ah ha, Yeah, and that's a huge stigma. That... They don't need mental health services because their issues are with their developmental disabilities.

K: And... What's really interesting is that research shows us that 30-40 % of our population... more than the general population will have some kind of mental illness. And... Then there is some research that says that people with intellectual disabilities don't remember trauma, they don't have the insight to process trauma.

P2K1A: Oh bull.

K: They, you know, those kind of things. So... it's been...

P2K1A: See, that's just crazy.

So why do you think that is... that there wasn't an emphasis in school about ID or psychiatric diagnoses.

P2K1A: You know, I think it is a lack of knowledge. I also think its society not recognizing the needs of people with disabilities. I mean...I think we've come a long ways with the deinstitutionalization, but I also think that there still is a mindset, everything is with their disability. That there's no... They can't have a dual diagnosis with anything. Which is completely untrue.

K: Yeah, yeah. So ...

What kind of traumas do people with ID experience?

P2K1A: Oh... I... being in the institution, that... um... so many things went on...prior to people really taking a look with people with disabilities. And they were sexually abused,

emotionally, physically... I mean... I think they have run the gamut of abuse. And in turn, some of them have had issues with alcohol and drugs with trying to cope with that.

K: Yeah, I have a substance abuse group.

P2K1A: God love you honey, I believe it, because it's... it's very common, especially with the higher functioning folks.

K: Yeah, And I also look at... what I've found, even in my work with trauma... as you go into the schools and how they were bullied and teased.

P2K1A: Yeah, yes

K: And, I mean... I have one client that... even... she doesn't read the rest of her group. She's just automatically triggered. And thinks she is being teased by her group... And she will take off.

P2K1A: And it's not that way, but that what she... it triggers her

K: It just triggers her.

P2K1A: Bless her heart.

K: Yeah, yeah.

Describe how the symptoms of PTSD might look like in a person with ID.

P2K1A: Well I would assume they are similar to anyone, but I think... you know ... isolation, I think um... I think they have the same physical symptoms... around... they can wet the bed, no matter what age. Well something is triggering that trauma... um... I think they can tell us... I think they can say "Hey, this happened to me." We see behaviors from it. We see... anger, we see... physical aggression. We see... um... Yeah, I mean... yeah

K: What about, like dissociation and flashbacks?

P2K1A: Absolutely, absolutely. I think the flashbacks sometimes may look... I don't know that someone who doesn't know the population, they may see them more as hallucinations versus flashback. I've run into that. Because that is just how their... Their sure how to describe what is going on for them, but absolutely I've seen flashbacks.

K: One of the things that I've seen... this pattern over and over and over again, is um... the person having a flashback and then making a false allegation towards somebody.

P2K1A: Allegations, Yes

K: And I've seen this pattern and I haven't been able to find any research on it.

P2K1A: Oh, I'm sure. Right

K: But in my work... and, you know, I come back and they're saying, No, this guy touched me, and yet that person wasn't even there that day.

P2K1A: Ah ha.

K: And... but something triggered them, or they go to the staff that did that because that is the first person they saw. But they were in their own flashback.

P2K1A: Well it's interesting too, because I have a gal who was abused by a provider, when... the first time she moved out from her mom's. She's now been back with her mom for years, but when she has a seizure... a clustered seizure... that sent her brain back and she will start making accusations with anyone that is around her. So like... she'll say, "You hit me, why did you hit me?" And her mom is like..."what do you mean, I'm sitting right" ... No she didn't, but she's so in it... that she's actually in that moment of that abuse... and the seizure triggered it. It's very interesting, seizures and how that plays into all this too.

K: Yeah, yeah

P2K1A: Ah ha

K: Yeah, Interesting.

K: Well, I think this is an easy question for you.

Would you work with a person with ID who had trauma and PTSD?

P2K1A: Absolutely, I'd prefer it.

K: Some of these questions are geared towards people who don't, but I had to keep them pretty...

P2K1A: The same

K: Why would you do that?

P2K1A: You know... I find... I feel gratified in helping people grow and learn about themselves. And I think that there's even more gratification seeing someone with a disability work through issues that people pushed them to the side for years, and years, and years. And so I'd... And so ... just the little steps forward that they make, I think is awesome. (39:35)

K: Describe what kind of training you would need to work with people with ID who had trauma PTSD, or more training, what more would you need.

P2K1A: You know, I think if someone was just coming in, I think they have to be trained in both fields. Like, they really need to understand how both systems work....because they're so different, and yet they interact so much. I think, for me even... I think...um... any new training and ways to work with folks in different manners such as EMDR... um...you know, I think mindfulness is a great technique to work with our folks. And as new things come up... I think just training and then figuring out how to use those with our folks, with people with disabilities. Everything can be used with them.

K: Adapting

P2K1A: Yeah, you just have to figure out how to work it.

K: The big thing that I noticed coming around is acceptance and commitment therapy.

P2K1A: Yeah, I saw that too. Yep, ah ha

K: Yeah, so...

P2K1A: I actually am thinking about taking one next month

K: Oh, are you?

P2K1A: yeah, I am, yeah.

K: I was thinking about that, but I'm doing the Counseling Association conference.

P2K1A: Oh Yeah,

K: Yeah, yeah. They're paying for it. There are my CEU's

KAY: I know, I just got the flyer for that actually.

K: There are only a few more days. Yeah... Yolom is going to be there, so...

P2K1A: Oh he is...

K: I know...

P2K1A: I love Yolom, I might have to go to that.

K: Well, you better get on

P2K1A: Tomorrow, yeah I saw that, my ... got reversed

So let me ask you this...And you sort of answered that...

Describe how you might modify or adapt your treatment approaches for PTSD for people with ID.

P2K1A: You know... I think the biggest part... really understands their level of understanding. You know, if you're dealing with someone who... you know, that thinks like a teenager... you do not have to modify much, you know... If that's their level. If you have someone who's more childlike, who's more functioning at a 8 or 7 year level... they're not going to understand the words... so you're going to have to maybe act it out more for them or be more creative in using expressional type ways to get them to express it. Um... you know, I love giving anyone a way to express themselves through something else first. They... It's hard for our folks to...be in that movement of the trauma, and so... you have to do it step by step. You know, you get them to express it through something else and so I think it's just their level of understanding and what can I use with this particular... type of... and using with them.

K: Yeah...

Describe your overall perception of trauma treatment for people with ID.

P2K1A: I think it is very limited. I think that the people who do it and know the systems are great, but I don't think there are a lot of resources to for people to access to receive the treatment they need.

K: Amen

P2K1A: Ah ha

So has your perception changed since the start of this interview?

P2K1A: You know... it has a little bit. There's more, I think... resources that I don't know about. And you know, just talking with you, and... I think... also knowing that there is not a lot of research out there and you know, I think there needs to be more.

K: We should almost start are own... well I know that they have.... um...What is it... a chapter for... is it... intellectual disabilities? I don't know if we even have a chapter any more through AAIDD or whatever the whole ...

P2K1A: Thing called, Yeah, I haven't heard of anything.

K: And we don't have anything through NADD

P2K1A: No, Ah ha

K: You know, there is just such a handful of us... it would be so nice to have... you know, a group.

P2K1A: Quarterly get together or something to talk about it.

K: Yeah, wouldn't that be nice.

P2K1A: Okay, there you go Kathy...

K: Wait, wait... Let me get through school first. One of the research articles that I read that was... um...just because... um... you're not... you know... you're not in a research study, you should go on ahead and document and tell your stories.

P2K1A: Within you own experience.

K: Right, right... you can submit those to the NADD for their bulletin.

P2K1A: Really?

K: Yeah, you can... any of those. So you can write them up. So what I have started to do... is I started filming my EMDR sessions.

P2K1A: Oh... cool

K: Because eventually, I'm going to do that study. So those that give me permission and we just do... any... you know... I also filmed a person with ID who has a narcissistic personality. Eating disorders, and just getting really mad at me and cussing me out. So anything like that ... or someone that doesn't have very many verbal skills... I have been able to film that as well. So hopefully I can incorporate those into whatever trainings or presentations... or that kind of thing.

P2K1A: Perfect... so that is cool honey... I like that.

K: So... You know what?

P2K1A: That's it.

K: That's it.

P2K1A: Oh honey, that was painless.

Appendix H: Full Transcript Sample of Participant with Experience Working with People with ID

Title: P5L1a:

Record date: 4/5/2016 9:13:55 AM

Record time: 43:06

Recording file name: P5L1a:

Okay, so before we start the interview, I'm just going to read this statement and then you can answer true or false.

P5L1a: Sure, okay

K: For the purpose of trustworthiness, validity, and possible conflict of interest Please answer the following question before we continue. As the researcher, I have no affiliation with you or your business, and between us we have no clients or business affiliations in common. True or false

P5L1a: True

K: Just wanted to get that in there. Alright, so...

Describe your practice and the type of clients you see.

P5L1a: Sure, um... I'm an LPC, I've been seeing clients for 18 years, primarily all of them have a developmental or intellectual disability, or I work with family members who have a family member that have a child or an adult that has developmental disabilities.

K: Okay, and um... So that's all you do?

P5L1a: I do some sibling groups. I also do sexuality and relationship groups with individuals with ID.

K: That's a main area of need.

P5L1a: Yeah, another therapist and I do that together.

K: Oh, that's nice.

P5L1a: We really have enjoyed that.

K: Yeah, we used to do the PAIRS group here, but it was so hard to keep people coming and transportation, and a time when everyone could be there.

P5L1a: We actually did with the school for their transition group.

K: Oh nice.

P5L1a: We thought we were going to be doing more than the group and more people came in to look at it and were worried about the information, be taught. It was a political thing and it didn't pan out like we thought.

K: And that such a very important, especially in that transition.

P5L1a: Absolutely.

K: They didn't get it. They didn't get it.

P5L1a: You know, they worry about liability, you know, but...

K: Yeah, even if the parents would sign a permission slip.

P5L1a: Yeah exactly. And we talked to parents, I mean we followed total protocol, but the school board was worried. It's kind of like; oh don't give them that information.

K; Oh... Well that's how they get hurt. You know.

P5L1a: Right, exactly, exactly.

K: Oh my goodness, that's something else. Okay,

So you described your credentials and the number of years of practiced.

You're an LPC; you've been practicing for 18 years. Any other credentials that you have?

P5L1a: No... I don't think

K: You know any memberships with any ... NADD, American Counseling Association, any professional organizations.

Describe the types of payment and funding options you provide with your clients?

P5L1a: Okay, um... almost all of my patients are paid through Medicaid, through the CES waiver.

So that is waiver?

P5L1a: Or the SLS waiver, I do have private pay; um... that's pretty much it. I don't take any insurance.

K: No Medicaid or Medicare?

P5L1a: Medicaid, well through the waiver. I've only been signed up to be paid through Medicaid, through the individual's PARs.

K: Right, so no, just straight Medicaid waiver. No Medicaid /Medicare. Is there a reason why you didn't go that route?

P5L1a: I haven't needed to. I mean I've got a full caseload with opportunities more and more if I want. So I have never really had to explore any other means. Also, many of my clients have Medicare and LPC's can't bill Medicare.

K: Right, right. So, you probably contract with community centered boards.

P5L1a: Yes, all four of them in the metro area. So I get all four of them.

K: Okay, Alright. So...

Can you tell me a story about what made you choose the field of psychology and human services?

P5L1a: Well, I have a brother with intellectual disabilities and um... got involved in the field in the early 70's because of him I think. Um... and after my third child was born I decided I wanted to try something different. So I went back to school to become a counselor. I really was not intending to do it with this population and as I was going through school, Wow. This is a really neglected area with the people I have worked with for many years and it was also a... an easy way to get clients cause I knew so many people, so many agencies that I had worked in privately, so I went to one of the community centered boards and said can I talk with your resource coordinators and to see if there was a need for this, and of course everyone said, Oh.. We don't have any therapists, so it kind of evolved from that. My passion has been people with intellectual disabilities since I was 20.

K: What was it like in the early 70's.

P5L1a: Well, I actually worked for the state, at the institution.

K: Oh... so you did the institution.

P5L1a: And I actually worked there a year and met a group of people who were associated with the Advocacy agency, who were looking into deinstitutionalization and early intervention. And so I got into early intervention first, that was with an agency, it was the first um... early intervention in the metro area. It's kind of how my career started. Then I moved to a school for people with ID in a different county and that's when I got involved with the community centered board in that area. And you know... did some case

management ...did the family support program and that's when I went back to school, thinking I was getting out of the field.

K: You know... I...where I started up North with the deinstitutionalization movement. That was a little behind because; boy the... it was a smaller one up north. That's where I started and moved towards their residential and day programs. That was in early, early um....late 80's and early 90's

P5L1a: That was a long time ago.

So where did you go to school and why did you choose that school?

P5L1a: Well, I went to a city college for my undergraduate because it was what I could afford. My family did not have much money. Um...

K: What was it in?

P5L1a: It was in human service. .Um... I actually got an associate degree in human services. And then I went to work at the institution, and then I went back in social welfare, and finished up a bachelors in social welfare.

K: At the city college?

P5L1a: Yes... and then I ended up getting the LPC through um... up north.

K: That's where I got my undergraduate.

P5L1a: Because it was an off campus program that was in the city and it every other weekend and I had 3 kids, so I choose it because it was a really convenient way for me to do it.

K: Yeah, I saw that program. Um... and in fact, I think a couple of our people did that program because it worked out so well.

P5L1a: I mean its intensive weekends.

K: Right

P5L1a: It worked so well.

Describe the types of courses you took for your LPC.

P5L1a: Theory, um... Ethics um... testing... all the standards. They're not coming to mind.

K: Yeah, any electives that comes to mind.

P5L1a: It was a pretty strict program and this is what you took. Yeah

K: To meet the state requirements. Yeah, that was the same with mine.

P5L1a: Yeah

So what is your therapeutic orientation and describe how you came to choose that orientation.

P5L1a: Reality therapy works wonders in my practice. I think that and at the end, it really aligns well with cognitive behavior therapy, but what I really like about the tenants of that therapy is that, you're looking at... you know... behaviors your trying to satisfy, four major psychological needs. And that the need to belong, the need for freedom, the need for fun, and the need for power. And you look at this population... Gosh, these are all the areas that they are really lacking. So when I was in school, I just went Wow... not even thinking about working with this population, but I remember learning about reality and thinking in terms of my brother. Gosh, these are all the areas where it is lacking for him, having those needs met. So instantly, I thought, boy if I were ever to pursue my career in this arena, I would really use that as a therapeutic...

K: Is that Glaser's work

P5L1a: Yeah absolutely

K: I like his work because, you get to make the choices, you empower them, they have all the power. You can choose this, but this consequence will happen

P5L1a: Exactly

K: You choose that and this consequence will happen.

P5L1a: Absolutely, exactly. You're making that choice. Yes and... you know what I discovered is, they are meeting those needs, but often time in very dysfunctional ways.

K: Right

P5L1a: It's a nice framework to... okay, let's look at... let's look at are these needs being met. How are these needs being met? How can we do that in a more healthy way?

K: And it just seems like it works really, really well with families. Because then families can model exactly what you are trying to give them

P5L1a: Yes, right,

K: Yeah, I like that, I like that.

P5L1a: And then solution focused played into my orientation, because you know, there are just some, some techniques that seem to work with this population, like the miracle question. I always use. The scaling, particularly for so many of my clients that are not able to read at high levels, some not at all. Try to scale 1 to 10 really works and they get that.

K: I use the pictures and yeah, and even if they are nonverbal, large medium and or small.

P5L1a: Yes, Yes, exactly.

K: Yeah, we learn so well to adapt to certain things.

During your schooling, how much emphasis was placed on trauma and PTSD.

P5L1a: Boy... I just don't remember much at all. I really don't. And that was early 90's so, you know, when we heard about it, very little, very little was mentions.

K: Yeah

How did you obtain, knowledge, training and experience in trauma and PTSD?

P5L1a: Well it just sort of came up, a need realizing... when I first started my practice I had read an article that 80 % of people with ID had experience some kind of abuse. And I didn't believe it. So the first 3 years I tracked it and it came out 90% of the people I served. So it made me start thinking about, this is Post Traumatic Stress that we were seeing and I then... was sort of would... like..., Wow, this is the same thing that is happening to our vets and I started reading about it. I went to some workshops on it. I never really changed the way I had planned to see clients.

K: Ah ha

P5L1a: I just looked at it differently in terms of... particularly if someone came in who had been raped or if there had been a violent attack or something. Um... I still knew I was going to use my same framework. But I realized that through my reading and workshops... I wanted to make sure we were stable. And that's when; you know... my approach is not going right to the trauma and what happened. If they want to talk about, we talk about it, but with this population, trust is so important.

K: Ah ha

P5L1a: So... we really... I really try to down play talking about that, but building the trust. And going into the home the best way to do that. You know... people say to me,

“why would you... you know, I don't get paid for that transportation, which sometimes like... You know

K: Yeah, yeah

P5L1a: It really isn't a big money maker, um... but being in their homes, you just get to see so much.

K: So much more, absolutely.

P5L1a: So much quicker... you see the neighbor and the looks on the... and begs for cigarettes. You see..., you know... the vulnerability in the community... and they don't lock their door. You know, you just get to see them as a whole person.

K: And you see a lot of their adaptable skills too. Where they are... and that sort of gives you so much better idea of how you can incorporate other tools.

P5L1a: Exactly, Exactly

K: With that

P5L1a: Yeah, yeah

K: So I forgot... um... your practice is all in home.

P5L1a: All in home, yeah. And we get creative. You know... You can... I guess a room at um... at a library. Often times we've done that. We've been at McDonald's in a corner away from people. We have had sessions in my car. We do where we can find private space. That is what we do.

K: Right, right, yeah... It works.

P5L1a: So, back to what I was saying. First we look at stabilizing, build the trust and stabilizing and doing some soft stabilizing stuff. You know, I do tracking. Let's about how you physically feel when you feeling the affect this trauma. And let's talk about how feel when you're not, you know and let's compare those. What does it feel like when you're tense versus when you're relaxed and not thinking about the trauma? Looking at the sensory. We talk a lot about sensory. You know, are there smells that set things off. How do you feel about touch? Doing narratives. And then talking about really good positive experiences and what that feels like and how can you get to that place. We do a lot of that framework before we actually really get into that, you know, talking more about what happened.

K: And that is sort the next question is...

What theories and approaches do you use to treat trauma and PTSD?

Do you stay with the reality therapy because it's very real and...

P5L1a: Yes, right

K: You're bringing in...

P5L1a: But we do... Yeah

K: The resourcing and stabilization

P5L1a: Yes, Self-stabilizing

K: Self-soothing

P5L1a: Self soothing, you know. I don't do EMDR, but, I... you know. I will send my clients off to people who do. Because I think it can be really helpful. I just have never, you know... I've been so busy; I've never really developed any other things other than exactly what I do.

K: Right, right

P5L1a: Music therapy, I'm a real believer of that. I will send them off to music therapist if I don't feel like I'm getting results. I talk about music with my clients too. Listening to music. I call it wrap tight in a blanket, put on your head phones, Mindfulness, All the mindfulness. I've done reading a lot about that, incorporating that.

K: I've been looking into the Acceptance and Commitment therapy. You know, accepting, yes this happened to you and commitment to change.

P5L1a: Yes, absolutely. I try to down play the terminology. Post-Traumatic Stress disorder. Our folks have been labeled with so many disorders and their traumatized by that. They feel dysfunctional because they have this. And they have this. So I talk about Post traumatic Stress Disorder is, let's not look at the disorder part, let's look at the survivor part of it. And that... We... we always go to... yes that happened, but look... look at how you survived. Look at how well you're doing despite all these things.

K: Right

P5L1a: Really play on that positive parts of that.

K: That's great. You know there is a little bit of research out now on how EMDR with this population has become, it is affective, but it's in the Netherlands.

P5L1a: Wow, That's interesting,

K: Yeah, and I've been doing it for 10 years. I've actually videotaping some of my clients now, so we can actually see the shifts, and how we adapted it, and how we use it differently and yet still getting results.

P5L1a: Right, right... So, but it's not the first thing I go to. I mean, it's like that's down the road. That trust is so important. It is so important, and, and really very difficult to establish sometimes.

K: Well and a lot of times with the people that we serve, some weeks and for weeks on end for a time, it's putting out fires.

P5L1a: Absolutely... You know, it's just like all of a sudden they are moving, or they have a new roommate.

K: Oh my gosh, yeah, Right

P5L1a: And then they have to get a new job or someone left at the day program.

K: Yeah, right, Right. And of course then they just broke up with their boyfriend that they just call each other the whole time.

P5L1a: You know... I get emergency calls because the cat won't eat. That kind of stuff. But you have to pay attention to that.

K: Right, so you know there's weeks on end that you are not doing any, necessarily trauma, even therapy. You're doing problem solving

P5L1a: Yes, Exactly, right. Coping... I was with a client yesterday that I've been seeing who I have been seeing for 8 years and we kind of went back to base one. Her coping skills aren't working. What do we need to do? How can we revisit this and um... and my struggle is... is that fine line... I'm not your case manager, but you end up doing that.

K: You do, and my boss keeps telling me, Kathy that is a case management job.

P5L1a: It's really hard. Yes

K: I call the case manager and say this is what has been reported to me and I usually have the person in the room with me. You know for confidentiality or their giving me permission. And let them talk on the speaker.

P5L1a: Yes, right, absolutely

K: And just say, this is what is going on, and wanted to know if you wanted to follow up with it.

P5L1a: Yes, I get the release that first day and I say... you know what; we need to be a team here. I spend a lot of time again I don't get paid for it, calling resource coordinators or team leaders or family members, or...

K: Bill that under consultation.

P5L1a: Oh... You know, because I haven't been all the years.

K: Yeah, you can ask for consultation units.

P5L1a: So... ask for consultation hours.

K: Yeah, yeah

P5L1a: So you bill it separately than the individual.

K: Absolutely. So especially if I'm consulting... your recommending this is going on or for you to go to IDT to provide recommendations.

P5L1a: Yes...

K: And SP's because you are giving recommendations and education the team.

P5L1a: See and I go to all of those. I didn't realize you could bill, but you can bill for them under consultation. That's good to know

K: I'll make a copy of the state's definition because I have it here, because the way you have to write the goal.

P5L1a: Right, right

K: Your service plan goal.

P5L1a: Ah ha, Yes

K: We can... Mental Health Medicaid case management is a lot different,

P5L1Aa Right, right, yes

P5L1a: Yeah, Yeah, Well and I think that a lot of my folks are not using all the money in their plans, so... it could be a good impact.

K: No, we're doing fine. I'm making sure it's still going because this is good info. So, okay, Alright

How would you describe a person with intellectual disabilities?

P5L1a: What a good question. Individuals who have challenges cognitively. Um... and sometimes behaviorally, ah... but folks who are very capable of working through some of those challenges. And that was what I first got into this business. It was amazing how many referrals I got from clients who had been to the mental health system and were denied because the therapist said there's no way they can do the work.

K: Yeah

P5L1a: Or what about... that is... You know, I have some people who were really, really low functioning actually.

K: Yeah, Yeah

P5L1a: And have been able to do some real deep work.

K: And well, some of the research says that those... people with ID don't remember trauma. Why are you going to bring that stuff up or you know... they have no insight for therapy.

P5L1a: Yeah, I had an individual the other day who I have been working with for a long time, who wanted to talk about high school. And this is a man who is in his 40's. Brought it out of now where, never talked about it before, but the teasing and bullying, something had sparked it. So some really, really painful stuff he has been caring around. And I said, "Did you ever tell your mother?" No, I didn't tell my mom, because she would be mad at me. I mean... how he carried that pain for 20 some years.

K: Yeah

Where do people with ID live and what do they do?

P5L1a: They live in host homes, they live in their own homes, and they live with family. Um...sometimes they are married and live independently and... Um...What do they do, was that the other question.

K: Yeah, what do they do?

P5L1a: They go to work, they go to day program, they go to dances, they go to church, they...um... go in their community. Coffee shops.

K: Yeah... okay

What kind of stigma or stereotypes do you feel people with ID experience?

P5L1a: Where do I start, that's a barrier that we are having trouble with. Um... I think the biggest barrier is that they cannot live normal lives and I...I think family members still carry, promote that stigma for their own family members.

K: What about in accessing mental health services.

P5L1a: Yeah, I think there is a huge stigma that it doesn't help this population. Um... that it's not available for them because of their disability. This is not mental health, it's their challenging... you know, developmental... behaviors

K: Yes, Yes,

P5L1a: Yes, exactly, yeah, they don't need it. They've got a case manager.

K: Right...okay

Tell me a story about your experiences with a person with intellectual disabilities.

P5L1a: Just anyone?

K: yeah

P5L1a: Okay... a woman who was in her 30's who um... she had severe cerebral palsy. So... very difficult for her to communicate with people. Speech was very difficult to understand, so she hesitated getting help, but she really needed someone to talk to. She had been in a relationship with a man and felt she couldn't talk to him about. So I started seeing her and we worked really hard... um...on understanding her speech. Um... 10 years later, I'm still seeing her. Um... she had become involved with a staff member at an agency that she worked at. I think he was a van driver. And it ended up being a very loving relationship. It wasn't an exploitive relationship that everyone thought it was. He ended up being a very important person in her life. But we did a lot of work with staff and family and helping other understand. And then this man got brain cancer. So we went through the whole trauma of losing him and mom and sister died within a five year period after that.

K: Lots of loss

P5L1a: So the loss issues with her, but most importantly, being someone she could... she never talked to anyone... she had spent, um...8 years in the institution, with... she saw some horrible stuff, but because she was nonverbal, they thought. She didn't talk to anybody and was in a wheel chair, staff would talk things in front of her... that were going on with other clients.

K: Didn't think... yeah

P5L1a: She... just for 8 years. She was treated like a vegetable, having no idea that cognitively she was a very bright woman. I think she is one of my favorite stories because we have done lots and lots of work.

K: That is something though, I think that... also...that... the people we serve, it takes longer in therapy.

P5L1a: Exactly, Exactly. And you know, I've been seeing the same therapist for 10 years. To me, it it's not a big deal, but it does come up. Like... you know Wow, 10 years. And I do have some clients that I go to their annual meeting and say... we sort of plateaued and I'm not sure we can go any further. And that person says. "No, I want to see you still." and that's an ethical dilemma for me. Sometimes

K: Right

P5L1a: Often times, because I feel... so if the need it...let's do once a month and do maintenance. But I have some people who I've seen for more than 10 years that are still growing.

K: Right, right

P5L1a: You know, and that is sometimes hard for people to judge... You've been seeing her for 12 years. You know

K: Right, right

P5L1a: I know, but I have proof that we are still making progress. But it's the ones where we kind of quit making progress that is hard for me. Because they want to continue. And staff wants them to continue. Staff say, Oh they enjoy this. And I say is there a better way we could be using this money now.

K: Right, yeah

P5L1a: I get caught up in that.

K: Yeah, I get that too, but I also get others that say, "There's nothing more I can do for her" and then they come to one of us and its like, "Oh" and we go in a different direction and they just blossom.

P5L1a: Right, exactly, yes

K: But it does take time.

P5L1a: Yeah, it does take time. And for this woman who had never shared anything with anybody, even family, the trust issue took a long time because, one, she didn't trust that I was really going to understand her.

K: And take the time.

P5L1a: And take the time. And so... I tell you... I told people this... My best work is with people that are difficult to understand because you are focused the whole time.

K: Right

P5L1a: Your mind is not wandering. And that's my best work.

K: Yeah

P5L1a: And I think having a brother, his speech was very difficult. I've learned from a young age, so it's kind of a gift I have. I don't mind taking clients who have difficult speech because I can usually get it.

K: Yeah

During your schooling, how much emphasis was placed on people with intellectual disabilities?

P5L1a: None, zero, it was never mentioned.

How much emphasis was put on mental illness and psychiatric disorders with people with intellectual disabilities?

P5L1a: Oh... we didn't talk about people with developmental... really, in my entire program, it never came up. Because I watched for it. It was never mentioned.

K: Why do you think that is?

P5L1a: I think that it was so out of the realm at that time that this was not something that could benefit people with special needs. They talked about people with physical disabilities or the blind, you know...but not intellectual disabilities. It was never mentioned.

K: Yeah, yeah

Describe what kind of trauma that people with ID experience.

P5L1a: Well... sexual trauma, physical, physical abuse, um... taking advantage of, being vulnerable in your community.

Um...those are the big ones I deal. And it's not very... trauma... but being ignored and I don't know, what category, but its traumatizing ... for feeling like no one is paying attention.

K: Yeah, but I think, you know...you having the same staff person for 10 years and all of a sudden that person leaves. That can be traumatizing.

P5L1a: Yeah, yes

K: You talked about the bullying and teasing in high school.

P5L1a: Yeah, the verbal abuse

K: Right and people don't think that could be traumatizing, but for our folks... when it is day in and day out.

P5L1a: Yeah, the change in staff is huge. It's huge. The loss... that... that whole...the trauma around loss, because they are continually experiencing that. Continually...because of staff turnover. That is what happens. And they get very attached to those... the van drivers. I can't tell you how many of my clients love that person who picks them up every morning and takes them home every day.

K: Right, it's a connection.

P5L1a: Those are the people they talk about.

K: It's a connection

P5L1a: Yeah

Describe how the symptoms of PYSD might look like in a person with ID.

P5L1a: Oh... Sleep disorders, eating disorders, anxiety, anger, aggressions, depressions is huge...depression is a big one. I'm not sure about what you want. Oh... Physical illness, clearly somatic... somatic complaints

K: What about flashbacks or dissociation?

P5L1a: Yeah, you know... I have not seen the dissociation kind of part, but clearly dreams, nightmares

K: Right

P5L1a: Flashbacks, yeah, I hear about that, for sure.

K: I have tracked this and I have seen this in several of my clients. And I don't know if anybody else has seen this. But when they are in a flashback, usually the first thing that happens afterwards is that they make an allegation like to the van driver, or to a staff person or the first person they see.

P5L1a: Yeah, that is interesting.

K: Yeah, and I've seen... you know... I don't have a lot, but it just seems like they are in the moment of that thing of what happened to them. And maybe...

P5L1a: Right...because that false allegation does come up. That would be really interesting to keep a look at that.

K: Yeah, I've seen the flashbacks. And...and...For that, you know... for several, I have recommended allegation protocols. Just to make sure because... I mean... this is serious stuff and if we know it is trauma, and we know... you know that..., it just comes... and they're there thinking that it's happening and they see this person... And that's...

P5L1a: Yeah, it's real to them. Yeah...So...

K: I've just seen that.

P5L1a: Yeah, That real...I totally need to think about that.

K: Yeah... so...We'd almost have to get everybody that worked ... with our population, you know... to track these type of things and then put the study together.

P5L1a: Ah ha, yeah

K: You know... because I think individually, we don't see enough people...

P5L1a: Right, right

K: So that would be a good way to do that. Okay... So... Well yeah...

You would work with a person with ID with trauma or PTSD?

P5L1a: Absolutely, yeah... I get a lot of those.

K: Yeah, okay

Describe what kind of training you would need to work with people with ID who have trauma or PTSD. Would you need more or do like the... direction you're that going... or...

P5L1a: Me personally, you saying.

K: Yeah

P5L1a: Yeah, no, I think that the ...the tenants that I have built on work really well with it ... again, I read whatever I can.

K: Right, right always learning

P5L1a: Yeah, always learning. You know I do go to workshops... um... but reading... I love to read. I love to read anything that has to do with psychology and you know so... I probably... just keep up on some of the latest stuff.

K: Right, right...And you talked a little bit about how you would modify or adapt your treatment approaches for PTSD for people with ID, especially with the communication route. How do you do that with a person that has difficulty communicating?

P5L1a: Um... Well, you know, use pictures, we use scales, um... we do a lot of scaling, lots of scaling. I like to do magazine pictures, you know... you know, here's a picture of a couple. What do you think they are talking about? What do you... and I've actually cut pictures out of magazines and post them on cardboard and pull them out and "let's talk about this, you know... doing that. Often times, taking it out of their personal life. A picture of someone else's life. What do you think these people are feeling? What if this person did this to this person? What do you think ... How would this person relate. Taking it out of the personal sometimes really helps them be able to open up more and talk about it. But ... you know... I actually had a client, this was a long while back, he was totally nonverbal and was...was acting out aggressively... and believe me, I don't know how many sessions we did, 10, 15 sessions in... by using books, by using pictures... ah... pictures of the family... she was able to identify... there was a brother in the house who was sexually abusing her. She was able to communicate that without verbally communicating it. You know... so there always a way. Again, it takes time, hitting it at the right time,

K: Building the relationship

P5L1a: Having the right the pictures, building the relationships.

So describe you overall perception of trauma treatment for people with ID.

P5L1a: My perception of it?

K: Overall

P5L1a: Overall...okay... Well I think that... that overall... this population is not being treated like they should be because it is being overlooked as this is just their diagnosis of a developmental disability. Um... so I think it is being overlooked. Um... You know, when I say... when I first started tracking it... 90% of my folks I was working with had experienced some kind of abuse. I think it should be... every therapist, should be using techniques that you would use with people with post-traumatic stress with this population.

K: So the trauma informed treatment.

P5L1a: Yes, yes,

K: Just knowing about it.

P5L1a: Yes, yes... I mean you almost have to know about it because it is such a traumatized population.

K: Right, right.

So has your perception changed since the start of this interview?

P5L1a: Um... I don't think so... I mean, I think that.. Ah... it something that I am very aware of... you know... something that I treat, something I make...

K: It's your passion.

P5L1a: Yeah, yeah. I... I keep in touch of a circle of women we all went to graduate school together. And we meet about 3 times a year, I think there is about 8 of us. And it is interesting we graduated around the time in the same program. And all the different avenues we took in terms in profession. Someone is working with the schools with bullying. Someone is working with social services doing attachment trainings with foster parents. A couple people have private practice, one specialized in... Eating disorders. I mean it... but when we get together and talk, Occasionally one of these people will say. Hey I just had a referral from a client with ID and I'm not sure how to deal with it. I always say, no different, no different than you would... except it will take more time, you have to do more visual... you have to... so I think there is... through the years I've realized that more and more of our folks are coming into the arena of therapists that are not specific, or... trained in ID.

K: Right and some of those get referred out.

P5L1a: Yeah, exactly.

K: So that's the interview. It's so nice to have a conversation about it.

P5L1a: Yeah, Well, I am glad I could help.

Appendix I: Full Transcript Sample of a Participant Without Experience Working with
People with ID

Title: P6L2b
Record date: 5/9/2016 9:04:12 AM
Record time: 1:16:28
Recording file name: P6L2b

K: Okay, we're recording. It's on, it says so. Okay.

So I have to read this statement, okay and you can answer either true or false. Okay. So for the purpose of trustworthiness, validity, and possible conflict of interest, please answer the following question before the interview takes place. As the researcher, I have no affiliation with you or your business and between us we have no clients or business affiliation in common. True or False.

P6L2b: True

K: That's right, Okay, alright

Describe your practice and the types of clients you see.

P6L2b: Forensic... counseling. I am seeing clients who are coming out of the Federal Bureau of Prisons. Transitioning into a halfway house situation for a six month period, before they are placed on Federal probation.

K: Wow

P6L2b: So, there are a lot dual diagnosed people with serious federal crimes.

K: Like what?

P6L2b: Bank robbers,

K: Wow

P6L2b: High level drug dealers, international, um... Sex offenders.

K: Wow

P6L2b: Mostly drug dealers.... I'm trying to think.

K: So are they staying at the halfway house or are they ...

P6L2b: They're staying there.

K: Okay, so they have to do their drug treatment as well individual therapy.

P6L2b: Yes, Each... um... there's a special program in the Federal prison. It's a TC type of program... therapeutic community, and they're in that in prison for about 9 months to a year, and then um... they're given an incentive to have a year knocked off their sentence, inside. Um ... If they continue to come out and do a transitional, follow up, aftercare program, then that's partially what I do. And that would be about six months, Um... and it's considered out patient, even though they are living there. My program is outpatient. They do one group and one individual each week for the time that they are there for 6 months... and that's focused on, um... Their criminal lifestyle and substance abuse. Then I get a lot people who are referred for strictly mental health, so they had issues in prison, um... with depression, anxiety, abuse, a lot of trauma, lot of PTSD. Um ... A few schizophrenics, um...lot of bipolar and a lot personality disorders.

K: Oh yeah, I'm sure of a lot of antisocial, narcissistic,

P6L2b: Borderline

K: Borderline, Oh my...

P6L2b: So... but I'd say that even the ones that are not flag as mental health, have got a lot of PTSD, because the federal prison system is not, um... a very civilized environment, so if they go in without PTSD, the going to come out with PTSD, because there is a lot of racial stuff that goes on. It's very hierarchical. There's a lot of violence. Stabbing, is almost a daily occurrence.

K: Is there gang relations there?

P6L2b: Very much so and it is... is based on race. So ... and you pretty much have to gravitate to that in order to be protected. So it is specific ... you know... kind of culture... and most of the people that I see, I'd say, the average sentence that they have done inside the federal prison is probably about 6 years.

K: Wow

P6L2b: Some longer

K: So even acclimating to the community.

P6L2b: They come out and they um... Just crossing the street is too much to handle.

K: Wow... so are these mainly men or...

P6L2b: I do have a few women, but mostly men.

K: Do you do the groups also.

P6L2b: I do all the groups and all the individuals.

K: So how many groups do you run a week?

P6L2b: Two groups a week.

K: How many individual do you have?

P6L2b: On average ... 20.

K: Wow

So ... Describe your credentials and number of years in practice?

P6L2b: I'm a licensed professional counselor and I started being a counselor in 1978.

K: Wow

Did you have to do any... any certifications to work with this population, as far as forensics, the prison population?

P6L2b: A background check primarily, but my experience... you know... it's um... 95 with an agency, you know, and just falling into that area, but I've done continuing education... you know ... workshops, on-line things. So ... Agency trainings, um...

K: We'll get more into that here too.

How do you get paid, what's the funding?

P6L2b: The halfway house is a for-profit organization and incorporation. They have 1, 2, 3, three halfway houses and 3 outpatient clinics.

K: So what kind of funding do they use?

P6L2b: There is federal funding ... federal contracts and department of corrections contracts. So they get contracts.

K: But do the clients pay?

P6L2b: No, they have what they call subsistence for their room and board, but for the therapeutic services, they don't pay a nickel.

K: So what about the outpatient?

P6L2b: There may be copays.

K: So this part of the halfway house is all contracts and... it's all corrections. Because ... the halfway house also ... just has your regular community people that go in... you know, don't they?

P6L2b: No, court ordered, probation, parole...

K: So they must of gotten in good with the department of corrections, because I always thought the halfway house was ... just... you know... for a while there ... maybe this has changed, they were your basic rehab place that anybody could go into. You know...Not anymore?

P6L2b: I think they have always been affiliated with corrections.

K: Maybe that was another halfway house.

P6L2b: Yes ... that was residential, No ... I think they had a residential part, but I think that was all substance abuse.

K: So when you were doing your practice, did you take any insurance or any kind of funding other than the department of corrections. I know in the past we used to take some funding from the department of Voc. rehab.

P6L2b: Yes, I think I had a couple of Voc. Rehab... there were vouchers from district court. I did not take Medicaid and I could not bill Medicare because of being an LPC. Most of the people I saw really didn't have insurance, so ... I take that back. I would submit a generic insurance bill to submit claims on their own, but I did not process them myself.

K: Superbill or the third-party payer?

P6L2b: Yes

K: But that was costing you more, just didn't work out?

P6L2b: In 2009, when the economy... flattened out, I thought my clients were punking me. Because almost... the majority of my clients at that time ... I would say. "I needed talk to you, I need to talk with you, I need to work out a payment plan. I got laid off. My hours got cut." And they couldn't pay their fees. And I couldn't pay my bills, and I got strung out with making allowances with my landlord for about 3 months, and I got so far behind, that I just... it... I cut my losses.

K: That's too bad.

P6L2b: Yeah, bad timing.

K: Yeah, Well most clients didn't have insurance... so how could you take insurance.
Okay

Can you tell me a story about what made you choose the field of psychology and human services?

P6L2b: I think that, as an adolescent... I got real interested in life, why, how things happen, and I would... I remember trying to have philosophical conversations with my peers, who would... started to avoid me. Ha, Ha, Here she comes. Yeah. There were a few that were of similar mind, you know... that I ended up being friends with, but there was a counselor quality... you know... to my personality and my approach to life. And, then unfortunately... fortunately and unfortunately, that's one of those... situations where I got pregnant as a teenager and had to start working. So... I got a job with federal, what it is... the Federal Center, doing lab work and they, had a stay in school kind of program. They were willing to pay for my college education to get a chemistry degree. So I could continue and have to work so many years and not ... to not pay them back. Took my first chemistry class, passed the classroom stuff, you know... flying colors, but my math sucked. And they wouldn't pay for tutoring. They couldn't pay for tutoring. So they recommended that I go talk to people in human services... because I had a very psychological way of understanding thermodynamics. (Laughing) You know, yeah... Energy and stuff like that. So I went and got... you know... it fit. And ... I enrolled in the human services department, and continued and got my bachelors, and here I am.

K: Yeah... *So where did you go to school?*

P6L2b: A city college

K: Was that undergraduate, or your bachelors?

P6L2b: Yeah, for my bachelor's degree

K: Where was your master's?

P6L2b: Agency counseling at a college up north.

K: Oh...My bachelor's alma mater.

Why did you choose those schools?

K: Were you living in up north?

P6L2b: No I did the off campus.

K: Oh okay

P6L2b: So...They had it at in the city. That's was the main reason, being a single parent.

K: Right and you went to the city college because that was where the Federal Center would pay or...

P6L2b: It was the lowest, you know in terms of tuition and it was location mainly.

K: Yeah, I think that is for a lot of people. Cool.

K: AL righty ... Okay... So...

In your master's degree, describe the type of courses you took for your degree?

P6L2b: Basic counseling skills, group, individual counseling, I guess that... let me go back... basic counseling was theory.

K: Yeah, theories of counseling?

P6L2b: Yeah, let's see, statistics, life span, um... I know I've taken more.

K: Abnormal psych, probably, and some research design.

P6L2b: Yes, that was the stat course.

K: Just your basic psychology courses. History of psychology, probably

P6L2b: That was in the theories.

K: Any tests and measurements?

P6L2b: Yes

K: And um... let see... what else...the theories of personality, I think we had... that was different than abnormal psych, just your basic core psychology classes. Okay

So what is your therapeutic orientation and describe how you came to choose that orientation? Has it evolved through the years?

P6L2b: Um... It has evolved through the years. I guess one of the things that I have found is that one approach does not fit all. I guess my basis has been a humanistic orientation.

Um ... You know... the client centered and attitude. Um... because I think that my success has been primarily based on rapport and therapeutic relationship. And then once that is established it's a lot easier applying CBT. And in terms of maybe...strengthening the client um... with some skills and strategies and tools to cope... and that kind of minimizing... some of the daily on-going stress inference with life functioning, mostly on an emotional basis. And then, the rappers strong, clients have got... you know..., an adequate skill base that they've practiced for a while. And then the core issues can be addressed. I finally got my EMDR training.

K: Good for you.

P6L2b: I finished that last year.

K: Excellent, Who'd you take it with?

P6L2b: No, a woman... from a counseling agency. I think is what she does. Really nice, mellow woman, and that's shameful that I don't remember her name.

K: That's alright.

P6L2b: I know it's something counseling. Her email is...I remember that.

K: During your schooling, how much emphasis was placed on trauma and PTSD?

P6L2b: Very little.

K: Okay...

And what experiences made you go on ahead and specialize or get that EMDR training or do more in trauma and PTSD?

P6L2b: In all the years of my work as a counselor, I would say that about 90% of my clients have got trauma issues. And that includes not just the big T, but the little t. And that's... it doesn't matter, their all significant. There are things are unresolved that get carried on... and they... they spill into everyday functioning.

K: So would you say that part of your orientation is Shapiro's adaptive information processing model?

P6L2b: Sure... how those things happen as you're young and how they continue to affect you as you go now and in the future.

K: I think it's a good one. And that's what... you know... that's how I got into it because when I was doing the domestic violence stuff, I got so frustrated because the program was so containment oriented. You know... they get their 9 months in or 36 months in or

however it is and get them out. And yet, here were these core traumatic issues that were not being resolved.

P6L2b: And so the behavior just keeps on continuing. And the recidivism rate, you know... we were seeing 2, 3, 4 domestic charges.

K: It's just like... that's when I shifted. No, I'm going for the core issue and that's why I got my EMDR training. It was to... to frustrating for me. You know.

P6L2b: I have started to plant the seeds with the bureau of prisons. Um... because they are very specific as to following the CBT orientation as best practice, okay. And I just have started mentioning... you know... some of the possibilities incorporating the EMDR.

K: So they do not let you do EMDR?

P6L2b: Not yet... no... Yeah, but I've done some um...I've done some exercises with people using the...

K: Bilateral stimulation?

P6L2b: Yeah, bilateral stimulation, I've got the tappers. Just to incorporate some coping mechanism. But not doing... you know... the full EMDR protocol. And that's been so helpful.

K: Just getting a peaceful place and that resourcing.

P6L2b: Yeah, allies, that kind of thing. Ah ha... I've talked through those kinds of things with clients... with the little guy and the big guy. And without the stimulation, you know, behind it. You know... so kind of back to the question... is kind of... you do what's seems to be workable, what the client is receptive to. Which is pretty open when the rapport is established, and they are very motivated to, and they feel safe to process some of those kinds of things. In my experience, that piece right there, makes the difference in terms of recidivism, pro-social lifestyle and these are my... you know... goals, general goals of treatment. And sobriety, that there's no longer this attachment to the negative self-image and addiction as much.

K: I want to go back just a little bit, when you said that very little emphasis was placed on trauma and PTSD during your schooling.

Was it just part of the categories of anxiety in the DSM and that kind of thing?

P6L2b: Yeah, in my bachelor's it was in abnormal psych and when we went through the major categories. And then in my graduate class... same kind of thing. It was just... yeah, one more of the diagnoses possible, diagnoses.

How did you obtain your knowledge and training and experience in trauma and PTSD?

P6L2b: I mean throughout my experience, especially... there were so many traumas... that mainly... I got EMDR trained and um... CEU's and classes, but it has always been out of the... you're doing it on your own.

Is there a specific workshop or training experience that really got you into that, the, sort of built your orientation around trauma and PTSD?

P6L2b: Give me a minute. Nothing as far as training comes to my mind. Um... but like you were saying, you know... working with the domestic violence people, I guess... Let me back track. There was one book I read. Donald Dutton, The batterer. Turned me around, started me questioning um...the etiology, you know..., and, it all started coming up with trauma experiences in childhood and that wasn't being addressed.

K: I think he was the one that really brought to my mind, how he sort of... really, talked about the male borderline personality disorder in the batterer and how that being, you know... just not being able to attach to that relationship, and just the jealousy and the all the things that go on with the borderline personality disorder.

P6L2b: Yes, and the... which, I'm trying to think of which attachment, I'm thinking it's the disruptive attachment, which later causes the borderline, either Madonna or Whor, kind of thing... type of thing. Initially as a defense maneuver, you know... as trying to deal with those kind of things, the inconsistent parenting and attachment, you know... but carrying on through, throughout adult relationships.

K: His books are really good. For my Masters, I did that. I did my whole thesis on domestic violence and the difference between the therapy for male and females.

P6L2b: Yeah, but see, I'm not so sure... because it all should be trauma based. Seeking safety, I started to use that in my domestic valence classes as an adjunct... the men's groups. Lot of good stuff in there and they all related to it. I didn't tell them it was "Seeking safety." I didn't hide it, but as far as material, using the materials. Oh man... Powerful.

K: Yeah... Yeah,

So what theories and approaches do you use to treat trauma and PTSD?

K: You know we talked about the adaptive information process, but is it all CBT theories or are there other theories that you use?

P6L2B: um... You would ask, um...

P6L2b: Um... I... I'm not so sure... you know... where to put myself in any of those things, but what I believe is that... as we are growing up, and the limited cognition that we have, we do the best with what we have. And in the process, we have incomplete conclusions in the life span sense. But at the time, that stuff works, but if it becomes habituated, and a lot of the schemas that seem to be enduring, become habituated. So I think that, it's more of an adaptive type of thing and it becomes... you know... just like any really good learning. I've become so habituated and therefore, we operate on a subconscious level, automatic. So we get triggered, we respond, but we don't have that conscious thought process anymore. The brain is so wonderful and efficient when it comes to that. And so, as we get older and we need to change those approaches, it doesn't occur to us... let's go to counseling (laughing). And having somebody say... "What about and how does that work for you?" Or. "Does it work for you anymore?" And modify, you know... the approaches... the conclusions and becoming more comprehensive, now that you are older and you understand more. What is that looking like now? Back then you only had this little tiny piece of the whole... you know the whole puzzle... now you got more. What does it look like to you and has the perspective changed, and when the perspectives change then the conclusions change and the emotional piece changes. And then the behavior changes. So it's maturation.

K: It's almost like that operant conditioning. That... you know... especially with the substance abuse almost..., you know... they continue to use because it makes them feel this way because they can't deal with the issues that are coming up or how they are being triggered. The habituation goes on. Once they get sober it...

P6L2b: The thing with the substance abuse, I've learned... it's more complicated than that. I've learned. You've got belonging, the peer group, expectations, values, or my opinion, lack of. But then there are the values, they don't match mine. The whole process of using... the habituation of that.

K: And the addiction?

P6L2b: The whole... what to do... you know... kind of thing... and who you're with and where you go and all of that and the whole lifestyle becomes pretty set.

K: I... There's also a biological... The gene, you know, if you have the gene....

P6L2b: I think, I shy away from the genetic stuff because of the powerful messages that I've gotten from my clients from the nurturing kinds of stuff, not just the nurturing, but the belonging where do I belong, with who do I belong and what lifestyle do I belong... to find that gestalt shit. Meaning and purpose... comfort zone kind of thing. All the clients talk about comfort zone. What do you mean by that? And that's what they have described. The people... places, and things. Where I should be... who I am, type of thing. More so than the physiological addiction. Because once their mind set starts to change

and they start to consider that they can belong other places, and that they can be somebody else. The physiological stuff becomes very low.

K: Oh really?

P6L2b: Unless its heroin... opiates... that's a very strong physiological thing that's forever. I'm thinking...the other ones... the other drugs have got more of a temporary psychological thing that maybe within a couple years can be pruned. So I don't think a genetic thing that's necessarily because I have seen people do that, just by placing themselves in different places.

K: Yeah, you know you have to.

P6L2b: Relief, type of thing. And am I making sense?

K: Yeah, Yeah

P6L2b: So, this comes back to probably a very basic belief on my part that... the attachment and not just early attachment, but how we continue to attach throughout our life is really the issue,

K: Absolutely, Right

P6L2b: Thank you for giving me the opportunity to clarify that.

K: That's great, Yeah, So... Okay, So we are going to change here.

How would you describe a person with an intellectual disability?

P6L2b: Um... Well, it could be organic,

K: Ah ha,

P6L2b: It could be, I guess, organic in terms of genetic or injury. It could be organic in terms of um...tissue damage from substance abuse.

K: Right

P6L2b: Like math or a person, like that kind of thing. That comes to mind. But I think for the most part, it's um...disruptions and the developmental process. So if somebody is in a very chaotic and busy environment, they don't have time to develop and they quote in quote, in a normal way. Or according to the brain's growth. Um... so they may miss it and so of those... things, if you miss it, you miss it. Um ... Other things can be, you know, relearned or learned. Um... or compensated for or modified, you know, later on. but I do think it's, you know, at least from my experience, most of the people I see, um... are very

concrete, and their not developmentally disabled, not all of them are organic. Um...So what happened, you know, it's a... what they've had to do in order to survive, to get through life? Um... has disrupted, you know, that cognitive process in the growth, cognitive growth.

Most of the people we serve have had this developmental disability and intellectual disability since birth.

P6L2B: Ah ha

Where do you think people with intellectual disabilities live and what do they do?

P6L2b: There's such a large spectrum, that I'll have to answer that... they... they are all of us and they are everywhere and we are everywhere.

K: I like that. I like that.

P6L2b: Ah ha, and that's a relative thing too because there can be certain areas that um... can be prominent and above average, while other areas are below average. Um... Depending on the holdup of the developmental process. What happened when, you know.

K: Right, yeah

So what kind of stigma or stereotypes do you feel people with ID experience?

P6L2b: Misfits... loneliness... Maybe not full-blown hopelessness, but discouraged.

K: How do you think the community stigmatizes or stereotypes them?

P6L2b: Well, if they're into criminal behavior... low life's, which a lot of them... make... a lot of mine, you know... some of the lower functioning, resort to crime. Um...stupid, damaged, this is kind of, sort of related, not direct, nimby, not in my back yard, go away, you know. We don't want to know anything about you.

K: Right, okay...So...

Do you have a story about any experiences that you've had with a person with an intellectual disability?

P6L2b: Shew... I got somebody now that I have been working with several months and I... I don't have any kind of clinical documentation, as to level of functioning, it's just... the interactions are so difficult that something... is... there are challenges there. Um... very concrete. I've learned to not, um... present abstract challenges, to be very, very black and white, very basic. Um...And very little feedback in order for this person to stay open to me... not get defensive. Um ... And consider different points of view. So rigid, so...

you know, on a one track. Um... and so it is my job... is trying to... what about this... what about that... what about different lifestyles so you don't keep going back to prison. Um... increasing support... encouraging a better self-image. You don't have to deal drugs; you can do something else in your life. What would you like to do? Um... Not feeling like an odd ball, you know there's that... that thing that goes along... and its difficult. Um...

K: Do they do any... like any intelligence testing at all.

P6L2b: No... No, Mental Status exam is all I go by. I can go... So if they don't pass that, I can use that and say, inappropriate referral.

K: Is that right.

P6L2b: But other than that, No. And so... you know. I find myself as clinician, um... being very in tune to his body language. Um... what he is... what he's trying to communicate because it's important for me just to paraphrase, so that I've found initially... Whoa, I missed... I completely misunderstood where you're going with that.

K: Would they misunderstand what you were saying because they may have heard the first couple of words or the last couple words and went from that.

P6L2b: Yeah, so it's... yeah, the tracking thing needs more attention.

K: And so you talked about if they can't pass the mental status exam, it's an inappropriate referral, where do those people go.

P6L2b: It hasn't happened yet, I don't know.

So during your schooling how much emphasis was put on people with intellectual disabilities?

P6L2b: A mention

K: In what capacity?

P6L2b: In the human services department, they did have a specialty when I was going there. They had specialties. And...

K: Was this up north or in the city?

P6L2b: No, in the city, yeah, so... They had psychiatric, they had corrections, they had developmental disability, and they had um.... Oh gosh... Psychiatric, did I say psychiatric?

K: Yeah

P6L2b: Yeah, geriatric,

K: Forensics, or was it behavioral analysis or behavioral.

P6L2b: You know, I think so, it was more... Yeah, there were five of them. So, yeah... so maybe there were some classes if you chose that specialty that would have gone into that a little bit more in depth. I took psychiatric, so I wanted to get a more general clinician.

K: Now was that was in the 70's... 78

P6L2b: Yeah 78, 79, and 80

K: That might have been... yeah a bit little more. Because the institution was still pretty big then.

P6L2b: Oh yeah we went to the institution, um...as a... you know... kind of going and before we chose our specialty.

K: Ah, okay

P6L2b: We went to different field trips, visited different places that pertained to each of specialties.

K: Right, cool

P6L2b: So...

How much emphasis was put on mental illness with people with intellectual disabilities?

P6L2b: None, I don't remember... nothing.

K: Why do you think that is? Even on your psychiatric track.

P6L2b: Substance abuse, I'm sorry. Um...you know, I can speculate...

K: Okay

P6L2b: The instructors didn't have the expertise, the comprehensive understanding of dual diagnosis back there... that didn't even exist.

K: Right

P6L2b: Um...And there were very few instructors that seemed to really care about us being, becoming comprehensive clinicians.

K: Wow

P6L2b: I didn't..., you know... I felt that from a couple

K: Right

P6L2b: But the others, you know... kind of going through the classes and the information and having stimulating classes and... some of the classes didn't even cover relevant exercises.

K: I remember, even in your class that I came to. You know, giving an overview of DD, that was probably the only exposure they got of people with intellectual disabilities.

P6L2b: Yeah, I bet that is true. And so, but I'm really focusing in on the qualifications and experience, the lack of qualifications and the lack of experience of the instructors. You know... they're, what to do they call it, Acad...

K: Academia

P6L2b: Academians, instead of hands on clinicians, most of them. And if they have had some, it's been very little experience. Um... to be able... that's how I have learned stuff. I'm sure that's how you've learned a lot of stuff is you see people and you go... Oh wow...

K: Yeah

P6L2b: You know... you've got all this stuff. You are the DSM. (Ha, ha)

K: Right

P6L2b: You know... What do I do now? Nobody told me about this.

K: Right, Yeah, I just know that... you know, this has been my passion, so even through my training, I always put that... I took that training and put it towards everything that I knew about people with intellectual disabilities and then went through the research with intellectual disabilities, which is very little compared to some other fields in mental health.

P6L2b: Ah ha

K: So... okay

So what kind of traumas do people with ID experience?

P6L2b: The same kind as anybody else, and that includes all the above, anything and all the above. Every now and then, even these 30 some years, I hate this... but there may be... you know... twist and turns that are new, you know, that it's like... WOW. I wish I didn't hear that.

K: Yeah, Yeah, I hear you.

P6L2b: Ah ha... and that kind of follows into what I believe, um... and I'm not saying that... this is it, but all of the mental illness, um... if it's not... you know, if it's not an organic thing... or really based on adaptation that the... what's considered to be a mental illness; anxiety, bipolar, the most common one... depression. Their adaptations... you know to life events as little people.

K: Yep

P6L2b: And we learn these defenses and survival skills. The mental illnesses are survival skills... from what I hear. And when people talk about their stories, it makes so much...of course you have depression. Why wouldn't you.

K: Right

P6L2b: You know... you'd be crazy if you didn't. You know... And even a lot of the psychotic stuff that I've... you know... the client's that have opened up a little bit more about their auditory hallucinations and then... as well as some of the visual ones, are so theme based. Um... and so connected with these early trauma things... this makes all the sense in the world. You know... maybe it's not a psychotic disorder at all. It could be PTSD with dissociation or flashbacks.

K: You know, or they are reliving something, you know... and so ... being able to truly separate that out, you know. And that... maybe that is part of the issue. My folks, they come in with a laundry list of diagnoses. It's like, are you kidding me? And of course, some of those... bipolar, PTSD, ADHS all overlap so much.

P6L2b: Ah ha... So what are you showing me today? Or part of...

K: Oh yeah... oh I forget my key, and then I couldn't remember where I was supposed to go... or I didn't have my coat. Or whatever, and it's like, that's the ADHD.

P6L2b: Ah ha, Ah ha, Ah ha

Can you describe the symptoms might look like in a person with ID?

P6L2b: Anger, paranoia, um... Substance abuse... Denial... Entitlement

K: Oh

P6L2b: Over compensating

K: Okay

P6L2b: I've got to be somebody... I kind of figured this one out recently. Why are all my clients' narcissistic? It drives me crazy. But yet, they all have this... these things they are trying to hide.

K: Deep wounds

P6L2b: Ah ha, and so if there is somebody that is so much better um... and they demand, you know that they are so much better... that's... what a beautiful smoke screen.

K: One or the other.

P6L2b: Ah ha,

K: Yeah

P6L2b: Um... with trauma, intellectual, borderline. That probably should be up higher.

K: Oh yeah, we get that quite a bit.

P6L2b: Um... Depression, anxiety, um... crime

K: Ah...Okay, yep... And I have all this. Okay...

Would you work with a person with ID who had trauma or PTSD?

P6L2b: I think I do...

K: Okay, IQ's lower than 70.

P6L2B: I don't know. I mean, like this one person that I've got now. I. . . if I was a betting woman... I'd say he has low IQ.

K: So let's say, even a lower IQ came in and they couldn't pass the mental status and you would say... it would be an inappropriate referral due to cognitive ability or um... may not be able... to do therapy. Um ... Because we get that all the time.

P6L2b: I wouldn't be able to do it because I don't have the resources. Um... and there is a... a level of expectation in a lot of programs. You've got to read this stuff. You've got to

be able to comprehend it. You know... and you've got to be able to do the assignments. Write them. You've got to be able to share. You know these kinds of things in the group exercise.

K: Would you... Even knowing the guys in your groups, would you think they would be vulnerable to exploitation, if those guys saw... okay this guy, he's missing something.

P6L2b: Yeah... the one I've got now gets challenged and that's part of the program. We check each other.

K: Right

P6L2b: Okay, that's a big TC concept. You know... its healthy confrontation and not in a mean kind of way. Um... but calling each other on different distortions, um... I think my clientele... there's considered inmates, and so they don't want a new charge of assault because then they'll go back for many, many, many, many, many, many, many more years.

K: Right

P6L2b: And so I have that as a motivator. Um... which I think a lot of people don't have, but still... ostracizing, um...non verbal's, rolling of the eyes, but in individual sessions, I talk to the other people how its rude and um... talking in general senses to try to educate them about, you know... there's some people that think that of you... you know, all of us. So put yourself in their shoes. How does that feel? You know, to be responded to in that kind of way. We do the best we can with what we have right?

K: Right. When you say... lack of resources....

Describe what training or what would you need to work with a person with ID with trauma or PTSD.

P6L2b: Flexibility with respect to um... the curriculum... standard practice. Because not everybody fits into that.

K: Right... Specifically regarding their disability. What kind of... training

P6L2b: That's an excellent question. I mean, it's a training staff. Not just for staff, but... you know, incorporating it more into the curriculum for the clients.

K: Bringing it down

P6L2b: Ah ha... I am the only one with any kind of background in that whole facility. I think the case managers have to have a bachelor's in criminal justice, but other than that... nobody has nothing. Most of them don't have any college. (1:08:20)

K: Oh really

P6L2b: Ah ha

K: You are the only one that has a master's degree there?

P6L2B: I'm the only counselor there.

K: Oh really

P6L2b: So with this one that I'm working with, that I think is lower functioning. I have brought it up, um...in some of the staffing's we've had... but I just think... you know... he just doesn't understand. And I don't think anybody...

K: Cares

P6L2b: knows... know what the hell I'm talking about. "He's being a jerk". There's a reason he's being a jerk, he doesn't get it.

K: Well no because you're not explaining it in a cognitive way that he can get it. Yeah

P6L2b: And so... yeah, there's... just the environment. You know...

K: To me... that's a stigma... Or... or you know, maybe it's discrimination. I don't know... that they are not even willing to look at it. That this person... and then he's being set up to fail.

P6L2b: That's with a lot of them because it's..., were saying and we're coming back to the beginning. There's so much, I've pulled a couple of the security staff... young people... with no college background. What they do is answer the phones, they check the rooms and they do UA's. You know, pretty basic stuff... and um... they... I've pulled one girl in particular and it's um... Trying to be very brief and saying that a lot of the guys here have had some pretty rough, you know... backgrounds, and not criminal wise. I'm talking about how they grew up and the lives they had and everything else. And I said to her, "We need to be careful that we're not... just one more of those people who made them who they are today. Because we want them to be better don't we?" "We want them to go out and be successful don't we?" So I've had to be very concrete with staff sometimes.

K: So... in your therapy with this gentleman who you probably think has an intellectual disability. How would you adapt... your adapting your approach to him? Whether it is CBT or attachment by... you're very concrete with him. What else are you doing adapting that treatment for him to be successful.

P6L2b: I am focusing more on encouragement...even though you might struggle, even though things may be frustrating, you can do this. We can figure it out.

Describe your overall perception of trauma treatment for people with ID.

P6L2b: Listen... Have to listen...Have to be patient... As they may go here and there and all over the place... that's part of it. I guess..., part of the process and...Um...validate their feelings, um... acceptance... and encouragement. I mean... I kind of look at the dynamics more so.

Has your perception changed since the start of this interview?

P6L2b: Been able to clarify something that I haven't put into words before. Good job... Thank you for that. There is a push finally, and for trauma treatment. And hearing more and more and more.

K: Yeah... alright, that's it. Thank you.

Appendix J: Full Transcript Sample of a Participant Without Experience Working with
People with ID

Title: P4M3b
Record date: 4/4/2016 9:26:06 AM
Record time: 45:10
Recording file name: P4M3b

K: We're on. Okay, it's working. Yeah... today is April 4th, 2016 and I am interviewing P4M3b. Okay and for the purpose of trustworthiness, validity and possible conflict of interest. Please answer the following question before the interview takes place. And you can answer true or false to this. As the researcher, I have no affiliation with you or your business and between us we have no clients or business affiliations between us.

P4M3b: True

K: Okay, got it.

So describe your practice and the types of clients you see.

P4M3b: I... Well I just started at a new place. I've been there for about a month. It's a private practice where I am a therapist there that specializes in trauma and addictions.

K: **And what type of clients do you see?**

P4M3b: I kind of ... meaning?

K: Age, group or just...

P4M3b: I... I... I don't currently have any adolescents, but I do adolescent, so mainly though adults, you know 18 and older to anything.

K: But is it just trauma and addictions issues, or do you do depression, anxiety?

P4M3b: I do... I do a lot of panic and anxiety disorders, related to trauma mostly.

K: Right, Alright

Describe your credentials and the number of years in practice.

P4M3b: I am an LCSW - Licensed Clinical Social Worker. Um ... I've been in practice since 2010, so 6 years and um... currently, I have my application in for my LAC, but that's not... been approved yet.

Describe the types of funding or payment options that you provide for your clients.

P4M3b: I see mostly private clients. I do take insurance.

K: What kind of insurance.

P4M3b: Right now I take United, and I'm trying to get on other panels, but ... it's a longer process.

K: Any Medicaid or Medicare?

P4M3b: Not currently, but that's one I am waiting on.

K: In the city, or.... Have you found any reasons that their not accepting new providers, or....

P4M3b: I'm not completely sure because I wasn't... I... I have somebody handling that. She is taxed with it and I just don't know what she needs. From my understanding there hasn't been an issue like that; it's just the process of getting on.

K: So are you looking at the different county Medicaid BHO's.

P4M3b: I believe so.

K: Oh okay, I think up north has one too, but I'm not sure what that is.

P4M3b: I also take victims comp.

K: Oh okay, that makes sense. Is that through the city or is that all the counties.

P4M3b: Ah... Currently, the city, obviously... they... I have a few clients from a different county that have followed me from my previous position.

Tell me a story about what made you choose the field of psychology or human services.

P4M3b: Oh gosh... I don't know if I have a story. I'm kind of like that. I had a therapist when I was a teenager who just helped through lot stuff, it was kind of on and off for 10 years and I knew when I was 16 I wanted to be a therapist. So it was always something that I kind of knew I was going to do.

K: And why trauma and addictions?

P4M3b: Well, addictions were not something I thought I wanted to do. That was more something I fell into. I always thought I absolutely didn't want to do addictions, but my

first job after undergrad was a case manager for adults on parole and probation. And I started with that company and ended up staying for a long time and went to grad school and actually went back to that company as a therapist. Um ... I studied trauma, that was kind of my focus in grad school, and it became really apparent to me, the connection and the link between addiction and trauma.

K: Absolutely. Yeah, I did... I did all my hours and everything... in fact, in my Masters level, I was doing my CAC work. Do you have a CAC as well?

P4M3b: I just... am going straight for the LAC. So, I have nothing. (laughing).

K: Yeah, I decided... well I'm getting my LPC... I don't want to have to pay, you know... It was pretty expensive to register as a CAC and... but, you know... and still pay for my LPC. So, I still can do addiction work, you know. And my internship during my graduate work was with small agencies that did domestic violence and addiction work, and if there is a DV charge and alcohol was related... guess what... you're doing the substance abuse work to.

P4M3b: Oh yeah, Oh Yeah.

P4M3B Yeah... I did... The company I worked at as a case manager and then back as a therapist. It was all mandated training like that. It was frustrating because those classes are very surface level in adults. And we were discouraged to get to any of the root of the problems.

K: Right, Right, Yeah

P4M3b: No, we followed the curriculum. (7:40)

K: The curriculum. What company was that?

P4M3b: It was called that company.

K: Oh yeah, I know them.

So where did you go to school and why did you choose that school?

P4M3b: I went to a private university for my graduate degree.

K: Was your undergraduate degree in a psychology as well.

P4M3b: It was in social work from a university in this state. And I chose the private university. I wanted to stay in Colorado. Um... and kind of the only 2 schools at that time that I was aware of that had a higher clinical focus.

K: Okay, alright

Describe the type of courses you took for your degrees?

P4M3b: So they had tracks at the private university, so you chose what track you wanted to be on. I chose families and stuff. Um... and then they also had certificate programs, so I did the trauma certificate program. Um ... So most of my classes were actually in family counseling and theories and practices with, with that. Um ... and then trauma therapy and stuff.

K: What kind of classes did you have with your trauma certificate?

P4M3b: There were only 2 of them. Um ... One was... I can't remember what the first one was. It was more just kind of... theories stuff and behind therapy and then the second one was intervention to... to trauma.

K: Okay, and...

What is your therapeutic orientation and describe how you came to choose that orientation.

P4M3b: Kind of the theories that I practice?

K: Yeah, Yeah, just kind of your whole orientation, your foundation.

P4M3b: I... I ... when I first started as a therapist, I was very CBT based.

K: CBT or DBT based?

P4M3b: CBT, very much so, because it was....what we had to do at the company. We had to do specific therapy there.

K: Oh...

P4M3b: So I was very comfortable. After I left the company, I was much more open to, you know, I got to do whatever I wanted. So I still do use CBT, but when I working with trauma, the main thing I use is EMDR and CBT type skills.

K: So with that... orientation is... is... Would you say, sort of in that adaptive information processing model and dual attention focused?

P4M3b: Ah ha

K: Yeah, I do EMDR even with my clients here (laughing) I actually... well that was my original dissertation... was adapting the EMDR protocol with people for intellectual disabilities.

P4M3b: Oh wow

K: Yeah, Okay.

During your schooling, how much emphasis was placed on trauma and PTSD?

P4M3b: Because I was on the trauma certificate program, I had more than... than most people. Since I left the private university, I've done a lot of work with providing supervisions for a lot interns from that university. And they've completely changed it. They don't have the certificate on trauma anymore. All of their classes are trauma informed. Which is very cool to me. That was not how it was when I was there.

K: And I am finding that... that is very new. In my interviews... because in my classes there was nothing, and in some of my interviews there was nothing. You know, there was no emphasis on it... it was just part of the anxiety group that you learned about in abnormal psych.

P4M3b: Right, Right

K: And now, there's so much more about trauma informed. In fact, one of my participants said that her professor told he, this is new. This is the new way of doing things and it needs to be part of every aspect of your... of the client that you are looking at.

P4M3b: Yeah, definitely. I've seen a huge increase in trauma. That is used in teaching.

Describe what experience made you specialize in trauma and PTSD.

P4M3b: Um... I... I hadn't... I had my own kind of personal trauma, that... that I had to work through and... Honestly, there was something about when I was studying trauma that was very... I just seemed... I got it, I really understood it, and I understood how, you know, how deep it goes, you know, to the brain stem level and it was more, it was tangible for me to understand the intervention and it just was... it was just always interested in it. It was fascinating thing to me, and what it does to the brain.

K: So you were saying, because the next question... you've sort of done some of this.

How did you obtain your knowledge and training and experience in PTSD?

K: You had the certificate... um...and then... did you... did they offer EMDR at the private university?

P4M3b: No, no, I took that... actually, more recently. I took it at the Institute.

K: Oh yeah, that group.

P4M3b: Yeah

K: She does a really good work with that.

P4M3b: She's amazing.

K: Yeah, Yeah

P4M3b: I want to be her when I grow up.

K: Yeah, I did mine a long time ago. It was in 2002. And I... actually... though I had Andrew Leeds, he was our level I and then a... Oh god... who was level 2? Shapiro was there, for my level 2.

P4M3b: Oh really

K: Yeah... And so, that was really exciting.

P4M3b: I've taken a few of the clinical stuff, so those kinds of trainings were kind of covered, like...

P4M3b: My sister also, she's trained in trauma yoga.

K: Oh yeah

P4M3b: So that's another kind of avenue I've... like to look at.

K: Yeah and there's neurofeedback, but unless have EEG machine.

P4M3b: Right

So what theories and approaches do you use, to treat trauma and PTSD?

P4M3b: CBT kind of informed, I don't do the traditional CBT. Um... A lot of... I just say trauma informed treatment, so a lot of kind of... stuff to calm the brain down. Which... which could fall under EMDR. I do a lot of mindfulness, a lot of kind of grounding work.

K: A lot of resourcing?

P4M3b: Yeah

K: Any EFT or containment?

P4M3b: I am fascinated by EFT, and I know some about it, I've never formally trained in that.

K: Do you do any consultation that EMDR, the EMDR consultation group?

P4M3b: I'm... or we're trying to start one now. So the people that I went through the training with... there's a group that is trying to get on set up, monthly, to do.

K: Have you ever gone to the EMDR regional meetings?

P4M3b: I haven't. I would love to.

K: They are once every Friday and I will email out that link so you can get on that. Okay, so... Let me just ask you...

How would you describe a person with intellectual disabilities?

P4M3b: Gosh, I don't know. I... you know, my concept of... you know..., ID is somebody that has been born or had it... or born with it or had a... you know a TBI or something like that. Where it is a different way of processing information.

K: Okay

P4M3b: It definitely seems like... not experienced with working with ID.

K: That's alright, that's why you were chosen.

What do you think about, where do they live and what do they do?

P4M3b: Um... I hate to... categorize, but, an entire group of people.

K: It's alright, that's alright. I just want you to be natural.

P4M3b: I mean, I think it's... I would... I assume... there's a spectrum. I mean... sure some live on their own...you know, can be very high functioning. I'm sure some with families and other live in... in centers, treatment centers.

K: We did the host home model, where people... residential agencies hire people and they go and live in their home and that person... the provider is responsible for medical and all of that stuff.

P4M3b: I would think there would be some really awesome benefits to that, but also maybe some destruction. I don't know.

K: Um... In some ways.

P4M3b: Depending on the host family...

What do you think they do during the day?

P4M3B I imagine a lot of them work or um... if they are able to work...I would hope... you know that there's a community there, kind of community support of something to do.

K: Yeah we call them, day programs, yeah day programs.

P4M3b: Yeah, sure.

What kind of stigma or stereotypes do you feel people with ID experience?

P4M3b: I think... I mean I think there's a lot of uneducated around people with ID. Not saying that I... I myself don't know a lot, but... I think people can look at them... I'm sure they get awful judgement and people think their stupid or, you know... it's even though it's surely a different way of understanding information. I can't imagine what kind of... some of the things that go with that population go through.

What about as far as stigma for mental health services?

P4M3b: I would imagine that it is a very under treated population. They think it would be easy to go right to the ID and focus on that and not focus on other things as well. Yeah, I mean... They are a marginalized population... are at a higher risk to be victims and have major trauma, that would be my guess.

K: Yeah, Yeah

So do you have a story about any experience that you've had with intellectual disabilities.

P4M3b: Um....

K: Whether it's in your schooling or..., you know, someone you came upon, or...

P4M3b: Um... I honestly have not worked with anybody with ID. That's something I know I'm not school in and so I would refer out. So I don't have any really professional experience with that. Um... I... My best friend, you know... he..., for my whole life... her step brother... was diagnosed with down syndrome, so it was something I was around a lot and...

K: How was he treated with his family and what did they do?

P4M3b: They were a fabulous family. My friend's father worked a..., like the... he used to be... he's retired now. He was the head of a hospital and his wife...

K: Was that here in the city?

P4M3b: Ah ha, So, I mean... they provided a great home for him. I mean they worked really to do anything to help him.

K: And integrate him.

P4M3b: Yeah, to the state where he was pretty high functioning. Yeah

K: I think that is what people don't understand. That's... well... we'll get into that.

During your schooling, how much emphasis was placed on people with intellectual disabilities?

P4M3b: None, I cannot tell you that that came upon...

K: Even like with assessments, testing?

P4M3b: Um... I honestly don't remember anything. If there was... it would be very minimal.

K: And...

How much emphasis was put on mental illness and psychiatric issues with people with intellectual disabilities?

P4M3b: None

K: None

P4M3b: Yeah

K: Why do you think that?

P4M3b: That is...I mean it is an interesting question to ask. I would imagine that it can be probably viewed as a very much as a specialization, you know, if you want to go into that, then you study it further. I don't know.

K: And yet there are no classes to actually. Where do you get your experience, doing the work?

P4M3b: That's awful. If... I mean, if there was a class... I was not aware of it. I mean, I don't want to say there wasn't for sure. I definitely wasn't aware if there were. I doubt if there was. I've worked with interns that go to the private university for years. And no one has brought anything like that. That's awful.

K: Yeah

P4M3b: Yeah, that's something I haven't thought about.

What kind of trauma do people with ID experience?

P4M3b: Um... I would assume there are a lot of assaults... I had... at my previous employment, even though it's not ID. I had a client that was blind and just with that disability, I mean, she had been assaulted countless times and serious, serious assaults..., rapes... but as far as just... you know being pushed and you know... being groped as she's walking down the street. I ...I know that's not a straight comparison, I would imagine, you know... predators can view them as a vulnerable population and easy to target.

K: Sexual, physical assault, taken advantage of.

P4M3b: Yeah, I would hope with all the anti-bullying stuff, there would be a big change in that. I don't know.

K: Yeah, But I'm... we're still getting it.

P4M3b: Yeah, I know, I have an eight-year-old nephew. I know it is definitely still going on.

Describe how the symptoms of PTSD might look like in a person with ID?

P4M3b: I would imagine they would look the same, but I would also imagine that they would go unnoticed because they would be attributed to the ID and not PTSD. For some... I would think... I mean, I don't know. I would imagine they would look the same.

K: Pretty much, Yeah, I think we see it on the developmental level.

P4M3b: Yeah.

K: Because a lot of times we don't know what happened to them and they can't necessarily... a lot of times... they can't tell us what happened to them. So it is sort of hard to put that trigger in and then...

P4M3b: And it, I mean... it's interesting to me that there are things that would say that... especially with what we know about trauma now. Knowing, you know, we don't have to... a lot of times, you don't have that memory, but trauma tells us cellularly, in our bodies, its ... Wow. The body tells us so much. I like to a lot of mindfulness and self-soothing resourcing.

K: It's amazing.

Would you work with a person with ID who had trauma and PTSD?

P4M3b: I would want to but I would also not want to practice outside of my scope. I wouldn't know.... thinking there's so much I didn't know. I don't know. Um...Now I want to know more.

K: That's great, that's fantastic. Well okay...

Describe what kind of training you would need to work with people with ID who had trauma or PTSD.

P4M3b: I'm wondering... are there specific trainings out there or is it more... I mean... like it's a very under represented, I don't even know where you would go to get training.

K: I used to do a training here on Trauma Treatment.

P4M3b: Okay, really. I would totally be interested in that if you ever do that again.

K: I have a whole training on it, Yeah, so, Yeah... And what that looks like and what it can look like. And that's why I am going to start pulling in my films with that as well.

P4M3b: Okay

P4M3b: I mean, I would imagine what you kind of adapted to different language used, would be helpful... but

Describe how you might modify or adapt your treatment approaches for people PTSD for people with ID?

P4M3b: Um... I mean, talking about it now and thinking about it, I mean... I'm sure there's just some...It's like meeting any other client where there at... I guess. Um ... I think you..., I hear ID, you know, of the clinician...it's like... okay, that's outside of my

scope. I don't even... I haven't done anything to... to try on that, so... I can do a lot more, absolutely.

K: Yeah, just simplifying language.

P4M3b: Right

K: And even using shorter sentences, or breaking the sentence up, yeah. Going with that language. Once you get the language piece down...

P4M3b: Yeah, that is kind of what I was saying... like once you learn to adapt the language... and we have to do that we any of our clients, you know. I have some clients that are very intellectual and you know... I adapt the terminology. Their very... you know... clinical way with them and then others that don't want to know any of that, you know.

K: Right

P4M3b: And so, we do it, you know, already, it's just... there has been a barrier for me... for sure.

Describe your overall perception for trauma treatment for people with intellectual disabilities.

P4M3b: Um... Meaning, what I think it looks like?

K: Yeah... just your overall perception.

P4M3b: Talking today... it seems like it's very under... my guess is that a lot of trauma goes unnoticed or unrecognized, or not worked with. When there's, like for me, EMDR is a very kind of... I love it because it is a very tangible thing to do. Um... and we can adapt EMDR protocol to anything and so... you know, it makes sense to have EMDR... would be... be a good. I think it would be a very good intervention as long as you had the right language with it.

So has your perception changed since the start of this interview?

P4M3b: Yeah

K: How did it change?

P4M3b: Well, it's just, to me... it's like... you know... in social work we talk about... I'm so proud of being a social worker. I love that title, and so much of that is recognizing marginalizing populations and we talk, you know... in school or in school, with colleagues... we talk about minorities of race and religion and... Economic status... all

these groups and ID is neve..., is not one of those that we talk about and that's a little shameful to us... to us I think. I think that it's something that...needs to be talked about more.

K: Yeah, trainings... Yeah

P4M3b: Yeah,

K: That's been what I've gotten...

P4M3b: Yeah... if there was a training, I would definitely go. Yeah

K: Alrighty... Cool...Any other questions or anything?

P4M3b: No

K: No? Okay that was it. Thank you so much.

P4M3b: Sure.