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Clinician Factors in Psychotherapy Disparities for People With Intellectual Disabilities and Co-Occurring Mental Illness

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CLINICIAN FACTORS IN PSYCHOTHERAPY DISPARITIES FOR PEOPLE WITH INTELLECTUAL DISABILITIES AND CO-OCCURRING MENTAL ILLNESS

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Dissertation Approval

This is to certify that the thesis presented to us by B. Timothy Barksdale on the 5th day of June, 2012, in partial fulfillment of the requirements for the degree of Doctor of Psychology, has been examined and is acceptable in both scholarship and literary quality.

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Abstract

An estimated 4.5 million Americans with intellectual disabilities (ID) have lived in the community for over twenty years now, following the closing of institutions that once isolated them from the public (Scott, Lakin & Larson, 2008). It has since become evident that this group has the same and more vulnerabilities of developing mental illness than the general public but often lack access to therapeutic service (Whitaker & Read, 2005). Unfortunately society's lack of interaction with and education about this population has contributed to a number of misconceptions and fears. The hypothesized variables for the behavioral health disparity included: level of exposure to people with ID, attitudes about people with ID and specialized education offered for providing therapy or other behavioral health services to people with ID. Psychiatric and psychology trained clinicians were asked to identify current practices, and experiences relative to people with ID, as well as thoughts about providing therapy and related services to people from this group when psychopathology is diagnosed. This study sought to identify 1) factors that influence clinicians to currently provide therapeutic services to the ID population and 2) factors that would influence clinicians' willingness to provide services to this population. The research, conducted via a survey distributed to behavioral health clinicians throughout Pennsylvania, showed that clinicians are prone to bias, have limited exposure and receive little education or experience in working with people with ID. The benefit of this study comes from the report of those surveyed, indicating that if they received education and training; they would be more likely to add people with ID to their therapeutic caseloads. These finding help identify target areas for addressing the disparity experienced by people with intellectual disabilities, relative to finding clinical therapists, psychiatrists and therapeutic groups willing to meet this population's behavioral health needs.

Table of Contents

List of Tables

Chapter One

Statement of the problem

It is estimated that about one to three percent, of the U.S. population or at least 4.5 million Americans have the diagnoses of intellectual disabilities - formerly referred to as Mental Retardation (AACAP, 1999, Larson, 2000). This indicates that more than one in ten families in America has a member that would score less than seventy (70) on an IQ test and would have significant difficulty in at least two areas of adaptive functioning (DSM-IV-TR, 2000). People with intellectual disabilities (ID) are members of society who continue to experience discrimination when it comes to accessing quality behavioral health services that include evidenced-based psychotherapy and quality psychiatric support (Dagnan, 2007). A wide range of mental health challenges exist (excluding challenging behavior) with estimates ranging from ten to sixty percent of this population. In comparison, the rate is twenty-eight percent (28%) for mental illness in the general population (U.S. Department of Health and Human Services, 1999).

People with intellectual disabilities encounter stress through challenging life events, similar to those experienced by mainstream Americans. These stressors can often lead to states that include grief, anger, depression, anxiety and psychosis. When untreated, there is an increase of substance abuse, aggressive behavior, suicide attempts, and emergency psychiatric hospitalizations for people with ID, just as for the general population (Dodd, Dowling & Hollins, 2005; Taggart, McLaughlin, Quinn and McFalane, 2007; Yoonas, Akintan & Sandson, 2007; Hartley & Maclean Jr, 2009). Research conducted over a decade ago, revealed the reluctance of psychotherapists to provide treatment to people with intellectual disabilities, although the specific reasons had not been substantially researched (Bender 1993). Although research and treatment are widely accepted in Europe, particularly in the UK, practicioners in many areas of the United States have been slower to respond to the needs of this population (Taylor, Lindsay and Willner, 2008).

In a statewide series of focus groups conducted throughout the Commonwealth of Pennsylvania, one of the most relevant findings was the belief that most universities do not properly prepare clinicians, and that clinicians are rarely offered other training opportunities to provide therapy for people with intellectual disabilities (McFalls & Brown, 2009).

In Pennsylvania and in many states in this country, people who receive services and funding for having an intellectual disability (ID) are often supported in a separate funding system from people with ongoing mental health needs alone. This becomes a problem when people with ID require supports for behavioral health issues or mental illness. The separation of these two services, based largely on funding, serves as a major barrier to the mental health treatment needs of people with intellectual disabilities (Taylor, Lindsay and Willner, 2008).

Numerous studies have been conducted showing the efficacy of evidenced-based psychotherapeutic treatment for people with intellectual and developmental disabilities. (Dagnan & Jahoba, 2005; Korn, 2007; Sturmey, 2005; Whitehouse, Tudway, Look, & Biza, 2005). In the UK, a significant number of experienced therapists demonstrate how treatment, especially cognitive behavior therapy, can be very effective in addressing the mental health concerns of people with ID (Willner, 2009). In the United States, however, there appears to be a disconnect between clinical therapists and the community of people with intellectual disabilities. Despite the large number of researched and available therapeutic interventions, a shortage of therapists willing to provide behavioral health treatment to this population remains a concern in this country (Hurley, Folstein & Lam, 2003).

Purpose of the study

The current study is designed to assess the education, practices, experiences and attitudes of behavioral health therapists on the topics not only of providing therapy, but also of the willingness to provide therapy to people with intellectual disabilities. The purpose of the study is to determine those internal and external factors that prevent professional therapists from providing adequate treatment to this population. Therapists in the Commonwealth of Pennsylvania will be used as a sample of the United States population of therapists. By assessing the correlates of limited behavioral health services, those variables can be addressed in the development of training programs that will be more likely to promote behavioral and policy changes for clinicians, psychiatrists, behavioral health facilities and university/professional level training programs.

Relevance to Goals of the Program

Of all of the therapeutic approaches used for people with intellectual disabilities, Cognitive Behavior Therapy (CBT) is the most widely researched treatment as it is applied to this population (Beail, Nigel, 2003; Sturmey, 2004). Consistent with the goals of the Clinical Psychology Department for the Philadelphia College of Osteopathic Medicine (PCOM), this research highlights these studies and identifies how practitioners can expand their practices, their teaching and their research horizons by including the treatment of people with intellectual disabilities in future and existing practices. PCOM has a philosophical goal that includes, “educating professional clinical psychologists to enable them to meet the individual and collective mental health needs of all persons, with attention to diversity of social class and abilities, by use of comprehensive, empirically-supported cognitive and behavioral therapies, in an effort to provide holistic multidisciplinary health care services”. The research of attitudes, education, exposure and practices regarding therapy for people with intellectual disabilities, substantially addresses that goal. This research also fulfills the program’s aim of training culturally-competent psychologists to be leaders and advocates in working with underserved individuals. As a student of clinical psychology, a behavioral health consultant and therapist serving people with intellectual disabilities, this researcher demonstrates a commitment to the practitioner-scholar model through the clinical application of research methodologies to answer scientific questions involved in my immediate practice and community involvement.

Chapter Two: Literature Review

Intellectual Disability Defined

Currently referred to as people with intellectual disabilities (ID), this population is still identified by the term “mental retardation”. According to the text of the revised fourth edition of the Diagnostic and Statistical Manual (2000), people are classified as such when cognitive functioning is determined to be significantly below average through intelligence testing, yielding a full scale IQ of two standard deviations below average intelligence (100). Diagnostically, an IQ of 70 or lower with an onset occurring before the age of 18 meets this criteria. Aside from intellectual functioning, further diagnostic requirements include having two or more signifiant deficits in adaptive behavior, in areas such as communication, self-care, social skills, self-direction, home living, interpersonal relationships, use of community resources, academic skills, work, leisure, health and safety (APA, 2000).

When identifying best practices, definitions and any relevant information about people with ID, it has been the tradition of the medical community, and subsequently the American Psychological Association, to follow the lead of the organization that has been in the forefront of advocacy, treatment and research for the population since 1876, The American Association of Intellectual and Developmental Disabilities (AAIDD). This association currently defines intellectual disability to be characterized by significant limitations both in intellectual functioning and in adaptive behavior, as expressed in conceptual, social, and practical skills, which are apparent prior to the age of 18. For the diagnoses to be made, five conditions are expected to be present which include ; 1) limitations in functioning within the context of community environments typical of the individual’s age, peers and culture; 2) Valid assessment that includes recognition of differences in language, communication, sensory, motor, and behavioral factors within the person's cultural context; 4) strengths are recognized along with limitation and 5) the person's ability to improve with appropriate supports is considered (Schalock et al., 2010)

The DSM-5, the next expected version of the Diagnostic and Statisical Manual, as of April, 2012, proposes a shift to the term Intellectual Developmental Disorder (IDD); in this version, the levels of severity are reduced from four levels (Mild, Moderate, Severe and Profound) to three levels, thus eliminating the classification of "profound" (Using a profound level or severe/profound level was still under discussion during the ongoing revisions of the DSM-5). Criteria will continue to involve intelligence and adaptive functioning deficits. However, rather than the diagnoses being predominantly weighted on intellectual quotient numbers, the proposal is to have IQ scores shifted to the descriptional text of the manual, with a greater emphasis placed on the person's overall cognitive profile and level of adaptive functioning when making the diagnoses (APA, 2012).

People with intellectual disabilities often need various levels of support for activities of daily living and self-care. However, being listed in the Diagnostic and Statistical Manual does not automatically imply the need for mental health interventions. Intellectual disability alone is not a disorder to be treated by therapy or medicine. As with the general public, psychological and psychiatric intervention is not needed until a person with ID is experiencing biological, environmental and or substance related conditions that disrupt thinking, emotions, relationship and daily functioning significantly enough to be diagnosed with a psychiatric disorder. Researchers in the field of intellectual and developmental disabilities have used the term "dual diagnosis" to describe a person with an intellectual disability experiencing mental illness (Butz, Bowling, & Bliss, 2000; Fuller & Sabatino, 1998; Prout & Strohmer, 1998). It is now being recognized, however, that people often have more than two diagnoses when proper assessment is conducted and thus the term may not be appropriate. Co-occurring diagnoses is currently the preferred term. Therapy for people with intellectual disabilities and one or more existing psychiatric diagnoses was examined for this study.

Historical Terminology

In America the main advantage for a person with ID to receive a diagnosis of “mental retardation” has been the accompanying access to specialized services that includes funding, education, housing, medical benefits, staffing and transportation benefits. Unfortunately, also attached to this diagnostic label is the likelihood of discrimination, isolation and mistreatment (Tsakanikos et al., 2006). A label used to identify a group of people can be very significant in relation to how the group is regarded, valued and treated. Hebert Lovett (1985), an early proponent of cognitive therapy for people with intellectual disabilities, captured the issue in his statement,

> “When we talk about “the retarded”, we blur the fact that some of these persons have a sense of humor, while others are moody, some gregarious and talkative while others are shy and quiet” (p. 52).

The terms used to describe people with, what is currently known as, an “intellectual disability”, appears to have paralleled the level of treatment and discrimination experienced by this group throughout history. There are records dating back to ancient Greece and Rome documenting the fact that people with intellectual disabilities were killed by family members to relieve the family of this “burden”. Ironically, the French word “cretin”, the first known term used to describe members of this group has the literal translation of “still Christian”. This early term implied the idea that despite the differences, these individuals were still human beings worthy of basic dignity (Blundell, 1998). This theme continued through medieval times when people with intellectual disabilities were seen as "Children of God" (les enfants du Bon Dieu), but they were often referred to as "fools" or "jesters", corresponding to their societal roles, i.e., that of people who were mocked for their slow wit and lack of intelligence. Biblical scholars, initially, pitied the population and spoke of a need to comfort the "feeble minded", a term that lasted throughout the 18th century (Rosen, Clark, & Kivitz, 1976).

The term "idiocy" was originally used to describe all forms of intellectual disability until replaced by the term "feeble minded" as a generic term. "Idiocy" was eventually reserved for describing those falling in the most severe range of disability (Schwartz, 1952). In a report on the conditions of people with intellectual disabilities to the Commonwealth of Massachusetts in 1848, prominent 19th century United States physician and abolitionist, Sam G. Howe used the following terms to establish a scientific classification for "these unfortunate beings". The term "Idiots" was used to describe what was considered the lowest class of intellectual functioning for persons seen as: mere organisms, or masses of flesh and bone in human shape, in which the brain and nervous system have no command over the bodily movements, thoughts or emotions. (Howe, 1848). The term "Fools" was used for a higher class of idiots with a brain and overall nervous system that had partial control over movement, thoughts and emotions but with only a glimmer of reason and adequate speech. And finally under Howe's classifications; "Simpletons" or "Imbeciles" were considered the highest class of people, from this group, who possessed harmony of nervous system and movement with enough reason for individual guidance but not enough for social relationships (Rosen, Clark, & Kivitz, 1976).

By the early 1900s, with the introduction of the intelligence quotient (IQ), Dr. Henry H. Goddard, a prominent American psychologist and eugenicist in the early 20th century is credited for a classification system of people with lower intelligence, based on the Binet-Simon concept of mental age. Under Goddard’s system, individuals with the lowest level of mental functioning (a mental age of three years or less or an IQ of 0-25) were classified as “idiots”; those with a mental age of three to 7 years or an IQ of 26-50 were labeled “imbeciles”, and the term “moron” was designated for those with a mental age of eight to 12 years of age and an IQ of 51-70 (Zaretsky, Richter, Eisenberg, Myron 2005). As a eugenicist, Goddard believed that sterilization of people with intellectual disabilities was a societal cure (Zenderland, 1998).

Around 1895, the term “retardation” is first seen in the writings of Lightner Witmer, who is regarded as the inventor of the subspecialty of "Clinical Psychology" and the co-founder of the world's first psychological clinic in 1896 at the University of Pennsylvania (Rosen, Clark, & Kivitz, 1976). Witmer received his training for working with people with intellectual disabilities when serving as a consulting psychologist with the Pennsylvania Training School for Feeble-Minded Children at Elwyn (Witmer, 1907). Witmer notes that his attention was first drawn to the “phenomena of retardation” in the year 1889. In his writings, Witmer reveals a detailed theory of classification and etiology including retardation, relative to origin or function. He categorized general retardation, retardation in school work such as spelling, retardation caused by brain injury, and pedagogical retardation, based either on delayed cerebral development or the result of inadequate education (Witmer, 1907). Witmer believed that an IQ score alone could not be used to diagnose people with retardation.

Terms such as "ament", " retardates", "feeblemindedness", "mental defective", "brain crippled" and particularly "mental deficiency" remained commonly used in various communities well into the 1950’s. (Witmer). The term ament was a classification sometimes used to group people labeled as " imbeciles, feeble minded and idiots" in a category separate from a dement classification, in which the onset of mental deficits is later in life. (Rosen, Clark, & Kivitz, 1976). In 1961 the term, "mental retardation", was used by the American Association of Mental Deficiency to describe people with sub-average general intellectual functioning (IQ below 85) and impaired adaptive behavior. Through academic, scientific and political debate the IQ criteria for mild mental retardation has changed over time from 85 to 75 to the current cut-off IQ score of 70. This AAMD definition was used in the second and third editions of the Diagnostic and Statistical Manual and in the eight revision of the international Classification of Diseases (ICD-8) in 1968, which made "Mental Retardation" the official medical, psychological and legal terminology for the next four decades (AAMR, 2002).

Due to the inherent stigma that came almost automatically with the word "retardation", a number of efforts were made to remove the negative connotations by using words such as "mentally challenged", but none of the alternative terms were effective in changing perceptions and the stigma remained. In 2006, the American Association of Mental Retardation, decided to use the term "intellectual disabilities", stating that this is a more accurate operational definition that characterizes the features or contruct of the disability, which includes intellectual functioning and adaptive behavior (Wehmeyer et al., 2008). With this determination, the organization announced the decision to change to its current name, the American Association on Intellectual and Developmental Disabilities - AAIDD, which became official in 2007 (AAMR, 2008). With its many name changes, the AAIDD has been very influential on the research, support, education and treatment of people with ID since 1876, originating at the Elwyn Institute in Pennsylvania (Rosen, Clark, & Kivitz, 1976) .

Recent Development in Terminology

On November 17, 2009, U.S. Senator Barbara A. Mikulski introduced *Rosa's Law*, a bill designed to eliminate the terms "mental retardation" and "mentally retarded" from the federal law books. The sponsor of the bill is U.S. Senator Michael B. Enzi of Wyoming, who is ranking member of the Health, Education, Labor and Pensions Committee. Under the law, current terms referring to mental retardation would be replaced with "intellectual disability" and "individual with an intellectual disability" in relation to federal education, health and labor laws. The law seeks to makes the legal language consistent with that used by the Centers for Disease Control, the World Health Organization and through his Committee on Individuals with Intellectual Disabilities, the President of the United States,

Rosa's Law was initially adopted in Maryland. Rosa is the daughter of one of Senator Mikulski constituents, who informed him of how the term mental retardation was being used in a discriminatory manner toward her daughter. Under the Individuals with Disabilities Education Act (IDEA), each student receiving special education services at public schools has an individualized education program (IEP) that describes the student's disability and the education and services to be received. Rosa has an intellectual disability, Down syndrome, and she was designated as a student with "mental retardation" in her IEP. This reportedly prompted people at her school to refer to Rosa as retarded, or as a "retard". Senator Mikulski followed up on her promise to Rosa's mother that if the bill became law in Maryland, she would take it to the floor of the United States Senate. (James, 2009). On September 22, 2010, President Barrack Obama signed this bill into federal law, making intellectual disability the legal term for this population at that time. As stated in the ID definition section of this document (page 5), The DSM-5, the proposed revision of the current Diagnostic and Statisical Manual, indicates a shift to the term

Intellectual Developmental Disorder (APA, 2012). Prior to the printing of this dissertation, The American Association of Intellectual and Developmental Disabilities (AIDD) issued a statement calling for the American Psychological Association to use the term “intellectual disability”and use the criteria established by this association.(AAIDD, 2012)

History of people with intellectual disabilities in America

When looking at the perceptions and the professional treatment of a group of people, it is helpful to examine the value placed on that group over the course of history, in order to shed light on current issues and attitudes towards this group. It has been 42 years since institutions, which warehoused people with intellectual disabilities, began to discharge people into the community due to increasing public and political pressures against the documented physical, sexual and human right abuses that took place across the country (Scott, Lakin & Larson, 2008). People with intellectual disabilities have been in this country since the pilgrims landed, but it has been documented that people were supported by their families and were often taught to contribute to the community to the best of their abilities. Originating in Boston in 1848, initiatives were established to educate people with intellectual disabilities. In Pennsylvania around 1852, schools such as the Elwyn Institute (formerly known as the Pennsylvania Training School for Feeble-minded Children), and The Polk Center were founded as welcoming havens and among only two places in the country where people with intellectual disabilities would be treated well, educated and returned to their families as skilled individuals. By 1877, however, a medical model was developing in which people with an intellectual disability were viewed as sick and in need of isolated treatment. This resulted in this population being sheltered from society in these same schools designed to prepare them for society, including Pennhurst State School, also in Pennsylvania, which became large institutions where people frequently lived for the remainder of their lives (Rosen, Clark, & Kivitz, 1976). For the next 70 years, nearly two generations of people were warehoused and frequently, abused, sterilized and neglected, in increasingly crowded institutions, from birth to death in some cases.

Starting in the 1940s many states began to abandon the practice of sterilization and institutionalization as a way of adressing intellectual disability. Supportive clinicians of the time were establishing the fact that children and adults with intellectual disabilities had a full range of personalities with the capability of becoming emotionally disturbed just as members of the general population were susceptable to emotional disturbance that could result in intellectual disability (Scheerenberger, 1983). By the 1950s, parents organized to protect and advocate for their children in institutions, with the largest organization of people forming The Association of Friends and Parents of the Retarded Children, which later became ARC (Rosen, Clark, & Kivitz, 1976).

From the 1950s through the 1970s a focus on educational rights and living conditions brought political and public pressure that led to a dramatic decrease in children with intellectual disabilities being institutionalized and an increase in adults being discharged from these institutions. Pennsylvania was the center of one of the most significant cases affecting institutionalization, when Pennhurst resident with ID, Terri Lee Halderman, filed suit in the district court on behalf of the residents of Pennhurst State School and Hospital because of the inhumane conditions and inhumane treatment that took place in Pennhurst. In 1986, this case led to the process of eventually closing Pennhurst and an increase in the national deinstitutionalization movement (Braddock, 2007). Starting in 1967, the population of people with intellectual disabilities in institutions dropped from close to 200,000 to approximately 37,000 by 2007 nationwide. (Scott, Lakin, & Larson, 2008).

Transition to life in the community

People were moved from institutions to the community because treatment in the institutions included physical and verbal abuse, having valuables taken by staff, participation in experimental surgery, being hosed down in groups for the purpose of bathing and being chained in cribs as adults to prevent disruptive movement. The transition from institutions to the community was a 20 year process, which did not immediately discontinue poor treatment or even this group's separation from society. In evaluating the group homes, community living arrangements, publicly licensed facilities and intermediate care facilities, where many people with ID were placed when moved to the community, a number of concerns were uncovered through media expose´, family activism and subsequent federal review of services. These group homes were often found to operate as mini-institutions where people continued to be isolated from the community and treated inhumanely. They were found to have few rights or choices for such things as, for example, where and with whom they lived, what they could wear, or choices about their daily activities. People with intellectual disabilities frequently traveled in groups, rode in provider- labeled vans, and worked in specialized workshop with few opportunities for employment in the community. Adults were frequently forced to share bedrooms with people they did not know and live in areas of the city where no one else wanted to live (Wolfensberger, 1976). It took the combined efforts of families, self-advocates (individuals receiving ID services who can speak for themselves about their experiences and expectations), concerned professionals, monitoring bodies, courts and legislators to ensure that people with intellectual disabilities were afforded the rights, freedoms and protections guaranteed to all Americans .

Today, under the Americans with Disabilities Act and other civil rights legislation, including the Fair Housing Amendments Act of 1988, people with intellectual disabilities live in the community in various ways; these include: being at home with their families, in their own apartments and houses, in group homes with one to three housemates or to a smaller extent, residential communities where people still share a residence with up to eight or more individuals (Kozma, Mansell & Beadle-Brown, 2009). Staffing levels are expected to be based on the person's needs. A group of direct support professionals may be paid to provide up to 24 hours of care and support. For those with greater skills of adaptive functioning, someone (paid or volunteer) may visit the home weekly to help individuals with more complex issues, such as paying bills, maintaining their home or planning activities.

It is common today for people with intellectual disabilities (ID) to work, participate in community activities, enjoy various recreational events and sometimes even get married and have children (Aunos, Felman, & Goupil, 2008; Llewellyn, Mayes, & McConnell, 2008). Along with the benefits of being in the community comes the subsequent stress that can accompany work, interpersonal relationships and the challenges of everyday life. Daily challenges become much more complicated for people with intellectual disabilities who may have behavioral phenotype-driven genetic syndromes, cognitive deficits, negative social interactions and/or frequently trauma histories (Mitchell, Clegg & Furniss, 2005; Antonacci, Manuel, Davis, 2008; Hartley & McLean, 2009). Over the last few years various psychotherapies, especially cognitive behavioral approaches have been developed to support this population who have been diagnosed mental health issues (Murphy, Powell, Guzman, & Hays, 2005; Taylor, Lindsay & Willner, 2008; Jahoba et al., 2009). The challenges now are to train more therapists and psychiatrists to provide these treatments and services to this population. The next section will provide a review of the literature on the mental health treatment needs of individuals with ID.

The Psychotherapeutic Needs of People with Intellectual Disabilities

Lightner Witmer was one of the first scholars to make the distinction between psychosis and retardation and the distinction between intelligence and competence (McReynolds, 1996). He is also credited with establishing the first university course on mental retardation in 1897. The school's focus included developing a psychological clinic that was supplemented by a training school to teach existing teachers, psychologists, social workers, and doctors the methods of observing and delivering treatment for children with intellectual disabilities that interfered with school progress. Witmer proposed training students for a new profession, which he described as a psychological expert with a career in the school or medical system, who specialized in examining and providing treatment to this population (Witmer, 1907).

At one time it was believed that people with ID could not benefit from psychotherapy (Willner & Hatton, 2006). In fact it was believed that such individuals lacked the intellectual capability or complexity to experience mental health related concerns such as anxiety, depression, or diagnoses involving psychosis. Research shows, however, that there are few, if any, psychiatric disorders that can be ruled out simply because the individual presents with an intellectual disability. The presence of the following disorders for people with intellectual disabilities that were researched as of 1998 include: affective disorders, anxiety disorders, psychoses, personality disorders, psychosexual disorders, impulse control disorders, and somatoform disorders (Prout & Strohmer, 1998). In 2004, it was estimated that one -third of children with intellectual disabilities have a co-occurring psychiatric disorder. The prevalence of psychiatric disorders of adults with intellectual disability are now estimated to be 10% higher than the general population, with prevalence estimates ranging from 10% to 60% (Fletcher, 2004, Koskentausta, Iivanainen & Almqvist, 2002; Whitaker & Reed, 2005).

Factors attributed to the large rate of psychopathology in people with ID include early psychological issues related to poor self-image, repeated experiences of failure, learned helplessness, fewer positive social experiences and low enjoyment of success. Other factors include histories of abuse, social stigma, compromised social intelligence and peer rejection. In addition, higher genetic predisposition to certain types of psychopathology and syndromes linked with certain behavioral and psychiatric disorder make the prevalence of psychiatric disorder higher (Dykens, 2000).

The awareness that people with intellectual disability experience a full range of clinical disorders has become so salient and documented, that a separate diagnostic manual was developed in recognition of the fact that adapted diagnostic and treatment methods were needed. In 2007, the *Diagnostic Manual - Intellectual Disability, A Text book of Diagnosis of Mental Disorders in Persons with Intellectual Disability* was published by the NADD (formerly the National Association of the Dual Diagnosed) in cooperation with the American Psychiatric Association to adapt the DSM-IV-TR criteria and categories to the different ways that people with ID can manifest and display symptoms for clinical disorders and genetic behavioral phenotypes (Fletcher, Loschen, Stavrakaki, & First; 2007)

People with ID frequently have difficulties in expressing themselves and communicating their concerns. Mental health problems can often be expressed through various behaviors that may hide the expression of psychiatric symptoms leading to a practice called “diagnostic overshadowing bias” (Sovner, 1986). This refers to the erroneous practice of behavioral health professionals and others, of attributing psychiatric symptoms or behaviors that stem from a mental health disorder as being characteristic of having an intellectual disability only (Krahn, 2006). For example, if a person has periods of displaying intense fear, has unusual rapid breathing, indicates stomach and chest pain, refuses to leave the home, or breaks out into sweats during unheated conditions, professionals may be less likely to assess the individual for an anxiety condition, if they realize that the person has an intellectual disability. This occurs despite the fact that anxiety problems are amongst the most common forms of psychological issues found in people with intellectual disabilities (Dagnan & Jahoda, 2005). Some still ask the question that is at the heart of the issue of diagnostic overshadowing bias: Do people with intellectual disabilities have treatable psychiatric disorders?

Behavior versus Psychiatric Diagnoses

Throughout the industry and in this document the fairly recent term “Behavioral Health” is often used interchangeably to refer to or to encompass concepts such as; “mental health”; “mental illness”, “mental wellness”, “mental disorder” and/or “psychiatric issues/disorder/diagnosis”. Mental disorders are often expressed by behavioral health professionals as disorders of the brain attributed to a combination of developmental processes, genetic disposition, biochemistry and experiences. When people with an intellectual disability act or react in a way that is viewed as inconvenient, maladaptive, disruptive or potentially dangerous, these actions are often labeled as “problematic or challenging behaviors” (Felce, Kerr, Hastings, 2009). It is important to make the distinction that not all problematic or challenging behaviors are associated with an underlying psychiatric disorder. Diagnosable mental illness is not a given for people with an intellectual disability. However, studies have shown that the process of making a diagnosis of mental illness in this population can be frequently flawed. These studies often demonstrate findings resulting from poor random sampling, and from wider interpretation of psychotropic medication need for people with ID in comparison with the way in which people from the general population are diagnosed and medicated (Whitaker & Read, 2005).

With that same consideration, behavior problems can also be present in people with ID, but not all people with ID display behavioral concerns, contrary to what is often voiced by many in the behavioral health community (Taylor, Lindsay & Willner, 2008).

Behavior problems, often referred to as challenging behaviors, are defined as overt actions or responses that may or may not be a direct symptom of a psychiatric disorder. For example, hitting, kicking, cursing, head-banging and stealing are examples of culturally prohibitive behaviors that can have a level of intensity, frequency or duration that has the potential of jeopardizing the physical safety of the perpetrating person or others in the vicinity. These actions may also place the person exhibiting the behavior in a position where access to community facilities and resources may be significantly limited or denied. These behaviors can often be a maladaptive response to a physiological, medical, historical or environmental issue not associated with a psychiatric disorder. Behaviors classified as physical and verbal aggression, or other disruptive acts, are viewed as being among the most significant problems for people with intellectual disabilities (Gardner, 2002). The research shows that behavior problems are greater in people with intellectual disabilities, as compared with those without intellectual disabilities (McClintock, Hall & Oliver, 2003).

It has been found that some of the reasons why such challenging behaviors can occur are higher rates of neurological irregularities, such as seizure activity in people with ID that may contribute to an increase in irritability, rage reactions and biologically- based anxiety. Other contributing factors to higher levels of behavioral problems may include the dependence on provider systems to supply housing and daily supports that often involve restrictions, limited independence and even victimization.

For people with intellectual disabilities these behaviors may have multiple functions that may serve different purposes (Tasse, 2006). People with intellectual disabilities can often have limited communication and limitations in other adaptive skills for dealing with various life stressors. Without a responsive support system, faulty learning can occur and disruptive behaviors may help people escape unpleasant events or may obtain what they want in the absence of skills (Griffith, Gardner, & Nugent, 1999).

Challenging behaviors can be an issue for the lifespan. The Individuals with Disabilities Education Improvement Act of 2004 (IDEA) makes the commitment to provide positive behavioral support for students with ID in the school system (US Department of Education, 2006). For adults with ID who display behaviors that are viewed as disruptive or dangerous, it is more common to obtain a Behavior Support Specialist, rather than a psychotherapist. For people working in this role, particularly when trained as applied behavior analysts, problematic behavior is viewed as a response that is related to environmental conditions or to faulty learning rather than as an underlying pathology (Sturmey, 2007). Behavioral support services remain the approach of choice for individuals who lack the ability to communicate their concerns verbally, or through alternative means such as picture cards, facilitated communication, telecommunication devices, signs, gestures or other methods.

Behavioral Intervention

Since the 1960s, following in the footsteps of BF Skinner, psychologists with behaviorism orientations were the first to explore the use of applied behavior science to prove that people with intellectual disabilities had the ability to learn and develop socially adaptive and appropriate skills. Applied behavior analysis (ABA), a science that uses modern behavioral learning theory to modify behaviors, is one of the first organized approaches to support people with intellectual disabilities. Applied behavior analysts use the observable relationship of the person’s behavior with his or her environment (Fletcher, 2010). By assessing the relationship between an identified behavior and factors in the environment, methods can be used to change or improve behaviors. In the mid-1980s, positive behavior support (PBS) was developed as a reaction against the over-reliance on aversive or contingency strategies frequently used by early behaviorist. Consistent with Applied Behavior Analysis (ABA), PBS relies on the functional behavior assessment) to identify the function that the behaviors serve, including physiological and environmental factors, in order to guide the intervention. PBS is often different, however, because of the emphasis on intervening more heavily on the target behavior’s antecedents versus its consequences (Tasse´, 2006).

The term “positive approaches:” is considered, by those associated with this type of support, to be a philosophy similar to PBS with a greater emphasis placed on listening to people with ID, documenting the person’s history in the plan and viewing behavior as communication. Positive approaches are based on the person’s choices, likes and interest in an effort to minimize any restrictive procedures, and to empower people with ID to maintain dignity and take control over their own lives (Lovett, 1996). It is important to note that with many behavior Support professionals, ABA, PBS and positive approaches are not mutually exclusive and a skilled professional can combine elements of the approaches to provide a person centered intervention, tailored to the individual. It is essential that the behavior support professionals, regardless of orientation, use a functional behavioral assessment, and are able to distinguish between maladaptive behaviors that exist because of reversible faulty learning, poor coping or classical conditioning versus serious psychiatric conditions that require medication and evidenced- based, psychological therapeutic interventions. Having been assessed behaviorally and psychologically evaluated, all interventions, hopefully, will incorporate the philosophy of positive approaches.

Today, Behavior Support Specialists often meet with caretakers about the behaviors and interact with and/or observe the individual in various settings that may include: the home, day time job location or places of a community-based routine. A functional behavioral assessment/analysis (FBA) is often completed by questioning and observing the person receiving the services and/or by obtaining information from caretakers regarding the disruptive behaviors. By determining the functions of the behavior, the behavioral patterns, antecedents, consequences and factors that are maintaining the behaviors, the FBA is used to develop a behavior plan, and documentation is designed to track and graph the target behaviors identified (O'Neil et al., 1997).

The parents, residential staff, day support workers and/or other caregivers, compose the person's team and are often involved in providing experiences and insights to develop the behavior support plan. These individuals are taught how to conduct the plan, which generally consists of a series of positive interactions, active and reactive strategies, as well as methods of redirection for increasing desired behaviors and skills of communication and self-direction. Simultaneously, techniques are taught to the team. These are designed to reinforce desired behaviors and reduce or extinguish problematic behaviors through approaches such as ignoring, correcting or redirecting the disruptive behaviors, avoiding the use of containment or restrictive techniques (Griffith, Gardner, & Nugent, 1999). This approach is common with the behavioral support specialist using applied behavior analysis.

Deciphering whether or not a behavior is a maladaptive response to environmental issues, or a target symptom of a psychiatric disorder can be extremely difficult. When people cannot express themselves through speech or sign language, how can anyone tell if crying, banging one's head or screaming is the result of being hurt by someone recently, a distant memory of trauma or a symptom of a schizoaffective episode? The recommended approach in conceptualizing the relevant clinical issues is, first, to rule out medical issues, second, look at behavioral habits and environmental factors via a functional behavior assessment and finally to identify psychiatric biochemical factors (McFalls, Persons & Nemirow, 2006). By taking this approach, reduction in the practice of medicating behaviors and ignoring psychiatric symptoms can be better achieved. For people with mild to moderate ID, problems involving emotions, thoughts and sometimes psychiatric disorders can be quite complex. Behavior support specialists often attempt to use behavioral interventions or to provide traditional therapy to these individuals. However, this is often outside of the boundaries of their training. Credential s can range from persons with a bachelors' degree to a licensed psychologists because regulation requirements vary from state to state. Organizations such as the NADD have developed clinical certifications for all levels of professionals working with people with MH-ID, with the goal to raise the standards of care throughout the country. Many states, such as the Commonwealth of Pennsylvania, have recently incorporated policies that allow only for the reimbursement of therapy services provided by licensed psychologists or psychiatrists (HCSIS, 2009). Behavioral health funding is still subject to rejection due to an ID diagnosis which is seen by advocates as diagnostic overshadowing bias. This practice underscores the need for behavioral health professionals, including those who work for managed care organizations, to be properly exposed to this population while being trained about the nature, cause and treatment of people with MH-ID.

Stress as a Factor in Psychiatric Diagnosis in People with Intellectual Disabilities

The atypical presentation of psychiatric disorders is one of the factors contributing to the barriers that people with intellectual disabilities face in regard to accessing mental health services. Sometimes the display of psychiatric target symptoms is frequently and inaccurately characterized as willful acting out, or as displays of behavior problems (Hurley, Folstein & Lam, 2003). This view is often facilitated by the person's inability to verbally express him or herself adequately when undergoing traditional assessments developed for people without intellectual disabilities (Moss, 1999). Frequently such displays of behaviors can be expressions of perceived stress. Psychological stress occurs when a person's interaction with the environment is perceived as a threat to his or her well-being or self-esteem. When the interaction exceeds one's resources to deal with the situation over time, the person's mental health can be at risk (Lazarus & Folkman, 1984). The death of loved ones, moving, changing jobs, medical illness and injuries are amongst the universal stressors that can cause difficulty and challenges to the mental health of anyone (Hartley & MacLean, 2009) Adults with intellectual disabilities are often perceived as being child-like with minimal problems and responsibilities. These adults then are often dismissed as not having a life complicated enough to experience stress. The reality is that people with intellectual disabilities often experience varied life events and circumstances that can frequently place them at risk of developing mental health issues (Brown, 2000). Not only can adults with ID experience stress from the same types of events at similar overall rates as the general population, but also there tends to be a higher prevalence of other stressors that disproportionally affects this population. These include less recognition of personal rights, unemployment, poverty, stressful family circumstances, few meaningful or intimate relationships, and poor social support (Deb, Thomas & Bright, 2001). Because people with mild intellectual disabilities may look or behave differently than observers may expect, they can become more vulnerable to negative social interactions. Without sufficient coping skills, these events may often be experienced more intensely, as compared with people from the general population (Hartley & MacLean, 2009). As with everyone else, stress comes in many forms for people with intellectual disabilities. In the general population, stress, particularly stressful social interactions, is the most common reported concern in people with depression and is found to be one of the key factors in maintaining the condition (Davila, Hammen, Burge, Paley & Daley, 1995). Clinical depression is reported to be a common diagnosis in adults with intellectual disabilities, with as many as one in ten people having the disorder at some stage of their lives (Lowry, 1998). Due to the current deficits in the abilities and efforts to detect and diagnose mental illness in this population, significant underestimation of prevalence is likely (O'Brien, 2002).

Research has shown that some of the most frequently experienced social stressors with this population can include: hearing the negative comments of others, being teased, hearing others argue, and not being listened to (Lunsky & Benson, 2001). Many stressors for this population are created by interpersonal skill difficulties such as conveying feelings, managing anger, asserting opinions, taking instructions and interacting with peers, family members, staff or people in the community (Hartley & Mclean, 2009). All of these factors can lead to issues that potentially create a need for therapy.

Stress in the form of trauma is another significant source of mental illness in people with intellectual disabilities. Researchers estimate that children with developmental disabilities were nearly four times more likely to be victims of various forms of abuse (neglect, sexual and physical abuse), as compared with children without a disability (Sullivan & Knutson, 2000). Research investigating trauma has described people with intellectual disabilities presenting symptoms of Post Traumatic Stress Disorder (PTSD) following traumatic life events such as physical abuse, sexual assault and motor vehicle accidents (McCreary & Thompson, 1999).

Another factor that can contribute to the development of trauma in people with intellectual disabilities is a history of having once lived in an institution (Sullivan, 1998). Research shows that living in institutions often presents a significantly greater risk of abuse than living at home with families of origin (Rindfleisch, 1998). The same researcher reported that individuals with an intellectual disability, who have spent much of their lives in institutional residential care, have a greater chance of having a mental illness due to some form of trauma. This leads to the high prevalence of PTSD in people who have intellectual disabilities with symptoms equal to diagnosed individuals without ID; these symptoms include flashbacks, nightmares, distress from reminders, avoidance of situations associated with the trauma, hypervigilance and increased arousal (Newman, Christopher, & Berry, 2000). Physical abuse and bereavement over the death of a parent, are reported to be amongst the highest contributors to the presence of persistent PTSD in people with intellectual disabilities. People with ID may evidence PTSD with reactions that include developing physical health problems and the displaying behavioral re-enactments, as comparedwith people without an intellectual disability (Mitchel & Clegg, 2005).

There is support that mental illness occurs slightly higher in children with intellectual disabilities than in children without the diagnosis (Whitaker & Read). In addition, people with severe intellectual disability are found to have more incidents of psychiatric disorder than people with milder forms of intellectual disabilities (Stromme & Diseth, 2000). When the overall body of literature is reviewed, more similarities than differences are found between people with ID and people without ID in regard to psychiatric disorder (Glenn, et al, 2003).

Assessment and Diagnoses

A debate continues over whether or not people with intellectual disabilities have actual psychiatric symptoms as opposed to mere challenging behaviors. Some clinicians question if this population could benefit from the subsequent interventions that exist for various psychiatric disorders. Without proper training or adapted tools, diagnoses can be a concern for a clinician asking a person to identify abstract concepts such as hallucinations or depression when the interviewer is unable to adapt questions and decipher feedback from people who do not have the same expressive and receptive skills of the general public (Silka & Hauser, 1997). Adding to the communication challenge are the social skill deficits and varied phenotype behaviors inherent to many people with intellectual disability; these may eclipse valid symptoms of psychiatric disorders (Hartley & McLean, 2009).

Over the years, significant strides have been made in developing assessment tools and procedures that aid in the problem conceptualization and treatment planning to address mental health issues of people with intellectual disabilities (Glenn, Bihm, Elson & Lammers, 2003). Some assessments are derived from self-reports or caregiver-assisted reports. Formal mental health assessments designed specifically for the ID populations include: (1) the Psychopathology Inventory for Mentally Retarded Adults (Matson, Kazdin & Senatore, 1984); (2) The Aberrant Behavior Checklist (Bihm & Poindexter, 1991), and (3) the Diagnostic Assessment for the Severely Handicapped (Matson, Gardner, Coe & Sovner, 1991). One important study, involving 46 people used modified versions of assessments to compare the cognitions relevant to depression and anxiety in adults with borderline to moderate intellectual disability with the cognition of people who had the same diagnoses without the intellectual disability (Glenn, Bihm, Elson & Lammers, 2003). This and similar studies report that people with mild to moderate intellectual disabilities respond similarly to the general public when assessed for depression, anxiety and cognitive distortions (Beck , 2001, Glenn, Bihm, Elson & Lammers, 2003).

Assessments have also been developed specifically for this population to measure disorders involving constructs such as anger (King, Lancaster, Wynne, Nettleton & Davis 1999), psychosis (Lewis, Haddock, Bentall, Kinderman & Kingdon, 2002) and grief (Guerin, 2009). Each assessment is able to clearly identify the targeted construct and differentiate mental health symptoms from communication or behavioral problem. The development and use of these instruments help significantly in reducing diagnostic overshadowing bias with statistical evidence of distinct psychiatric conditions. Still in the infancy state, research and development continues in the area of assessing psychiatric disorders, leading the path for continued development of appropriate therapeutic treatments for people with intellectual disabilities. Without the availability of therapists to serve as applied scholars conducting research on therapeutic treatments for this population, people with ID remains underserved in both assessment and in therapy provision.

Readiness and IQ for Therapy

The issue of evidence based assessment and treatment calls attention to one of the most popular debates regarding therapy for people with intellectual disabilities. Does an intellectual disability and subsequent skill deficits interfere with the person's ability to respond appropriately to various forms of therapy? Nearly 100 studies were conducted between 1968 and 1998, assessing the effectiveness of psychotherapy with this population (Taylor, Lindsay & Willner, 2008). Since the 1990s, acceptance has been growing for the idea that methods and models of therapy similar to those used with the general population can be used to treat people with intellectual disabilities when appropriate modifications are made. This research has been largely conducted in Europe, particularly in Sweden and the United Kingdom (Wilner & Hatton, 2006).

Psychotherapists increasingly use cognitive behavioral therapeutic interventions (CBT) with growing evidence that the majority of people with mild intellectual disabilities have the ability to participate in and benefit from CBT for a range of emotional and psychiatric concerns (Taylor, Lindsay & Willner, 2008). At present, CBT is proving to be effective in addressing concerns that include: (1) anger (King, Lancaster, Wynne, Nettleton & Davis , 1999; Taylor, Novaco, Gillmer & Thorne, 2002); (2) depression (Jahoba, Dagnan, Jarvie & Kerr, 2006); (3) anxiety disorders (Dagnan & Jahoba, 2006); and (4) even with teaching adaptive living skills such as grooming skills in men, which has substantial psychosocial benefits (Saloviita & Tuulkari, 2000). Some of the standard skills required to benefit from CBT include the ability to recognize emotions, link those emotions and events, and the ability to recognize cognitive mediation of emotions, the process of alleviating distress by modifying cognitive content and, realigning thinking with reality (Oathamshaw & Haddock, 2006). Additional skills needed for CBT include communication in the form of providing self-reports, the ability to use abstract concepts, self-monitoring, memory and the ability to understand the cognitive model (Stenfert-Kroese, Dagnan, & Loumidis, 1998).

The basic skills needed to participate in cognitive therapy can often include the ability to identify an activating event or antecedent from the emotional and behavioral consequences of the events. Another valued skill is the ability for a person to understand the link between beliefs and the behavioral consequences of those beliefs. Research has shown that people with moderate and mild ID often have these prerequisite abilities that allow the skills to be taught before therapy begins (Sturmey, 2004). One research study, using 19 men and 21 women with mild to moderate disabilities, found that 75% of these individuals were able to link beliefs, emotions and behaviors in response to exercises involving the recognition of emotions from pictures of faces and in describing the emotional states of characters in stories (Dagnan, Chadwick, & Proudlove, 2000).

Regarding how cognitive behavioral therapy is delivered to people with ID, a distinction is made between the *cognitive distortion* model as developed by Aaron Beck and the self-instructional training based on a cognitive deficit model developed by Donald Meichenbaum. In Beck's 1976, model cognitive distortions in the context of thoughts, assumptions and beliefs are identified and corrected. In contrast, the self-instructional training based *cognitive deficit* model (Meichenbaum, 1977) is more commonly used with people with intellectual disabilities, and serves as the basis of self-management interventions with a focus on deficiencies in the processes of how information is received and processed**.** For example, if a person was having arguments with people because of anger problems, rather than focus on distorted cognitions, the emphasis would be placed on addressing the person's social skill deficit and the needed skill development rather than on the cognitive distortions that led to the anger. Interventions such as role play would be used to give person adaptive, socially appropriate words and phrases to be practiced to replace existing confrontational language. To increase the strength of CBT interventions, therapists' adaptation of CBT techniques frequently include:1) facilitating valid self-reporting; 2) adapting to the client's assessed level of comprehension, and expression of abstract contents, and 3) assessing the environment's impact on the person, and promoting subsequent self-regulation skills (Stenfert-Kroese , Dagnan, & Loumidis 1998). Ultimately, the therapist would teach appropriate skills when deficits exist (Hatton, 2002).

One of the earliest studies exploring the use of CBT for people of a lower degree of assessed cognitive ability examined the threshold of IQ for showing improvement in therapy. Cognitive therapy for anger management provided to people with mild intellectual disability who were living in the community found that 4 of 7 participants showed no improvement after therapy (Willner, 2009). Rose, Loftus, Flint and Carey (2005) conducted a larger study, to assess improvement after cognitive behavior therapy for anger. Results indicated a positive correlation between verbal ability and anger management skill. On the other side of the spectrum, two studies conducted on the same population with anger management problems showed no substantial differences in response to treatment in relation to I.Q. Taylor and colleagues (2005, 2007) found that people with a lower IQ, on average, had slightly better results (Taylor et al, 2005; Taylor 2007). The two sets of studies differ, because the latter studies provided a higher dose of the treatment intervention. Taylor's study participants had two sessions per week rather than the weekly sessions in the earlier studies. Thus it could be inferred that increased therapy sessions would be assessed as a reasonable variable to adapt when deficits in intellectual ability exists.

In summary, the decision to use cognitive behavioral therapy should be accompanied by several steps. A comprehensive formulation should be derived, assessing the person's skill level, adaptive functioning, and ability to learn concepts associated with the therapy. There should also be an assurance concerning the ability of the therapist to adapt the assessment and interventions to each person regardless of I.Q. (within reason). In addition the identified patient's motivation, level of confidence, and level of support are important components to assess when adapting an intervention (Taylor, Lindsay & Willner, 2008) It is cautioned that the person's performance in intelligence tests should never be the sole basis for the decisions to accept or reject the person as candidate for cognitive behavior therapy or other interventions (Willner, 2006).

Therapy for people with ID.

Psychodynamic approaches with the ID population have involved some of the earliest research dating back to the 1930s (Whitehouse, Tudway, Look, and Kroes). Originating from psychoanalysis developed by Sigmund Freud, psychodynamic therapy is a less intensive form of therapy that promotes the belief that bringing the unconscious into conscious awareness promotes insight and resolves conflict. Psychodynamic treatment may involve using non-directive language that stays close but is slightly ahead of the patient's developmental level. Client/patient transference and counter transference issues are compared with daily interaction with others; there are reported results of improving the patient's ability to self- reflect with increased capacity for more mature object relations (Kilchenstein, 1999). Despite the history of research, it is noted that psychodynamically trained practioners are often the most reluctant of clinicians to accept people with ID and mental illness as patients or consumers for psychological assessments (Spangler, 2010). Other psychotherapies such as Client-centered and Interpersonal therapy have yet to yield substantial research with the intellectual disability community.

Controversy: Therapy vs. Applied Behavioral Approaches.

Peter Sturmey, psychology professor, radical applied behavior analyst and prolific writer takes a strong position against psychotherapy and particularly the growing studies supporting the efficacy of cognitive behavioral therapy for people with intellectual disabilities (Sturmey, 2006) He argued that these studies do not really provide empirical support because many studies are not randomized controlled studies, resulting in an inabilty to separate cognitive effects from the many behavioral intervention effects used in these studies such as social skills training and relaxation methods. In his early criticism of CBT, Sturmey (2006) accused CBT researchers of mislabeling behavioral interventions as cognitive behavior approaches. Sturmley contended that the mixture of treatment components and techniques used in the researched cognitive behavior therapy for people with ID makes it nearly impossible to factor out what is actually working to create behavior change. Sturmey argued that CBT proponents had an obligation to conduct more research with controlled studies, not only to better prove that CBT was effective in comparison with no treatment, but also to show that it was more effective than existing treatments, such as empirically supported behavioral interventions (Sturmey, 2004). He repeatedly disputed CBT research, maintaining that cognitive therapy, other CBT approaches and psychotherapy in general fail to establish or claim superiority over Applied Behavior Analysis, which he reported had the support of multiple randomized control trials and hundreds of single subject experiments (Sturmey, 2005). Sturmey's published research findings and methodological arguments against psychotherapy for people with intellectual disability, in favor of behavioral approaches, aroused a series of published debates between him and the community devoted to CBT for people intellectual disability (Beail, 2005; Hurley, 2005; King, 2005; Sturmey, 2005; Sturmey, 2006; Taylor, 2005).

Cognitive Therapy for People with ID

Advocates for Cognitive Behavior Therapy rebut the criticism of the research involving people with intellectual disability. Although *efficacy* research does remain limited , the effectiveness of particular interventions for specific study samples using CBT is well supported by effectiveness research. This research identifies the external validity to demonstrate the ability of treatments to generalize outside of highly controlled environments (Taylor, 2005). The metanalysis of CBT research demonstrates that people with intellectual disability can participate in face- to- face treatments involving the adjustment of feelings, attitudes, values and behaviors that do not involve behavior modification alone. (Scotti, Evans, Meyer & Walker, 1991). Assertivenness training , social skills and problem solving training involve cognitive and metacognitive skills of self-monitoring, self- evaluation, and self- management skills, along with behavioral principles that are commonly used in psychotherapy for people with or without intellectual disabilities (Hurley, 2005; Taylor, 2005). The problem with the claims that Applied Behavior Analyst is a more effective treatment for people with intellectual disabilitiesconcerns the fact thatat the time of the claims, there were no studies comparing psychotherapy to "behavioral interventions" (Hurley, 2005; Sturmey, 2006).

Applied behavior Analysis remains the treatment of choice when problematic behavior is the concern, especially for people who lack the ability to participate in reciprical communication. Cognitive Behavioral Therapy, however, has been found to be an effective intervention for people with mild to moderate intellectual disability and co-occuring psychiatric diagnoses, as seen in the following general outlines of symptom recognition and treatment.

CBT Treatment for Specific Diagnoses

Anxiety Disorders

Anxiety is reported to be one of the leading disorders diagnosed in people with intellectual disabilities (Deb, Thomas & Bright, 2001) Although the data relative to anxiety disorders have been validated only relative to people without intellectual disabilities in the ICD-10 and DSM-IV, the objective features of anxiety such as trembling, fear, flushing, irritability, etc., are observable in people with ID (Cooray, Gabriel, & Gaus, 2007). Taking the pulse of the patient or listening through a stethoscope are methods recommended for assessing the physiological symptoms of anxiety for people with severe to profound ID. Assessing for feelings of unreality or of feeling detached is difficult to assess in people with ID (NADD, 2007). Because adults with ID may exhibit a different pattern of fears and anxiety than people without an intellectual disability, there are now assessments specifically designed to assess anxiety in people with ID. The Fear Survey for Adults with Mental Retardation (FSAMR: Rameriz & Luckenbill, 2007), is a self-rating scale of "yes" or "no" responses that has been validated with people whose functioning was assessed to be in the mild to moderate range. The Glasgow Anxiety Scale –GAS-ID (Mindham & Espie, 2003) measures cognitive behavior and somatic symptoms of anxiety. It was developed and validated specifically for adults with mild to moderate functioning, using a three-point Likert scale with response options represented as pictures.

Treatment of anxiety often involves a deficit model in which anxiety management skills are taught and coping statements are generated, such as in the self-instructional approach in which participants are taught to repeat positive statements during anxiety- provoking situations ("I am doing a good job or I don't care if you watch me") (Chiodo & Maddox, 1985). Conceptually, it has been recognized that people with ID often have cognitions and behaviors associated with being stigmatized by society (Dagnan & Jahoda, 2006). It is suggested that people with intellectual disabilities may have an accurate perception of how they are viewed, similar to other discriminated groups. Therapeutic goals, therefore, may incorporate the development of a more positive self-image and the extension of social skills to address the reactions of others in order to reduce chronic anxiety (Jahoda & Markova, 2004).

Mood Disorders

Due to diagnostic overshadowing bias, it has been only since the late 1980s that behavioral health professionals have acknowledged the fact that people with intellectual disabilities do experience mood disoders. This is largely due to the pioneering work of a psychiatrist and a psychologist, Robert Sovner and Ann Hurley, respectively (NADD, 2007). It is estimated that people with ID experience depression at rates comparable to the general population, with a prevalence up to 10% (Rojahn & Esbensen, 2005). Sad facial expressions, tearfulness or crying, fatigue, and distraction, were the most common displays of DSM-IV criteria in people with ID. Socially inappropriate or self- injurious behaviors are often interpreted as depressive equivalents, particularly in those with fewer communications skills (Langlois & Martin, 2008). A tool that has shown promise in assessing mood related issues in people with ID is the Anxiety, Depression, and Mood Scale (ADAMS). The ADAMS was designed for care takers to observe and rate symptoms related to depression, and mania (Esbensen et al., 2003)

Cognitive therapy is supported to be an ideal intervention for mood disorders in people with ID, because correlational studies have found that depression as measured by the Beck Depression Inventory (Beck, Steer & Brown 1996) and the Psychopathology Inventory For Mentally Retarded Adults –PIMRA (Matson, 1988), showed a signicant correlation between lower rates of self-reinforcement and negative automatic thoughts (Nezu et al., 1995). Rather than traditional talk therapy, pictures are are often used for people with ID in order to conduct cognitive therapy treatment for depression and other mood related disorders. Pictures and words are used for agenda setting for each appointment and for the identification of negative thoughts. To monitor thoughts and feelings, to elicit underlying beliefs and assumptions, or to test the accuracy of assumptions, visual analogue scales are used, where participants can specify their levels of agreement to a statement or picture by indicating a position along a continuous line between two end-points (Beail, 2003).

Role play is also used to elicit automatic thoughts as alternate ways to think and act are practiced. Homework assignments often consist of practicing positive thoughts with self-recordings, using written, pictured or taped diaries (Lindsay, Michie, Baty, Smith, & Miller, 1994). Activity scheduling, reframing life stories to shift negative core schema, increasing the recall of positive memories and promoting more adaptive assessments of current life events are additional techniques proven to be effective for people with ID, particularly in the treatment of depression (Jahoda, Dagnan, Jarvie & Kerr, 2006).

Psychotic Disorders

The rates of psychosis are found to be consistently higher amongst people with intellectual disabilities than among people from the general population (Deb et al., 2001; Kerker et al., 2004; Taylor, Hatton, Dixon and Douglas, 2004a). A study found that individuals with a diagnosis of schizophrenia spectrum disorder consumed the largest amount of service resources in the UK (Spiller et al., 2007). In addition to observing odd behavior specifically unusual for the individual, verbal skills are almost essential to establish the presence of hallucinations, delusions, and disorganized speech when diagnosing schizophrenia or other psychotic disorders in people with or without intellectual disabilities. Self-talk can be common in people with ID, particularly in people with Down syndrome. Thus self-talk cannot be automatically interpreted as a symptom of a psychotic disorder without extensive knowledge of baseline behaviors and coping style.

The greater the intellectual disability the more difficult it becomes to assess, diagnose and treat (Smith, Haut, & Fleisher, 2007). Four instruments which have been shown to have good reliability and validity for identifying psychosis in people with intellectual disabilities are the Psychotic Symptom Rating Scale for Auditory Hallucinations (PSYRATS-AH; Haddock et al., 1999), Social Comparison Scale for Intellectual Disability (SCS-ID; Birchwood et al., 2000), Positive and Negative Syndrome Scale (PANSS; Kay, Fiszbein & Opler, 1987), and the Beliefs about Voices Questionnaire (BAVQ; Chadwick & Birchwood, 1995).

In the case of auditory command hallucinations (voices instructing a person to act or behave in a specific manner), it is suggested that the power relationship between the voice hearer and the dominant voice be determined to measure the likelihood of compliance with adverse suggestions. This can be done by identifying four dysfunctional core beliefs, 1) the voice has absolute power and control; 2) non-compliance results in punishment; 3) the voice has a significant identity; 4) the message or experience has personal meaning and 4) performing the command can be justified by the hearer (Barrowcliff, 2007). Intervention can include representing internal thoughts and self-talk using pictures, diary cards or thought bubbles such as those found in comic books. The person is encouraged to say the thoughts out loud, gradually decreasing the volume until no sound is uttered. This process is expected to assist the person in associating the internal voices with his or her own voice to increase the perception of control over the voices. The therapist adapts language and shares with the person or his or her caretaker, the antecedent-belief-consequence (ABC) of the person’s experience as a part of the rapport building/formulation phase of therapy to initiate treatment (Kirkland, 2006). Interventions include challenging identified core beliefs; normalizing negative thought content; guided discovery to show how hallucinations are synonymous with thoughts; identifying triggers to predict hallucinations; use of pictures to generate alternatives to self-critical appraisal; directly challenging the power of the hallucination and teaching strategies for dealing with anger aroused by the hallucination. This method of treatment has been found to be most effective with people with mild intellectual disability due to the level of interaction between the person and his or her therapist (Barrowcliff, 2007; Trower et al., 2004).

Sex Offenders

Sex offenders with intellectual disabilities are typically male, with mild disability and they are often known to the victim (McCarthy & Thompson, 1997). Because of the varied data sources and non-standard reporting procedures, researchers are hesitant to commit a prevalence rate to sexual offenders with intellectual disability (Craig, 2009, Lambrick & Glasser, 2004; Lindsay, 2002). The one area of agreement, however, is that having an intellectual disability does not make one more prone to moral or criminal sexual offenses (Holland, 1991). Despite this fact, the number of men with ID in federal prison for criminal sexual offenses, is substantial and appropriate behavioral health services are not being properly provided (Lambrick & Glasser, 2004)

The first line of treatment, proper assessment, can be conducted with sex offenders with intellectual disabilities using a number of well researched measures. Good test-retest reliability for sex-offenders and non-offending people with ID has been found with the Sexual Offenders Self-Appraisal Scale –SOSAS (Bray & Foreshaw, 1996). This instrument, consisting of 20 statements to which participants respond with varying levels of agreement or disagreement, examines the person’s cognitions about sex offending. Other scales have been modified for this population to measure empathy for the victim, using the Victim Empathy Scale -VES-A (Beckett & Fisher, 1994) and The Questionnaire on Attitudes Consistent with Sex Offending – QACSO (Broxholme & Lindsay, 2003).

A well-established treatment management framework for treating sex offenders with or with-out disability includes the Risk-Need-Responsivity Approach (RNR), which seeks to reduce offending behavior by eliminating risk factors (Andrews & Bonita, 1998). The alternate approach is the newer, Good Lives Model (GLM), which, in addition to addressing risk factors, looks to replace offending behaviors with pro-social ways of achieving life fulfillment (Ward & Steward, 2003). Regardless of the model used, research supports the use of cognitive behavioral therapy as the underlying mechanism for both approaches, with a proven ability for changing predatory risk factors and promoting sex offender pro-social behavior (Losel & Schmucker, 2005; Schaffer, Jeglic, Moster & Wnuk, 2010).

CBT- based group therapy often consists of psycho-education about body part names, about legal, illegal and risky sexual behavior, understanding choice, consent and age of consent, and distinguishing between social and sexual relationships. (Murphy, Powell, Guzman, & Hays, 2007). Intervention involves adapted group work on victim empathy, regulating emotions in stressful situations, challenging cognitive distortions about responsibility, intent and harm done to the victim, addressing interpersonal skill deficits and developing plans for relapse prevention through self-management and the use of resources. (Nezu, Nezu & Dudek, 1998).

Another form of CBT, Dialectical Behavior Therapy (DBT) also shows promise in successfully treating sex offenders with mild to moderate ID. This integrated model combines a range of cognitive and behavioral approaches with aspects of Eastern philosophy, specifically, mindfulness meditation. (Linehan, 1993) Research has found that the mindfulness training alone has led to reduced verbal and physical aggression and reduced injuries to others (Singh et al., 2008). Other skills taught include emotional regulation, distress tolerance and interpersonal effectiveness.

Many people with ID who are sex offenders may have other medical conditions, mental health diagnoses, neurological issues or their own histories of trauma. Proper treatment includes the comprehensive assessment and treatment of all of these issues. As with people without intellectual disability, successful treatment can not completely eliminate risk of repeat offenses

Other considerations

These are just a few of the researched problems and diagnosed disorders that have evidence- based, cognitive behavioral interventions developed for people with ID. Other identified CBT interventions for people with ID include treatment of anger and aggression (Antonacci, Manuel & Davis, 2008; King, Lancaster, Wynne, Nettleton & Davis, 1999; Taylor, Novaco, Gilmer & Thorne, 2001); treatment of obsessive compulsive disorders (Willner & Goodey, 2005), the treatment of borderline personality disorders (Lew, Matta, Tripp, Watts, 2007) and the treatment of trauma including PTSD (Razza, & Tomasula, 2004; Trappler & Newville, 2007)

When providing these specific interventions for people with ID, the clinician must consider the person's support system and method of communication. Many participants may be assisted by parents or paid caregivers. There are times when a therapist may choose a method similar to family therapy during which key people in the person's life are invited to become part of a therapeutic team. These people in the immediate social context of the person may be recruited by the individual and therapist to assist in monitoring early warnings signs; they are taught interventions to address symptoms to support the therapeutic process (Dagnan, 2007). Regardless of the therapeutic approach and diagnoses being treated, the goal is always to provide individualized supports for the person that accommodates the person's rights, wants and needs with respect and dignity.

There are several classes of barriers to service provision that will be reviewed next. The first has to do with systems issues. One of the most problematic barriers is related to the organization of funding streams for individuals, who overlap more than one service system.

Funding

Apprehension about adequate reimbursement is a frequently expressed concern from clinicians when the issue of treating people with ID arises. Research reveals that funding has proven to be an important ingredient in support of people with intellectual disabilities receiving therapy services. Most states are finding access to behavioral health therapy to be a significant challenge (Taylor, Lindsay and Willner, 2008). In personal communication, Anne D. Hurley, Ph.D, a psychologist and leading researcher in the field of Intellectual Disabilities, stated that Massachusetts has had long term success in having therapists serve this population. Dr. Hurley explained that the state has enjoyed funding of free standing mental health clinics and government reimbursement for Medicaid and Medicare, typically run by larger agencies, since the 1970s. These clinics provided child consultation and care to adults, largely made up of poor or working class people with major mental health concerns. By the late 1980s and 90s when people with ID were being reintroduced to the community from institutions, many of these clinics found a need to serve this population, often based on the financial benefits. Fees for service providers became the attraction to this population because billing was found to consist of the same process as with other adults and, at times, even easier because people with intellectual disabilities frequently had established diagnoses, a history of medication and staff members who were paid to bring them on time to the appointments. Initially clinicians were those who were familiar with this population by working in institutions, but other therapists simply tried it and found that they enjoyed working with these individuals. Today, these clinics still exist and it is reported that many young, licensed clinicians who have trouble finding work apply and are provided fees for service therapy. To reduce the no-show rate, many of these clinicians go to the group homes, workshops or other locations to see their clients. Because social programs are cut first during tough economic times, Dr. Hurley admits that, currently, even Massachusetts is being adversely effected (A.D. Hurley, personal communication, April 2, 2010).

Other states do not display this awareness and frequently funding streams for mental health and intellectual disabilities are separated, making it difficult for people with intellectual disabilities to access proper behavioral health supports (Taylor, Lindsay and Willner, 2008). It is reported that since 1971, most people with intellectual disabilities are made eligible for Medicaid and Medicare upon receiving the diagnoses. This works well for people who can access community behavioral health clinics in some states. In other states, however, reimbursement is often divided between separate funding streams such as behavioral health or intellectual disability or autism. When dealing with separate funding streams it is difficult for someone in the intellectual disability category to access therapy and other services from the Behavioral Health funding stream because of the poor rate of reimbursement to the clinicians (Spangler, 2010).

Additionally, some states seem to have selected behavior specialist services for people with ID as a way to provide a less expensive alternative to quality specialized therapeutic supports. For example, in the City of Philadelphia, $25, 000 may be set aside in the ID system for all psychological evaluations for the year. This will cover about 25 people in a system that frequently has a waiting list for psychiatric services of at least 1000 people at a time. Beyond that amount, reimbursement will often be refused (Spangler). Additionally, there are funding disparities at the federal level in research endeavors for the ID population. For example, spending for Down syndrome, a prominent etiology for Intellectual disability, saw funding drop from $28 Million in 2010 to $22 million in 2009 (Diament, 2012) . In conclusion, the availability and organization of funding acts as a barrier for psychologists and psychiatrists in providing behavioral health supports for the ID population.

Another barrier to accessing quality behavioral health services are the beliefs and attitudes both of the general public as well as of service providers when coming into contact with individuals with dual diagnoses.

Attitudes Regarding People with Intellectual Disabilities

It has been recognized that the way in which society views people with intellectual disabilities can have substantial influence on funding priorities, public policy, housing, education and access to community resources (Henry, Keys, Jopp & Balcazar, 1996). Since the late 1960s, when people with ID first began returning to American communities from institutions, data have been collected which has consistently indicated that attitudes toward people with ID have been negative (Antonak & Harth, 1994). Society also takes a negative view of people without an intellectual disability who seek mental health services (Vogel, Wade & Ascheman, 2009), thus people with ID and one or more mental health diagnoses are often doubly stigmatized. An examination of existing attitudes and biases are key, not only with the goal towards improving access to behavioral health services for this group, but also for the goal of positively influencing society views about this population in general.

Few studies have investigated the attitudes of American clinicians toward people with ID in regard to the willingness to treat this population in the US, but similar research has been done elsewhere. In the UK, where therapy is more frequently provided to people with ID, one study examined the factors that influence therapist to provide psychotherapy to this group (Mason, 2007). It was found that the level of the client's disability, the self-perception of the therapist's ability to provide treatment to this group, and the tendency to attribute psychiatric symptoms to having an intellectual disability (diagnostic overshadowing) were the main determinants about whether or not the clinician would consider providing therapy to this group (Mason).

The more confident the therapist felt about his or her ability to treat this population, the more likely he or she was to provide services; the higher the level of functioning of the person with ID also made the provision services more likely. Also the greater the therapists' understanding that psychiatric target symptoms were separate from the person's intellectual disability, the more receptive the therapists were at treating people with ID (Mason, 2007). This study, which used two surveys to compare therapists' attitudes regarding people without intellectual disability and those with intellectual disabilities, found that the perceived effectiveness of different styles of therapy were comparatively less important factors in therapy provision. Unlike the present study, Mason's research did not examine therapists' educational coursework or their prior exposures to people from the ID population as predictors.

A study conducted on behalf of the Case School of Medicine in Cleveland, Ohio did examine the effects of attitudes and exposure, using psychiatric residents (Ruedrich, 2008). With the goal of enhancing the clinical competence of residents for treating people with ID for mental health issues, the residents were required to complete a 3-4 month rotation working with a MH-ID population. Contact between the residents and these identified persons for treatment, took place in settings that included outpatient clinical contact, community visits and consultation in supported living apartments, group homes and sheltered workshops. Additional goals of this program's rotation were to improve the attitudes, comfort level, willingness and ultimately the number of psychiatrists providing services to this population. Twenty-one (21) residents who graduated from the program after completing the rotation completed a 17 item attitudes scale about people with intellectual disabilities living in the community (Keys et al., 1996) and 17 graduates completed the survey prior to undergoing the rotation. The results indicated that exposing the psychiatric residents to people with ID during residency training was positively correlated to more favorable attitudes and support for the rights of this population, in comparison with the group who had not been exposed to the population (Ruedrich et al., 2008). The implications of such exposure and training are that similar initiatives should be made available to current residents specializing in psychiatry, graduate psychology students during internships, as well as to psychology professionals in continuing education opportunities. This would address the gaps and disparities in mental health service provision to individuals with dual diagnoses.

Education of Clinicians

Clinicians who currently provide services to people with ID often report going into the field by accident or default because it is suspected that few college and university programs offer courses or even lessons about people with intellectual disabilities or people with MH-ID dual diagnoses. In the medical field, regarding education about intellectual disability, it is postulated that the lack of educational opportunity may lead graduates from programs in psychiatric studies to avoid the population (Graham, Herbert, Price, Williams, 2008). Education about the population is found to be a contributor to positive attitudes about the group. One study found that when medical students received education on how to communicate with people with intellectual disabilities, a significant change in favorable attitudes occurred (Tracy, Iacono, 2008). These results are not limited to psychologists because another study educated optometrists about treating people with intellectual disabilities. Statistically significant improvements were gained in self-reported attitudes, in knowledge of vision problems specific to the ID population, and in confidence in working with people in this group (Adler, et al, 2005). These few examples help to confirm how education specific to the ID population can improve attitudes and the subsequent likelihood that clinicians will provide services to the population.

Exposure to People with ID

In the medical and psychological profession, there is a requirement that before a license is granted, one has to interact and treat the population which one plans to serve. At the advanced stage of training programs, clinicians have the opportunity to become general practitioners or to specialize by participating in supervised treatment provision in the form of internship or residency placement. Despite the need, few internship experiences are offered for treating people with intellectual disability. Some of the same studies that found evidence to support the efficacy of education in improving attitudes and the likelihood that services are provided to people with MH-ID, endorsed exposure to the population as a key element.

In the study identified previously about educating optometrist to treat people with ID, clinicians receiving only didactic instruction about the population were compared with a group of clinicians who received didactic instruction and supervised contact (exposure) to treat people with ID for a minimum of two days. (Adler et al., 2005). The study found that, compared with clinicians who received lectures only, the clinicians who received the supervised contact had significantly better results on a follow-up, self-report survey about attitudes on treating the people with ID. This study is important because it highlights the fact that minimum exposure is needed to affect change in attitude and thoughts about treating people with ID. Likewise, the previously mentioned research with medical students receiving a three hour lecture about communicating with people with intellectual disability followed by direct contact with tutors with intellectual disabilities for participation in a communication exercise, showed that medical students could experience an attitude change even after a brief information session, combined with the exposure factor of interacting with people with disabilities **(**Tracy, Iacono, 2008, Ruedrich, 2008).

Conclusion

It is well established that people with intellectual disability can have genetic and biological vulnerabilities and/ or experience environmental factors that can lead to psychiatric disorders. It is also established that those who have intellectual disabilities are susceptible to psychological intervention and can thrive with treatment. For more than two decades, support for the successful use of psychotherapy for people with intellectual disability has been growing (Willner, 2009). The debate about which interventions are best for treating people with intellectual disabilities continues (King, 2005; Sturmey, 2006; Emerson, 2006,). Regardless of the intervention endorsed, it is important that the treatment is evidence-based with researched efficacy and that dignity is afforded in the delivery of treatment. Overall, research and more so, the actual treatment for people with intellectual disability and mental health challenges remain in the infancy stages because, for so long, people from this group were seen as ineligible for treatment (Willner & Hatton, 2006). There is no question that, as is the case with all research,more control studies are needed to properly identify the most salient factors that contribute to the successful treatment for this population.

What remains of concern regarding the debates about behavior support versus therapy is the sweeping generalizations used to describe people with intellectual disabilities. In one critique of cognitive behavior research and psychotherapy, people with intellectual disabilities are universally described as having slowed thinking, a lack of imagination and creativity and are impaired in their ability to recognize facial expressions (Sturmey, 2004). Those who have had the opportunity to experience the humor, artistic ability, wit and reciprocal friendships of people with ID can recognize that such blanket statements regarding collective imagination and creativity ignores the complexity of the disability and the individuality of the people described.

These statements risk the promotion of the stereotypes and stigma that self-advocates of this group and their supporters actively work to eliminate (Wehmeyer et al, 2008).

If the field is going to advance, then it is essential that people with intellectual disabilities are recognized by the researching and practicing behavioral health community as people first, who require individualized assessment of behavioral health, skills, strengths, needs and specific concerns. Subsequently, whether the issue is behavioral, psychiatric or a combined concern, the treatment approach should be based on an intervention that best addresses one's needs, delivered by a willing, unbiased professional clinician who has received the education to do so.

The following study asks clinicians about their views, experiences and practices relative to people with intellectual disabilities. By doing so, quantified evidence as provided by clinicians in Pennsylvania, identify factors that contribute to the knowledge of what motivates or influences clinician to provide services to people with intellectual disability. This study, therefore, becomes a tool for the advocates that support people with intellectual disability and co-occurring disability to affect the change that has been sought with the goal of increasing access to behavioral health services.

Chapter Three – Hypothesis

When it comes to accessing behavioral health services such as quality psychiatry therapy or emergency psychiatric care, people with intellectual disabilities are greatly underserved and underrepresented (Einfield & Tonge, 1999; Moss 1999). The research question is, "What factors influence clinical psychotherapists to provide or be willing to provide therapy to people with intellectual disabilities, as compared with the willingness to treat the general population of people with psychiatric disorders?" This study tested one new hypothesis and one hypothesis from a previous study that took place outside of the United States (UK), in order to answer the research question.

Hypothesis

1) The willingness of clinicians to provide psychotherapy to people with intellectual disabilities and mental health challenges as well as 2) the current provision of therapy to people with ID, are both influenced by provider variables such as education, exposure, and attitudes about intellectual disability and the treatment of their mental health issues. The assumptions about these dependent variables are as follows:

a) Exposure: Therapists rarely have the experience of encountering people with intellectual disabilities in daily interactions, which creates an experiential barrier. Historically, the largest movement of people returning from institutions to the community took place in the 1980s. People born after the mid-1970s are more likely to have grown-up in communities where people with intellectual disabilities lived and would therefore, show fewer biases about working with this population. b) Specialized education: Therapist in the United States are rarely educated about this population or given practical training and experiences to provide therapy or other behavioral health services to people with intellectual disabilities.

c) Attitudes/Personal Bias: Therapists share the many biases (fear, disgust, superiority, pity) toward people with intellectual disabilities that are held by society, which may interfere with the desire to work with the population.

The hypothesis of this study therefore is that 1) clinicians willing to provide therapy for people with ID will have higher levels of education (as measured by ID education) than their non-willing counterparts. 2) Clinicians willing to provide therapy for people with ID will report higher levels of exposure to the ID population than their non-willing counterparts, and 3) individuals willing to provide therapy for people with ID will report more favorable attitudes toward the ID population (as measured by MRAI-R) than their non-willing counterparts. Additionally it is believed that these same variables (education, exposure and attitudes) will be shown to have been influential on clinicans who are currently providing services to this population.

Rationale

A method to influence positive attitudes about people with disabilities is through education (Tait & Purdue, 2000) It is believed that there are few psychology, social work or psychiatry programs in the colleges and universities across the nation that currently offer substantial coursework or practical training (internship/practicum experiences) for working with people with intellectual disabilities. (Questions about colleges, universities and coursework are included in the questionnaire.)

With regard to the issue of exposure, it has been found that the combination of education and exposure can positively affect a clinician’s attitude about people with intellectual disabilities (Hastings et al., 1996; Ruedrich et al., 2008). The majority of people with intellectual disabilities living in the United States have been in the general population for only 20 -30 years, since the closings of institutions in America (Scott, Lakin & Larson, 2008). It took another few years for this group to become integrated into society. As a result, most people over the age of 30, including behavioral health clinicians, would not have had the opportunity to have encountered, grown up with, or have developed relationships with a significant number of people with intellectual disabilities in their communities. Recent research has demonstrated that contact with and exposure to people with intellectual disabilities positively affects attitudes of professionals, as evidenced by a number of experiments, including two involving psychiatric residents and optometrist students (Adler et al, 2005; Ruedrich, 2008).

In the field of disabilities, research has shown that the way to change people's behaviors toward people who are different is through attitude change (Antonak, 1994). Research has established that society frequently views people with intellectual disability very negatively (e.g., Horner-Johnson et al., 2002). Societies have often created an 'out-group' in people with intellectual disabilities, who are viewed as less than human because of their disabilities and perceived disadvantaged characteristics related to intelligence, awareness, and the ability to participate in the level of friendly or intimate relationship enjoyed by the majority of citizens. (Salih, 2007). Using the The Mental Retardation Attitudes Inventory Revised -MRAI-R (Antonak & Harth, 1994), one study compared the attitudes of undergraduate students enrolled in an introduction to special education course (n = 178) with students enrolled an introduction to political science course during consecutive Spring and Fall Semesters (Rice, 2009). The political science majors showed bias in relation to three subscales: Integration/Segregation, a measure of the respondent's view of integrating children with ID into mainstream classrooms; Private Rights, a measure of the view that landlords, school personnel, and others have regarding the right to exclude people with ID from certain homes, communities, schools, and the work place.

The third comparative, negative bias rated by the students enrolled in the political science courses was the Social Distance scale, which is a measure of a person’s willingness to recognize, live near or be associated with children with intellectual disabilities. The political science majors showed significantly higher levels of bias in relation to all three subscales when compared with the students enrolled in the special education course (Rice, 2009).

Chapter Four-Methodology

Overview

A recent series of focus groups conducted across the Commonwealth of Pennsylvania identified, as a major mental health disparity issue, the difficulty in finding psychotherapists who provide therapy to people with intellectual disabilities and co-occurring mental health issues (McFalls & Brown, 2009). The purpose of this study was to determine whether or not therapists' education, attitudes and experiences of being in contact with people with ID contribute to or inhibit their interest either in providing therapy to this population, or in their willingness to provide therapy to this population.

Design and design justification

A single survey design was used to gather information about clinician's education involving people with ID, experience with the population, as well as opinions and attitudes about people with ID. The survey/questionnaire was developed by the researcher. The survey contained several sections: a demographic background section, a section querying participants' experiences with, opinions and education regarding intellectual disabilities, and a section on participants' attitudes towards individuals with ID. The attitude questions are from the Mental Retardation Attitude Inventory –Revised (MRAI-R) developed by Antonak (2004).

Participants

The participants of this survey included master's and doctorate level professionals who currently practice or who are in training to provide direct therapy in the Commonwealth of Pennsylvania, as a representative sample of clinicians from this country . This group included psychologists, licensed professional counselors, social workers, pastoral counselors, and professionals who provide behavioral health therapy under the license of a professional provider.

Inclusion criteria

Participants had to be English speaking psychotherapists, psychiatrists and therapists with at least a master’s or doctoral degree, practicing under a licensed service in Pennsylvania. Students with at least a master’s degree who provide behavioral health therapy as part of their educational training were included in this study to provide information about future therapists.

Exclusion Criteria

People excluded from this study included non-masters /doctorate degree clinical therapists, therapists or students who have not provided psychotherapy within the last five years. Also excluded were non Masters/doctoral degree Behavior specialists and Non Masters/doctoral degree Applied Behavior Analysts.

Screening procedures

Agency contacts were asked to distribute surveys electronically or to provide email addresses of clinical professionals, based on inclusion criteria. Emails explaining the study informed potential participants of the inclusion criteria and reminded them, that in order to be eligible, they needed to fulfill those criteria. Additionally, the survey had questions regarding education (Masters or Doctoral Degree) and schools from which the degrees were granted that further assisted in screening procedures in the analysis stage.

Recruitment

Potential participants were psychotherapists from the Commonwealth of Pennsylvania, including behavioral health insurance providers from Community Behavioral Health, Magellan and Community Care Behavioral Health (CCBH of Montgomery County). Second, the website, Directory of Psychology Today® which lists providers throughout the Commonwealth of Pennsylvania was a significant resource for direct email solicitation. Third, participants were asked to pass the survey on to colleagues meeting criteria through word of mouth, email and Facebook® to generate a “snowball effect” in order to increase the number of participants, regardless of experience with the ID population.

Informed consent procedures

This study was a survey study with minimal risk to potential participants. No identifying information was collected from participants. This study did not require informed consent procedures; however, participants were informed of and provided with the identity and affiliation of the researcher. Participants were given a clear description of the study purpose and procedures with contact information for questions about the research. Survey directions stated that participation and answering questions was voluntary.

Measures

Prior to the survey, participants read an introduction describing the purpose of the survey, how it would be used and an explanation of the procedures involved. The survey used in this study consisted of three parts. The first part of the survey was a demographic query capturing information about age range, race, gender, job position, region, setting, services provided, degree and school attended. The second part of the survey was a 20 item questionnaire developed by the researcher that identifies the theoretical therapy orientation, experience, exposure, current practice, interests and concerns relative to working with people who have dually diagnosed ID. The survey contained questions on the participants’ experiences, knowledge and education that were guided by the literature, researcher knowledge and his experience in the field of ID and therapy provision.

Prior to being distributed, the Clinical Therapist Questionnaire on ID (CTQ-ID) was reviewed by three psychology professors, a psychiatrist specializing in ID and one practicing psychology consultant who is an expert in the field of intellectual disabilities and former regional president of the American Association on Intellectual and Developmental Disabilities (AAIDD). In addition the instrument was reviewed by four independent behavior health professionals composed of psychologists, behavior specialists and a college professor.

The third part of the survey included the Mental Retardation Attitudes, Inventory - Revised -MRAI-R (Antonak & Harth, 1994). This instrument has been a standard in evaluating attitudes about this population for over six years (Krajewski & Hyde, 2000; Krajewski, Hyde & O’Keefe, 2002; Rice, 2009). For use in this current study, Dr. Antonak, the chief developer of the instrument, was contacted. He reported that the validity of the instrument may be affected by substituting “intellectual disabilities” for “mental retardation.” For that reason the terms were not changed.

The MRAI-R is a 29-item self-rating inventory to measure attitudes toward people with intellectual disabilities. The MRAI-R has four-subscales which are integration-segregation (INSE); private rights (PRRT); social distance (SDIS); and subtle derogatory beliefs (SUBD). Each question is rated by the participant on a 4-point Likert scale. An example question is “I have no objection to attending the movies or a play in the company of people who are mentally retarded”. A psychometric analysis of data was obtained from 230 individuals for MRAI-R (Antonak& Harth, 1994). The results yielded satisfactory item characteristics which included: adequate reliability and homogeneity for the inventory; adequate reliability, homogeneity, specificity, and independence of the four scales; and support for the validities of the inventory and the four scales. Additional analyses revealed that the overall inventory and scale scores were not biased by social desirability responding. The inventory has been found to be useful for the investigation of attitudes toward individuals with intellectual disabilities and the relationships of these attitudes to relative policies and practices that affect this population (Johnson et al., 2002; Krawjewski & Hyde, 2000; Krawjewski, Hyde & O’Keefe, 2002; Rice, 2009).

Procedure

An e-mail was forwarded to potential respondents with a link for the survey. Respondents were directed to activate (click on) the link to begin the survey. Each person was directed to complete three web forms as part of this survey. Those forms included the therapist demographic form, the Clinical Therapist Questionnaire and, the MRAI-R (Mental Retardation Attitudes Inventory) Opinion Inventory. Upon completion of the three web forms by clicking the "Submit Survey" button, data were sent directly to the secure database of Philadelphia Coordinated Health Care, (PCHC) without any identifying information regarding the respondent. Data were exported from the SQL Server database to an Excel Spreadsheet, omitting any email or other forwarding information. The de-identified Excel Spreadsheet was available only to the researcher to be loaded into SPSS for data analysis.

A brief opening statement from Behavioral Health Managed Care Organizations (MCOs) urging the participation of the behavioral health agencies and private practice therapists was emailed as a cover letter to the survey. The survey was dispersed through email to behavioral health agencies and private practitioners dispersed throughout the commonwealth of Pennsylvania. This research was funded by a Developmental Disabilities Council (DDC) grant obtained by Philadelphia’s Health Care Quality Unit, PCHC, as part of an overall effort to address the needs of people with intellectual disabilities and co-occurring mental illness. In addition to targeted data base recruitment, snowball recruiting methods were utilized to increase survey participants. This method involves asking participating therapists to forward the electronic version of the survey to other providers, regardless of the parent provider organization affiliation or whom they see for services as long as the clinicians were licensed to practice in a masters or doctoral program for therapy or to practice under a licensed provider in the Commonwealth of Pennsylvania.

Approximately five hundred practicing therapists and therapy students living in Pennsylvania were invited to complete the emailed questionnaire/survey administered through the previously mentioned recruitment procedures (See Recruitment). Within sixty days of the survey distribution, the minimum target level of ninety responses was reached, thus allowing the initial data analysis to begin.

Analysis of Risk/Benefit Ratio

The risks of participating in this study were considered minimal. Participants were asked to provide information about their theoretical orientations, experiences with ID individuals, and questions exploring their beliefs and attitudes about individuals with ID. In the unlikely event that answering any of these questions would make participants uncomfortable, participants were given the option to choose not to answer that /those questions.

Potential Benefit to Participants

The benefit of participation was the contribution to the science of psychology and the expansion of best and inclusive practices in the field, particularly in the area of psychotherapy.

Potential Benefit to Others

This research will benefit people with intellectual disabilities, their families, associated professionals and the community at large by not only increasing the understanding of how psychological interventions are viewed and applied, but also what is needed to enhance services and supports to this population.

Potential Risk

The risks of participating in this study were considered to be comparable with those involved in participating in a job interview where the information that is shared includes basic demographic data, training history, professional background, views and related experiences.

Procedures for maintaining confidentiality

The survey did not collect information that could identify individual respondents. To further protect confidentiality, survey results were reported and will be published as aggregate data, further making any possible identification of individual respondents highly unlikely. To avoid the retention of email IP addresses that could potentially identify participants, the data were transmitted in an encrypted format. Firewall technology was used to protect the research from unauthorized access.

Chapter Five – Results

Description of Analysis

Variables were evaluated through descriptive statistics to summarize, organize and simplify the data. All information was derived from the three part electronic survey. First the sample was described in terms of demographics and professional variables taken from the first section of the survey. Two of the three variables from the main hypothesis, “education” and “exposure,” were obtained from the Clinical Therapist Questionnaire on People with Intellectual Disabilities (CTQ-ID). The dependent variable, attitudes, was obtained from the Mental Retardation Attitudes- Inventory Revised (MRAI-R) Opinion Questionnaire. This scale has 4 subscales, integration-segregation (INSE); private rights (PRRT); social distance (SIDS); and subtle derogatory beliefs (SUBD). Scores were totaled, recoded for reverse score variables and analyzed for internal reliability using Chronbach’s Alpha. The internal consistency for all subscales was satisfactory, ranging from .721 (PPRT) to .845 (INSE). The 4 subscales of the dependent variable of attitudes were tested with two MANOVA to examine a) clinicians’ willingness to provide services to people with intellectual disabilities (ID), as well as b) clinicians currently providing therapy. The variable of exposure was operationalized using the qualitative data from question twenty of the CTQ-ID. This question asked clinicians to discuss their levels of personal and professional involvement with people with ID, with their responses coded, as detailed in Table 6. This variable was examined with an ANOVA for therapists’ willingness to provide services, and a T-test with regard to actual service provision. The third dependent variable, education, also taken from the CTQ-ID, was examined with two chi-square analysis, one to examine therapists’ willingness to provide therapy and the second to examine actual service provision by therapists to the MH-ID population.

Additional analyses were conducted to determine if other factors influenced either clinician's willingness to provide therapy, or their actual provision of services. Other possible factors such as theoretical orientation of therapist and professional experience (years in the field) were examined with regard to willingness to provide therapy. Chi-square tests were conducted on nominal and ordinal data for "students" versus "professionals" and "younger therapists" (less than 5 years paid experience as a therapist) versus "veteran therapists" (over 10 years of paid experience as a therapist) and willingness to provide therapy. Other nominal data such as clinician race/ethnicity were not analyzed because there was too little variance in these variables to yield useful analyses. The following data were obtained from the three part survey.

Demographics

Table 1 shows that 339 clinicians responded to the survey. Two hundred and sixteen (*n* =216) of those respondents met the criteria for the study. The online survey was designed so that respondents who did not meet the study criteria were digitally unable to proceed to the remainder of the survey, based on the program design. The majority of the information in this study is based on the responses of up to 174 clinicians. The number of responses to each question ranged from 87 to 174 clinicians. The variable response rate occurred because responding to each question on the survey was allowed to be optional in an effort to attract as many participants as possible, yet being mindful of the time constraints of most respondents. The valid missing variables were used as a grouping variable to examine whether or not the missing cases were statistically different from the valid cases for all of the variables in the analysis. If the variables were metric, a *t* test was done for group differences. If the variable was non-metric, a chi-square test of independence was done to detect group differences. The calculations completed were based on actual responses per question. Another way missing data were addressed was by reporting the number of responses for each question prior to reporting the results.

As indicated in Table 2, the majority of the respondents were white (87.9%), female clinicians (67.9%), under the age of thirty-five years. The ages of the respondents ranged from 24 to over 66 years of age. The study has representation from 32 different counties of Pennsylvania, and study participants reported graduations from a total of 64 different college or universities. These responding clinicians represented psychologists, psychiatrists, licensed professional counselors, therapeutic social workers, pastoral counselors and other psychotherapists, as listed in Table 3. Other professionals listed included art therapists, behavior specialists, psychological consultants and certified school psychologists. As indicated in Table 4, the majority of the respondents were from outpatient facilities (53%). Other represented locations included day treatment facilities and private practices. Of the twenty-one individuals indicating “other”, respondents listed a specific work setting which included wrap-around services (BHRS), residential treatment, Veterans hospitals, grade schools, county offices and insurance companies.

Variables used in the Analysis

The CTQ-ID and MRAI-R were the sources for the independent and dependent variables for all main analyses conducted for this study. Means and standard deviations for all independent and dependent variables were calculated and are displayed in Table 5.

Clinical Therapist Questionnaire on ID (CTQ-ID)

The following is a summary of the responses obtained from the Clinician Therapist Questionnaire. Both dependent variables of the main analyses and two of the independent variables were obtained from this questionnaire.

Independent Variable: Current Provision of Services to People with ID

Approximately fifty-eight percent (57.6%) of one hundred and sixty-five (165) clinicians reported that they have provided therapy to people with intellectual disabilities and co-occurring mental health challenges (MH-ID) within the last two years. Forty-two percent of the clinicians reported that they do not provide therapy to this population (42.4%). Over fifty-one percent (51.2%) of the respondents indicated that they conducted assessments with this population and forty-nine percent (48.8%) indicated that they did no conduct assessments.

Independent Variable: Clinician Willingness to Provide Services

The survey asked the responding clinicians who did not already provide therapy to people with ID if they would be willing to provide therapy to this population. Results showed that 70 of 164 clinicians, or forty- two percent (42.4%), reported that they did not provide therapy to people with ID. Of those respondents, all but two clinicians responded to this question of "willingness to provided services." Of the sixty- eight (68) clinicians who responded to the question, nearly forty percent (39.7%) indicated that they were willing to provide therapy to people with ID. Nearly thirty-four percent (33.8%) report that they were unwilling and nearly twenty-seven percent (26.5%) were undecided.

Dependent Variable: Education

The responding clinicians received their education from 64 different colleges and universities across the nation. Education was operationalized by question 8 of the CTQ-ID, which asked participants if they had received education/training for working with people with an intellectual disability (yes/no). For education about individuals with ID, it was found that over sixty-eight percent of the respondents (67.9%) reported that they had not received education and of those that had received education, eighty percent (80%) reported less than two educational courses with information about people with ID. When clinicians where asked about the reasons why they did not treat people with ID, of 171 respondents, seventeen, or 35 percent (35.3%) identified not receiving education as the reason. Sixty -eight percent of all of the respondents (67.7%) reported that they were interested in receiving education about working with people with intellectual disability and mental health diagnoses (MH-ID). Sixty-four percent (63.5%) of 159 responding clinicians indicated that if they were trained or were provided education about working with this population, they would add people with MH-ID to their practices. The balance of the responses were split between those being undecided (18.9%) about providing treatment if trained, and those responding “no” they would not provide services even if training for working with MH-ID was received (17.6%).

Dependent Variable: Exposure

In an attempt to assess exposure as a factor to influence clinician willingness or current provision of services to people intellectual disabilities, question 20 of the CTQ-ID asked participants to describe their contact with members of this population: “Please briefly list and explain any experiences you may have had being around people with an intellectual disability (including family members or neighbors) and thoughts/feelings about the experience(s)." For analysis, a coding system was developed by placing the responses in one of four categories; "0" was coded for the category of "no experience" if the survey participant reported having no experience being around a person with ID. The code "1," minimal contact, was assigned for those limited to seeing or being in vicinity of people with ID. The code "2", basic contact, was assigned to those working with or having surface interactions with neighbors, friends, or family members with ID, and a "3," relationship contact, was assigned to those having an interactive relationship beyond work and basic greetings as indicated in Table 6. Upon reviewing the data it was found that only 87 of 216 participants responded to this question, which is forty percent (40.3%) of the total eligible participants. The data from question twenty of the CTQ-ID are positively skewed, with the majority (80%) of those responding to this question having had basic or greater contact involving people with ID.

Dependent Variable: Attitude

The MRAI-R (Mental Retardation Attitudes Inventory Revised) Opinion Inventory was included with the e-mail survey to assess the attitudes of the clinicians participating in this study. Participant's attitudes were rated in accordance to the four-subscales: integration-segregation; private rights; social distance; and subtle derogatory beliefs. The questions that measured the belief that people with ID have the right to be integrated into society rather than be segregated away in homes and institutions (INSE) had 140 respondents (80%), as did the set of questions that measured people's comfort with having people with ID in their friends, family and business social circles (SDIS). The measure of the belief that people with ID should have the same rights as people in the general population (PPRT) had 137 respondents and the measure of subtle derogatory beliefs against people with ID had 135 respondents (SUDB). This last item (SUDB) was reverse scored and placed with the others so that the higher the score the more favorable were the attitudes about people with ID.

Other Descriptive Findings from the CTQ-ID

Characteristics of People Served

Services provided to people with MH-ID were equally distributed among children (39%), teen-agers (41%) and adults (37%). People with ID over the age of sixty-five years represented ten percent (10%) of the reported caseloads. Sixty-eight percent of these respondents (68.4 %) reported treating individuals who fell within the mild to borderline levels of intellectual and adaptive functioning (IQ between 70 to 85). Nearly forty percent (39.8%) of the people served were in the moderate range (IQ between 35 and 55); fourteen percent (14%) of the people supported were identified being in the severe range (IQ between 25 and 25), and seven percent (7%) were in the profound range (IQ below 25 and extremely low adaptive function). Question five of the CTQ-ID asked people to clarify which disability affected the population they treated. Participants could check multiple populations. Approximately sixty-eight percent (67.8%) of 168 respondents reported "Intellectual disability." Fifty- three percent (52.6%) reported "autism" and fifty-three percent listed "PDD" as the disability of the people served.

Reasons for not providing services.

The top three reasons (out of 171 responses) given for not providing treatment to people with MH-ID, included: not having had training (35.3%), being too busy to provide treatment (14.7%), and not being exposed to this population (11.8%). The other reasons for not providing therapy to this population were selected by a much smaller percentage of the respondents. These reasons included: the concern that clinicians would not be adequately compensated (7.4%); concerns that office staff would not work well with this population (1.8%), and concerns about safety (1.2%). The belief that people with ID would not benefit from therapy was a reason given by the fewest number of respondents (1.5%).

Theoretical Orientation

In response to the CTQ-ID question number seven regarding therapeutic orientation, most clinicians answered with more than one orientation. Of the orientations presented, cognitive behavioral therapy and behavioral therapy were the most frequently endorsed (69% & 44% respectively), followed by Person Centered Therapy (25%). Interpersonal Therapy (20%) and Dialectal Behavior Therapy were the least identified orientations (5.3%) of the responding clinicians.

Other clinician factors

In an effort to obtain a greater understanding of behavioral health service provision, and willingness to provide services, additional questions were asked of the responding clinicians concerning their beliefs and experiences in working with people with MH-ID. The following qualities were explored as possible factors related to ID therapeutic treatment.

Perceived Ability

When asked to rate their perceived ability to work with this population, of 162 respondents, 38% believed that they would do a good job; 35% reported fair; 12% reported very good, and the 3.7% admitted having the belief that they would do poorly. The remaining 10% reported that they would not attempt to treat this population.

Access through referrals

When asked if they receive referrals and requests to work with people with MH-ID, the majority of responding clinicians (162) reported that they receive referrals *sometimes* (37%) and twenty-one percent (21%) reported *frequent* referrals. On the other end of the spectrum, thirty-one (31%) percent of the clinicians reported that referrals are rare and ten percent (10%) reported that they never receive referrals to work with this population.

Perceived efficacy/necessity of treatment

The issue of “diagnostic overshadowing bias” is discussed in the literature review. This bias explains that some clinicians believe that people with ID are unable to have true mental health diagnoses and will therefore not benefit from treatment. When asked to respond “yes,” “no” or “undecided” to the statement: “Behavior rather than psychiatric disorder is the primary issue with this population,” of 166 respondents, approximately forty percent (39.8%) were undecided; approximately thirty –three percent (32.5%) replied “No,” and almost twenty-eight percent (27.7%) replied “Yes”, indicating that behavior, not mental health, is the primary issue regarding people with ID.

Perceived Effect on existing business

The majority of 164 responding clinicians did not indicate that the discomfort of other patients was a factor in working with people with MH-ID. Nearly sixty-three percent (63.8%) answered “no” to the statement, “People with ID will make other patients uncomfortable” and ninety- one percent (90.9%) answered “no” to the statement ,“Providing therapy to people with ID will hurt business.” Taking an optimistic view, exactly fifty percent (50%) of these respondents answered affirmatively to the statement: “Treating people with MH-ID would increase business.” Approximately thirty-three (32.9%) were undecided and seventeen percent (17.1%) responded “no” to the belief that treating people with ID would increase business.

Summary of Findings Organized around the Hypotheses

Hypothesis 1: Willingness to Provide Services

Attitudes.

Using question two of the CTQ-ID, the attitudes of those who indicated that they were willing to provide services to people with ID, (*n* = 24) were compared with those clinicians who were unwilling (n=19), and clinicians who reported they were undecided about providing services to the MH-ID population (n=18). The analysis were completed for this subset of the sample who had indicated that they were not currently providing services to this population (N=61).

A MANOVA was computed using the 4 subscales of the attitude questionnaire as the dependent variable. This analysis was conducted to determine whether or not those indicating a willingness to provide services differed significantly on attitudes from those who said that they were undecided versus unwilling to provide services to this population. The main MANOVA analysis initially indicated significant difference on the combination of the four dependent variables, Wilks Lambda = .748, *F* (8, 110) = 2.15, *p*= .037, as indicated in Table 7a. However, follow-up tests found no significant differences for any of the 4 attitude subscales on the independent variable as indicated in Table 7b.

Exposure

For the dependent variable of exposure a one-way ANOVA test was conducted to see if respondents' levels of exposure with the ID population had an effect on their willingness to provide services. Exposure was reported according to no encounter (n=0); minimum contact (n=17), basic contact (n=58) and relationship contact (n=12) for a total of 87 responses. This analysis did not yielded significant results, F (2, 34) =1.21, p= .31. In this study, exposure did not appear to be a factor influencing clinicians' willingness to provide therapy to people with intellectual disability and co-occurring mental health diagnoses.

Education

Finally, the study examined if clinicians who indicated a willingness to provide therapy to people with ID differed with regard to education received, from clinicians indicating they either were not willing to, or were undecided about providing services to the MH-ID population. This analysis failed to find significant results X^2 (2, *n* =67) = 2.14, *p* = .344. In this study, education did not appear to be a factor influencing clinicians' willingness to provide therapy to people with intellectual disability and co-occurring mental health diagnoses.

Hypothesis Two: Services provided

Attitudes.

Using question two of the CTQ-ID, of 147 respondents, the attitudes of those who indicated that they currently provide services to people with ID (*n* = 86) were compared with those clinicians who do not provide services (*n*=62). A MANOVA was computed to determine whether or not those indicating that they currently provide therapy differed significantly from people who do not provide therapy to people with ID on attitudes about patients with ID. Wilks Lambda = .922, F (4,143) = 3.02, p= .02 as noted in Table 8a. The findings indicated that clinicians who currently provide therapy to people with ID have more favorable attitudes toward people with ID than the responding clinicians who do not provide services to this population. Follow-up tests were performed for each of the 4 subscales of the attitude scale, and each of these F ratios was significant, as indicated in Table 8b. This indicated that clinicians who currently provide therapy to people with ID differed and had more favorable attitudes on each of the 4 attitude subscales, as compared with therapists who do not provide services to this population.

Exposure

A t- test examined if clinicians providing or not providing therapy differed significantly by their levels of exposure to the MH-ID population. Exposure was reported according to no encounter (n=0); minimum contact (n=17), basic contact (n=58) and relationship contact (n=12) for a total of 87 responses. This analysis showed a violation of the equality of variances (Levene's test). Therefore the results for equal variances not assumed were, t = -2.54, p = .01, as indicated in Table 9. The results indicated that respondents with either some or substantial exposure to individuals with ID were significantly more likely to provide therapy than those indicating no exposure.

Education

The hypothesis that levels of education differentiate between providing service and not providing services was not supported by the findings. Of those not currently providing services, those who received ID education were no more likely to report providing services (n=21) than those without training (n=48), although the difference is in the expected direction. Individuals currently providing therapy were then examined in relationship to reported education. When comparing those receiving ID education (n=32) with those who did not (n= 63) with regard to providing therapy for the ID population, the two groups did not significantly differ, X^2 (1, *n* =164), p = 0.66.

Additional Analyses

Attitudes

A series of one-way ANOVAs was conducted to determine whether or not the ages of clinicians showed differences in attitudes on any of the four MRAI-R subscales. Results indicated significant differences among the oldest and youngest groups for all the analyses, as indicated in Table 10. On the Subtle Derogatory Beliefs scale (SUDB e.g., "Although social equality for people of all intellects may be the democratic way, a good many people with ID are not yet ready to practice the self-control that goes with it,"). Post hoc analyses (Tukey's HSD) indicated that the 56-66 and over age groups displayed significantly more subtle derogatory beliefs than the younger groups, relative to people with ID. The most senior clinicians' views were considerably less favorable as compared with the three youngest age groups regarding support of the private rights of People with ID (PPRT-private rights). On the social distance scale (SDIS), the 24-34 and 46-56 age groups scored significantly higher than the 56-66 and over age group regarding their willingness to live near or be associated with this population. On the Integration –Segregation scale (INSE), the 35-45 and 46-56 groups scored higher than the 56-66 and over groups relative to the belief that people with ID have the right to integrate into society.

T tests exploring gender differences for the four scales failed to yield any significant differences in attitudes, although mean scores were consistently (non-significantly) higher for females than for males.

Education

In a further investigation, a chi square analysis was conducted based on responses to the CTQ-ID question number eight, (Q8)“When obtaining your current degree did you receive education/ training for working with people with ID?” , was compared with responses to question two: “Do you provide therapy to people with ID?” Based on the responses, the groups were divided into three groups: Low level of training in working with people with ID, Moderate level and High Level; there was a trend that approached statistical significance whereby individuals with a moderate level of training were more likely (75%) to provide counseling than either the low-level (56%) or the high-level (33%) groups, X^2 (2, n=43) = 4.19, p = .12. Overall there were no significant differences.

Other Variables

Question number nineteen (Q19) of the CTQ-ID survey asked participants whether or not they would add people with ID and co-occurring mental health diagnoses to their practice, if they as clinician received more education about treating the population. Of 159, sixty- four percent (63.5%) indicated that they would add people with ID to their practices, but eighteen percent (17.6%) responded “no” and nineteen percent (18.9%) were undecided. Of 108 respondents who reported receiving no education for treating people with ID, those who currently provide therapy are significantly more likely to report that they would add people with MH-ID to their practices if they received education/training (75.0%) than their counterparts who do not currently provide therapy (50.0%), chi-square = 9.44, p < .01.

Respondents who noted Interpersonal Therapy (IPT) or Person Centered Therapy (PCT) as their main therapeutic orientation were significantly more likely to report already providing therapy to people with MH-ID (77% and 70%, respectively). IPT: X^2 (2, *n* =165) = 7.72, *p* =

.005. and PCT: X^2 (2, *n* =165) = 7.63, *p* = .006. It was found that that person-centered therapists were significantly more likely to provide counseling to DDID patients (69.7%) than clinicians who did not include person-centered as an orientation (47.2%), X^2 (1, n=165) = 7.63, p = .006.

Practitioners with a cognitive behavioral orientation were marginally (non-significantly) more likely (61.5%) to provide therapy to people with ID than their “non-cognitive behavioral” counterparts. Twenty-five percent (25%) of the responding clinicians reported to have predominant psychodynamic/psychoanalytic orientations and these clinicians were least likely to treat people with intellectual disabilities and mental health diagnoses (14%).

Chapter 6 – Discussion

Significance of the findings

This study explored several variables hypothesized to affect the provision of therapy and psychiatric services, or, if the respondents indicated they were not currently providing services to individuals with intellectual disability and co-occurring mental health diagnoses (MH-ID), their willingness to provide these services. The systematic exploration of the main variables education, exposure and attitudes, facilitated an understanding about the possible factors influencing the disparity of behavioral health service provision to people with intellectual disabilities. Clinicians, providers, caregivers and politicians who devote their time to this issue on a regular basis are provided descriptive data and information about what is needed to address the behavioral health disparity for this population. Significant effects were found for the main independent variables of exposure and attitudes for the dependent variable of actual service provision to people with MH-ID. These findings are discussed in light of the current study design. The descriptive data and the subsequent analyses provide additional support for the need of increased education, practical training, and experience (to develop improved attitudes about people with ID), as evidenced by those clinicians who currently provide behavioral health services for this underserved population.

Discussions as related to the variables

Two independent variables; willingness to provide therapy to people with intellectual disability and current provision of therapy to the population, were examined to determine if the clinician groups differed in education level, exposure level, and attitudes. In this study, clinicians willing to provide therapy did not differ significantly from clinicians who were not willing to provide therapy on the three dependent variables. Descriptive data did, however, identify that the majority of the respondents did not receive education to work with this population and that the majority of respondents indicated that they would be willing to provide therapy if they received more education. Upon examining the second independent variable, “current provision of therapy”, a significant result was found for attitudes and exposure in the main analysis; however, the t variables of education were not significant.

Attitudes

A major finding was that clinicians who provided therapy to people with ID were found to have more positive attitudes toward the ID population as compared with clinicians who do not provide therapy to this population. This finding held for each of the subscales used to measure clinicians’ attitudes. This finding is particularly useful because the clinicians who currently provide treatment are the most likely candidates to serve as ambassadors for expanding services through the attraction and education of more clinicians. The findings that their attitudes have become or have remained favorable after treating the population can send the message that this is desirable and likely rewarding work.

The finding that younger clinicians hold more favorable attitudes toward people with ID is one that requires some exploration. One of the explanations for this age effect can be found in the treatment history of this population. Individuals born before the 1970s were exposed to fewer people with intellectual disabilities due to the fact that the majority of people with ID were placed in institutions until laws were enacted to return this group to the community (Scott, Lakin, & Larson, 2008). Therefore clinicians under the age of 40 have had a greater opportunity to have experiences growing up in communities with people with intellectual disabilities when compared to their senior colleagues. Younger clinicians have had a greater likelihood of exposure and a better chance of developing more favorable attitudes toward people with ID. The findings regarding age, of course, do not suggest that all or even the majority of clinicians over the age of 35 years hold negative attitudes about people with ID. After all, the leading advocacy agencies for people with ID are led by seasoned clinicians, providers and family members of people with ID. More important than the age implication is what this finding suggests regarding the expanding capacity for tolerance in American society. An inference can be made about the increased awareness and acceptance of people who are different from the dominant cultural? appearance, behavior and or style of communication. As identified in the literature review, the actions taken to establish the civil rights for people with intellectual disabilities not only coincide with the closing of institutions, but also the equal rights legislation for this population parallel the more well-known civil right movements of the 1960s.

Two other questions of the CTQ-ID found results that can also be seen as indicators of positive attitudes toward people with ID. Clinicians were asked if providing therapy to people with ID would affect their existing business in regard to the people they currently see. Fifty percent reported the belief that providing therapy to this population would increase their business and over ninety percent (90.9%) of the respondents indicated the belief that treating this population would not hurt business. This vote of confidence can, likely, be interpreted as a reflection of favorable attitudes about the ID population.

Exposure

One of the promising finding of this study is the number of clinicians who reported that they are already providing services to this population (57.6%). Although this number is significantly lower than the access that the general population has to behavioral health services (Taylor, Lindsay, and Willner, 2008), it is still a surprisingly large number of clinicians who indicated that, at least in Pennsylvania, there is a foundation for growth and expansion of behavioral health service delivery to people with MH-ID across the state and, ideally, the country. Currently practicing clinicians represent the resources for on the job training, for seminar and college level education as well as the capability to form a pool of mentors, consultants, and supervisors for new and current clinicians providing therapy and other services to this population. The clinicians who provide therapy to this population report that they have been exposed to this population on levels other than their work, because family, friendships and neighborhood contact was also reported. This finding supports the research that increased contact positively affects attitudes and the likelihood to pursue ongoing contact. (Rueddrich, 2008).

Education

The current study indicates that only thirty- two percent (32%) of the participants reported receiving any education about people with ID, and 80% of those clinicians had fewer than two courses with information about people with ID. Even this amount of education likely represents over-reporting, because some of the follow-up qualitative data indicated that, often, in the courses mentioned, only one or two lessons were devoted to the ID population. Because the amount of education received by the participants was minimal, it is of no surprise that the statistical analysis of education as a factor failed to yield significance. In this instance, the fact that the variable “education” lacked significance actually supports the hypothesis that there is a deficit in the education on the subject of intellectual disability. The number of clinicians educated on this subject and the amount of course work devoted to this population is so minimal, that there was not enough variance on the educational variable for people who were willing to provide services, and those currently providing services, to serve as a contrast to those clinicians who did not provide services or those who were not willing to provide services.

One of the most substantial findings around the subject of education is that nearly 68% of the respondents indicated that they want to receive education and training for working with this population (67.7%). It is also significant that when clinicians were asked the reason why they did not provide therapy, thirty-five percent (35.3%) reported the reason as, “not being educated or trained about the ID population.” These findings identify the real need to offer dedicated courses and practical experience in the form of practicums/externships, resident training, internships, and post-doctorate training (exposure) to emerging therapists, psychologists, and psychiatrists. Teaching clinicians and giving them the experience of getting to know and to provide therapy and other behavioral health services to this population can be one of the most direct ways to address the treatment disparity for this population.

How the Findings Relate to Previous Work in this Area

One of the few studies examining the provision of behavioral health services to people with ID from the clinician's point of view was a study conducted in the United Kingdom that also utilized surveyed responses (Mason, 2007). The authors reported that perceived clinician competence, the level of the person's disability, and the diagnostic overshadowing bias were the top ranking factors that influenced the provision of therapy. A study was designed to explore the issue of diagnostic overshadowing, the practice of dismissing diagnostically evaluated mental illness as ID related disruptive behavior; this study requested that respondents answer "yes" or "no" to the statement, "Behavior rather than psychiatric disorder is the primary issue with this population." A third of the 166 respondents indicated that they believed this documented myth and forty percent (39.8%) responded, "Undecided." A majority of clinicians unwilling to commit "yes" or "no" made the examination of this factor related to clinicians' attitudes difficult to evaluate. There are at least two possible explanations for these findings. One explanation is that the statement is not a true measure of diagnostic overshadowing and the reader did not understand what was being asked. Another explanation could be that responding clinicians believe that mental illness is not significant in the ID population, and they were either willing to state it, or they answered "undecided" to be politically correct. If the latter is true, then the question does measure diagnostic overshadowing and members of the NADD (formerly the National Association of Dual Diagnoses) and the American Association for Individuals with Intellectual and Development Disabilities (AAIDD) would be disheartened but not surprised to hear that this thinking still remains in the field. The third possibility for the question of diagnostic overshadowing is the most likely; clinicians are not informed about the research of the last ten years and simply do not know much about the population. As this study and the literature review outlines, people with ID not only experience mental health concerns, but the population also experiences mental illness at a higher rate than the general population due to the elevated rates of stressors, abuse and trauma experienced by this group (Newman, Christopher, & Berry, 2000; Razza, & Tomasula, 2004; Hartley, & MacLean, 2009) regardless of the fact that that they live at home or that they have some form of supported living. This finding of diagnostic overshadowing underscores the need to educate clinicians on the differences between behavior problems and the target symptoms of mental illness, as well as on the best practices for the diagnoses and treatment for people with MH-ID.

The UK survey (Mason, 2007) also found that self-rated competence was important to service provision. In the current survey, the majority of clinicians indicated the belief that they would be fair to very good at providing therapy to people with ID. This study did not find the concept of perceived competence to be a factor in the willingness to treat or to the current provision of services to people with ID. Additional factors examined in this study, not covered the previous UK study, included such variables as clinician therapeutic orientation, amount of education received, number of referrals received for people with ID, reasons clinicians do not provide services, concerns regarding compensation for services, interest in receiving training on this population, safety concerns, perceived effects on business, and degree of perceived comfort by staff and other patient’s in being in the same office as people with ID.

A substantial issue arose regarding theoretical orientation. The majority of the responding clinicians had an orientation of Cognitive Behavioral Therapy (CBT) and Behavior Therapy (69% & 44%, respectively) which is a logical outcome because the majority of the research for therapeutic intervention for people with ID has been on CBT and behavioral therapy interventions (King et al., 1999; Taylor, et al. 2008; Beail, 2003, Hurley, 2005; Dagnan &

Jahoba, 2006; Sturmey, 2006; Taylor, Lindsay & Wilner 2008). However, the theoretical orientations, Interpersonal Therapy (20%), and Person Centered Therapy (25%), were reported as a primary orientation by most clinicians who currently provide therapy. This is a noteworthy finding, because very little research regarding these interventions in relation to people with ID is available. These findings demonstrate the existence of an evidenced- based foundation for current treatment (CBT & BT), as well as the need for additional research on the effectiveness of some of the treatments currently being provided (IPT & PCT).

Referrals have not been explored in previous studies. The research found that about forty-two percent of the clinicians responding to this survey report that they rarely or never receive referrals to treat people with ID, but the majority of respondents reported receiving some or frequent referrals for working with this population. This indicates the level of the demand for services for this group and the need for the expansion of therapeutic services delivery and subsequent funding.

A significant difference between the UK study and the current study lies in the participants who responded to the surveys. This survey went to psychiatrists and therapists regardless of the population they treated, who then attempted to identify which of these providers also treated individuals with ID; the UK study was able to specifically target psychiatrist and therapists who already worked with the ID population. This difference in the respondent population was likely due to the fact that the UK is more active in therapy delivery and research than the United States (Hurley et al., 2003). This evidences the need for further research, training and exposure of service providers to the ID population in this country. A previous study in the United States showed how providing supervised experience in working with people with ID to psychiatric residents increased the psychiatrists working with this population after graduation

(Rueddrich, 2008). The current study supports this research with the finding that clinicians reporting the greatest exposure to people with ID, and the ones currently providing therapy to the population, possess the more favorable attitudes about the population in general.

Relevance to the Study to the Theory and Practice of Psychology

Clinical psychology has the inherent goals of observing, describing, explaining, predicting, and influencing behavior. Therefore, by definition, the study and treatment of people with intellectual disabilities is extremely relevant to the theory and practice of psychology. The literature review demonstrates a sizable quantity and richness of research about people with intellectual disabilities. With this body of knowledge the fields of psychology and psychiatry are no longer in a position to ignore this disenfranchised population. Unfortunately, the literature review also demonstrates that people with intellectual disabilities continue to be ignored when mental health issues arise. Cognitive therapy and other therapeutic supports for people with ID have been put into practice in countries such as the United Kingdom with numerous studies on the efficacy of therapy in isolation, or combined with medical treatment of psychiatric symptoms (Dagnan, 2007). The United States has organizations such as NADD (formerly the National Association of Dual Diagnoses) and the American Association on Intellectual and Developmental Disabilities (AAIDD) that show the commitment to reach members of psychology and psychiatric professions to increase the support for this disenfranchised and underserved population. Communicating these and similar findings to organizations such as the American Psychology Association and American Psychiatric Association could help the members recognize that treating this population is built into the ethics and mission of the field, but that this work has a potentially larger benefit to society and the field of behavioral health. A clinician who is able to use his or her tools in a way that can be understood by an individual of a most basic intellect can only strengthen his or her abilities for working with the general population.

Suggestions for Future Work

An unintended discovery of this study is the finding related to the clinicians' endorsed theoretical orientations. Clinicians indicating that their main therapy orientation was Interpersonal Therapy and Person Centered Therapy were significantly more likely to report that that they were already providing therapy to people with MH-ID than any other therapists. It is the opinion of this author that between clinicians who still consider themselves eclectic, and those who have an expanded approach, these two theoretical orientations are generic enough to be the most highly selected. Opinion is being used here because after extensive searches, no evidence- based research or even anecdotal documentation is readily available about these two approaches, relative to people with ID. This study highlights the extensive research in regard to Cognitive Therapy, Behavior therapy, Applied Behavior Analysis, and even psychodynamic approaches. If other theoretical orientations such as Person Centered Therapy or Interpersonal Therapy are actually being used with the ID population then what is specifically occurring during treatment? Information about specific protocols and treatment approaches, as well as continued research can only help to further the needed supports and services for this population.

This study is unique because it is one of the few studies comparing clinicians who provide therapy to people with ID with those clinicians who do not. The research, however, had some clinicians speculating or attempting to predict their behavior, based on hypothetical scenarios. Because the goal of this study was to identify factors that actually promote the willingness to provide therapy, the duplication of this study in places such as the UK where more therapists actually provide therapy to this population would likely yield findings that would be more substantial and relevant to the stated hypotheses.

To make this study more experimental with outcomes that more tangible it would be beneficial to study clinicians that have not provided services to ID population but who report a willingness to take on new ID clients. It would be helpful to measure attitudes prior to and post accepting and treating ID clients and report level of change in attitudes. Another experiment could involve offering free education seminars, workshops and or lectures on providing treatment to people with ID. Later it would be important to report characteristics, and attitudes of the people who take these seminars and identify whether or not the attendees are people who already provide services to ID population or new providers that are not currently providing services to this population.

As stated in the discussion of significance, this current literature review and research can be used as a basis for developing college curriculums at therapy research sites and programs that offer practicum, internship and medical residencies. The literature review provides the history of people with ID in this country, the factors that contribute to mental illness in this population, and supply methods to diagnose and therapeutically intervene. The research offers highlights about how education, exposure and attitudes are factors to be addressed in developing educational program for clinicians and therapeutic programs for people with ID. The information gleaned from this study can be used to improve education and actual experience in providing outpatient and inpatient behavioral health treatment to people with intellectual disabilities with mental health concerns. The development of courses and work experiences at a university level will not only increase the number of competent professionals available but it would also have the potential benefit of expanding the field of psychology and psychiatry to provide better services to underserved populations, to develop a greater job market and to add to the perception of legitimacy to this area of the behavioral health profession that is currently viewed as substandard and charity work by many. With increased research, education and intervention, there is an increased likelihood that the quality of life for people with intellectual disabilities, their families and communities can improve. Most importantly, the expansion and improvement of behavioral health treatment to this population will represent meeting the needs of three million Americans who are currently underserved.

Limitations of the Current Study

There are some limitations to this study that are in need of acknowledgement. One of the main limitations was highlighted previously and concerns the fact that some of the clinician's responses were based on the hypothetical rather actual treatment provided to people with ID. Regarding the findings, another limitation is the correlational nature of the design. Although it is likely that people with more favorable attitudes towards the ID population choose to work more frequently and more closely with them, it is also possible, however, that clinicians' attitudes changed favorably as a result of having to treat people with ID who were randomly referred to therapists' offices over the years. .

Another limitation can be found in the study recruitment methodology. The e-mail survey was conducted with participants that were predominantly recruited through various data bases such as those belonging to different Pennsylvania Managed Care organization, professional organization and city and state data bases. It cannot be determined whether or not there are systematic differences between those who chose to respond to this study and those who did not (e.g., in terms of participation motivation and interest). Next, although the research participants were recruited from a diverse pool, we were unable to calculate the response rate of participants relative to how many people received the survey. Because multiple sources were used to recruit participants, it was difficult to know which administrators actually forwarded the invitation to participate to their members.

The study was developed and conducted with a predominant Pennsylvania perspective with limited generalization to the rest of the United States and to other countries. It is possible, therefore, that some of the interpretations and practical implications suggested in this paper may be limited to a regional or a Northeast American context. The living arrangements, level of support for people with ID, laws and access to services are different from state to state and as such, the associated implications for practice need to be carefully evaluated in this light. Thus, the extent to which the present findings generalize to other states and countries needs to be established in future research. This present study does, however, provide some valuable insight into the potential and the need for increased therapy services to people with intellectual disabilities.

The actual design of the survey could be improved in order to yield more substantial findings. Although a question on course work was included on the survey, there was no question about practicum, externship, internship or medical residency to address the issue of practical training experience. Additionally, the goal of question twenty in the CTQ-ID was to quantify the concept of exposure. The qualitative request of having people detail their experiences of being around people with ID received limited responses and therefore yielded limited data. It can be speculated that the level of self-reflection needed and length of time it took to answer this question may have dissuaded responses. A quantitative request that would have been more direct and effective in identifying the independent variable of “exposure” may have been: “Rate your level of exposure to people with ID with: “0”equaling no experience, “1” equaling seeing or being in the vicinity of people with ID- minimal contact, “2” equaling having family or neighbors with ID -basic contact, or "3” equaling an interactive relationship beyond work-relationship contact. Instead, this rating scale was used after the surveys were returned, as a method to code and score the qualitative responses. Finally the variable number of responses to each question was a concern regarding consistent data reporting. If this study was to be duplicated it is recommended that survey be shorter with a request that respondents answer every question.

Summary and Conclusions

The essential objective of this study was to shed light on the nature of and history of people with intellectual disabilities and the current therapeutic needs of a portion of this population that remains largely hidden, ignored, and misunderstood. This lack of awareness is not only by the general public, but also by the behavioral health professionals who would be logically responsible for treating and improving the overall quality of life for individuals with intellectual disability (ID) and for those who support them. People with ID have significant variations in the degree and nature of their intellectual abilities, levels of functioning, sensory issues, physical abilities, social skills and family backgrounds. The understanding of how various genetic syndromes can be factors is also important. When mental disorders are present, people with ID, it can, therefore present in various ways, both typical and atypical. It is important that those who provide support to people with ID work closely with trained and willing behavioral health professionals who can address psychological, developmental, biological, and social factors that may promote, precipitate, or maintain the presence of various mental health diagnoses. Unfortunately, people who provide daily support to people with ID and co-occurring mental health disorders (MH-ID) report that these behavioral health professionals, especially therapists, are not available.

In this study, therapists and psychiatrists reported that they had not received significant education in their higher educational programs to prepare them properly to work with people with MH-ID. The survey identified a significant number of clinicians with an interest in receiving training and possibly adding this population to their caseloads. A look at exposure found that clinicians who were exposed to people with ID and the limited number of clinicians who provide therapy to people with MH-ID had favorable attitudes about the population and the work they provide. As identified in the literature review, Lightner Witmer, from the University of Penn over 115 years ago, established the first university course for this population with a focus on developing a psychological clinic and training school to teach psychologists, social workers, and doctors to become experts in examining and delivering treatment to those with MH-ID. (Witmer, 1907). This research brings us full circle and shows that there are now evidenced- based methods to treat people with MH-ID. There are clinicians who are currently providing treatment and more who report a willingness to provide the treatment if trained. With the need and demand demonstrated, we are now in a position to further Witmer’s vision by offering university level education and practical experience to new and existing clinicians with a goal to increase healthy attitudes about this population through increased exposure and to ultimately reduce and eventually eliminate the disparity of behavioral health services to people with intellectual disabilities and co-occurring mental health diagnoses.

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Tables

Table 1

Qualifying Data for Study Eligibility

Qualifiers	No of Respondents	Qualified	Percentages
Master’s Degree	282 / 339	282	83
Provided Direct Service	282 / 339	271	79
Licensed to provide therapy	271/ 339	216	64

Out of 339 respondents, 282 had at least a Master’s degree in the required clinical areas. 271 were left when asked to have provided direct service to an individual within the last 5 years. 64% of the respondents, 216 remained for the survey once the requirement of working under a valid clinical license was met.

Table 2

Demographic of Qualified Respondent

Description	Number of Respondents	Number	Percentages
Age Range			
24-34	142	54	38.0
35-45	142	32	22.5
46-56	142	26	18.3
56-66	142	21	14.8
Over 66	142	9	6.3
Gender			
Female	140	95	67.9
Male	140	45	32.1
Race			
White	140	123	87.9
Black	140	10	7.1
Asian/Pacific Islander	140	5	3.6
American Indian/Alaskan Native	140	1	0.7
Latino	140	0	0

Approximately 32 people elected not to answer questions in the Demographic section of the survey once qualifying. SPSS only calculates the data entered thus there is no statistical data for the missing information

Table 3

Professions Represented in Study

Self-Identified Professions	Percentage of Respondents
Licensed Psychiatrist	16.7%
Licensed Psychologist	13.2%
Licensed Professional Counselor	04.9%
Licensed Social Worker	18.8%
Un-licensed Therapist	33.3%
Marriage Family Therapist	00.7%
Pastoral Counselor	01.4%
Psychology Student	15.4%
Licensed Social Work Student	01.4%
Other	07.0%

The largest group of respondents was unlicensed therapist (33%) these clinicians qualified for the study by operating in a facility that assumes licensure responsibility liability.

Table 4

Work Settings and Services Provided

Work Setting	Percentage	Services Provided	Percentages
Private Practice	23.8	Inpatient Treatment	10.5
Day Treatment Facility	5.6	Outpatient Treatment	36.1
Internship/Practicum	11.9	Psychotherapy	68.8
Community Outpatient Facility	11.9	Medication Review	18.8
Inpatient Settings	7.0	Assessments	59.0
Other	21.7	Group Therapy	25.7
		Psych Testing	16.0

Clinicians in private practices were the highest rate of responders while those in day treatment facilities represented the lowest rate of responders. Psychotherapists in private practices were the highest level of responders while those providing inpatient treatment represented the lowest. It is important to note that the categories were not mutually exclusive and clinicians could select more than one item in each category.

Table 5

Dependent & Independent Variables

Dependent & Independent Variables	N	Minimum	Maximum	Mean	Std. Deviation
Provide Counseling	165	1	2	1.58	.496
Q9 - Willing to provide services to ID Population	68	1	3	2.06	.862
INSE	151	1.00	28.00	21.5099	4.63878
SDIS	150	6.00	32.00	27.3733	4.31098
PRRT	149	4.00	28.00	21.5503	4.15646
SUDB	150	2.00	28.00	22.4333	4.08372
Q20	87	.00	3.00	1.8966	.66533
Q8 - Education	165	0	1	.32	.468
Valid N	34				

Independent variables: 1)Clinicians willing to provide therapy to people with ID
2) Clinicians who have provide therapy within the last two years
Dependent variables: Attitudes (INSE-SUDB), Exposure (Q20), and Education (Q8)

Table 6

Reported Exposure to ID Population

Code Key:
0 = No experience,
1 = seeing or being in vicinity of- minimal contact
2 = working with , family or neighbor - basic contact
3 = interactive relationship beyond work – Relationship contact

Question 20, Clinician Exposure to People with ID	Code
1. I worked as a behavior therapist for several years early in my career. I then worked as an Administrator of programs serving people with ID from case management to direct therapeutic services.	2
2. there are often misunderstandings about the nature of an intellectual disability; I've also observed very positive family practices in other countries where individuals with intellectual disabilities carry a great deal of personal responsibility and are very integrated into not only family but community life; regarding #16 above, I have had direct experience with patients telling me this, especially around vocational services (with OVR)	2
3. As an undergraduate I had the opportunity to work in a school for children and teens with Autism.	2
4. I learned Applied Behavioral Analysis techniques there and working with the kids was a great learning experience for me. I also had the opportunity to work with an individual diagnosed with Borderline IQ and a psychiatric illness in an inpatient hospital. I worked with this patient for one year and at times it was frustrating and sad as the progress was slow to non-existent at times, but it was a very rewarding experience. I do wish though that I had received better training as to how to work with this patient because I often felt that I was doing the individual an injustice.	2
5. It's incredibly rewarding work.	2
6. I work with children with autism primarily now, dual diagnosis, I am very positive about the experience in general although the general population does not understand it very well	2
7. I have worked at the Barber Center in Erie, PA, and the Institute for Behavior Change in Coatesville, PA as a TSS with children diagnosed on the Autism Spectrum and with intellectual disabilities. I have also worked at Devereux CARES in Downingtown, PA which is a school specifically for children diagnosed with an ASD and the vast majority also had a 'MR' diagnosis. I currently work as a BSC, MT, and outpatient intake clinician at Child Guidance Resource Centers in Coatesville and have done intakes for and work with children with various intellectual disabilities. I also have a 3-year-old nephew with Down’s syndrome and have volunteered with Special Olympics at various points since 2000.	3
8. Sadness for their family's situation and the sense of loss/grief these families experience when they confront the fact that their child/ sibling will always struggle with these challenges	2

Table 6

Clinician Exposure to People with ID, Question 20	Code
9. I am psychoanalytically trained, which makes it easier for me to observe behavior and understand it, so I am more able to understand the causes of distress in Dually Diagnosed patients, and not just add more meds. I enjoy the work. I get frustrated when I am unable to get support or supervision for dually diagnosed patients when they need it.	2
10. I mainly have clients who are on the Autism Spectrum. My experience working with them has been very positive and I have enjoyed it very much.	2
11. I have had some exposure through residential programs; in general I am uncomfortable with their trouble with ADL's, (including bodily fluids).	2
12. My experience has been limited	1
13. none	0
14. Limited experience with people with intellectual disabilities	1
15. My main experience has been one of frustration because I have, in several states, been in situations where the MR and MH system are at odds and both want to "turf" PEOPLE who need help. I think it would be fascinating and rewarding work. I would likely also be hard work, but all good work inevitably is hard or hard at different junctures. The seemingly ubiquitous nature of borderline IQ and the various issues around that is also of interest to me but also presents as a confound to assessment or can.	2
16. In my undergraduate education I received my special education certification therefore I had a practicum where I worked with individuals who have an intellectual disability. I have also worked with 4 individuals through my current work that have a dual diagnosis as well.	2
17. Getting to know how to relate to an individual is key to communication...what level of vocabulary can he/she handle? What are other ways of communicating that the person can understand? Touch? Music? Art?	2
18. I worked in a Dual Diagnosed program (RINT) for five years and two years on a crisis unit at Girard Medical Center.	2
19. CEO of provider agency in community homes and other ID services	2
20. Borderline ID students thought the years have functioned well in our highly structured setting.	2
21. We provide therapy to families with children at risk of an out of home placement. Part of the regulation is that the child or adult must have the ability to participate and benefit from the program. We have had children and parents that are limited and mild MR. As long as they are capable of participating in the program we will provide services.	2
22. I worked for 4 years as a Counselor in a community residential setting w/male & female adults w/MR & Mental Health Diagnosis	2
23. NA	0

Table 6

Clinician Exposure to People with ID, Question 20

	Code
24. Assessment, treatment, friends, supervision of staff treating - all good.	3
25. One close friend of my family's in my mother's home town of origin. For much of 25 years, we would see her and spend some time (30min-2hours) with her at my relatives' home or at a church function. I often felt sympathy for her but also was very aware of the joy she received from her surroundings and family most of the time.	3
26. Outside of my work with dual diagnosed persons, I was a county case mgr. in the MR dept.	2
27. They deserve equal respect, dignity and psychotherapy treatment.	1
28. I believe there is a significant deficit of placements willing to work with this population. I believe one of the main issues is that working with this population is very time intensive and insurance is not willing to reimburse for the time needed to treat this population. I find it to be very rewarding personally, but impossible to live off of.	2
29. A multidisciplinary approach and good communication with the patient's treatment team, family, school, and community resources is very important.	2
30. People with intellectual disability are very vulnerable to complex life experiences and need mental health support to help them navigate the world safely. "Safely" refers to helping the client to process events, perceptions of themselves and others, learning and relearning and practicing coping strategies...	2
31. Spent over 30 years working with individuals with ID and their families.	3
32. I have worked with individuals with MR and know 5 children with Autism in my personal life. It takes an open mind and patience to communicate sometimes but it is always worth the effort, as those interactions have always been enriching to me.	3
33. I have found that working with individuals with intellectual disabilities is challenging but when the primary problem is behavior that I am able to treat them successfully.	2
34. Not sure about their needs, etc. so often nervous about providing services	1
35. My cousin, now age 50, has an intellectual disability. I have had experience with this population all of life through my cousin and my father who worked in the field for over 30 years before he passed. While the experiences have been, for the most part, positive, I do not feel equipped or motivated to work with this population.	3
36. Willing to participate in treatment and shorter time to establish relationship with client. Initiate treatment process by being more open with therapist and family members; for the most part, we advocates for treatment population compliant with prescribed medications with limited to structured monitoring.	2
37. It has been my experience that these clients tend to be very affectionate and even excited for their visits.	2

Table 6

Clinician Exposure to People with ID, Question 20	Code
38. I worked in a community mental health setting for years and there was a social rehab program there where many of the clients with an intellectual disability spent their days. Some of them attended groups we did and I had varied experiences. Some were not interested in insight and understanding meta-cognition. However, others were.	2
39. Treated one child with a mild ID for several years. One of the most rewarding experiences of my life. Worked with children on the Autistic spectrum, some with ID as well, at another job; was extremely rewarding.	2
40. Specifically with clients diagnosed with autism, it is challenging to determine interventions because of the nature of one hour every two weeks outpatient therapy. I enjoy working with children with ID's because of some endearing personality traits I have noticed. However, it is difficult to know how much the therapy (specifically CBT) needs to be tailored to their individual learning methods.	2
41. None besides the clients that I work with	2
42. We are from a very rural community and unfortunately many individuals are not educated. We have tailored a lot of what we do, using information for children and teens to help teach individuals with ID about personal medicine, recovery and cognitive therapy. It is sometimes more pleasurable with this population as often they are interested in new things and are less bent on proving themselves and playing mind games with the staff.	2
43. I previously worked with the Dual Diagnosis population before receiving my master's degree and although it was a great learning experience, it was not a therapeutic position per say; however I am not focused on performing clinical work with this population at this time. This is not to say that I would refuse a case involving Dually Diagnosed clientele (however intellectual disability is an exclusionary criteria for the program which I currently work) because I have had previous experience in understanding the difficulties this population often experiences, but I would not consider myself to have been specifically trained to perform clinical work in this area.	2
44. Some experiences with patients, neighbors with mild autistic spectrum disorders. I am personally comfortable being with them, but uneducated in treating.	2
45. No family or neighborhood experience. Extensive clinical experience... I have consulted for the last 19+ years with an agency servicing individuals and have treated individuals with intellectual disabilities in my clinical practice for 24 years.	2
46. I especially like working with this population. However, a 15 minute med visit is usually inadequate given time needed to interact with the patient, the caregivers who accompany the patient, and documentation requirements of various agencies involved. Historically, reimbursement has been terrible because Medicare only paid 50% and no one else would pick up the rest (and Medicare isn't very generous).	2
47. I worked for 4 years at a school for the retarded.	2

Table 6

Clinician Exposure to People with ID, Question 20

		Code
48.	I feel very comfortable working with these persons. My cousin had Down's syndrome. I took care of several at Lebanon MHMR. But I am past retirement age and cannot handle more stress.	3
49.	I have in the past cared for quite impaired patients that came to me when I was doing hospital work. Usually they eventually transferred to a doctor or team associated with an institution, out-patient usually, which is probably a better approach for many.	2
50.	Find this uncomfortable.	0
51.	have had some training in this area in undergraduate school, including a practicum of one semester at a facility that works exclusively with this population Plus in my 24+ years of working as a therapist I periodically have had such clients (I could not even guess how many) & in my overall work with children, which dates back to June of 1971 I would encounter children with intellectual disabilities from time to time.	2
52.	Working with children/adolescents with an intellectual disability has been both challenging and rewarding. Although I have received a small amount of training (PDD, Autism-not MR), I have learned the most from actually working with those with ID. Generalizing, these children/adolescents have been friendly and quite responsive to treatment once they have created rapport with his/her MT/BSC and/or TSS. Families appear to be overwhelmed and tired when I first meet them, and at times for some time during treatment. About half of parents often reported that they believed that the child should be behaviorally managed/otherwise treated and could function as those without ID. Denial appears common that the child requires additional help. Sibling relationships are either really strong, but more often strained, as they do not fully understand the disability. Parents report using intervention/skills taught, but when observed, this appears to be untrue (about 50% again). Finally, the area requires support groups for these parents that include care during that time for their child with ID. I have had minimal knowledge about neighbor's experiences with people with ID. However, on one case, the neighbor appeared to attempt to sympathize and tolerate, particularly how the child's impulsivity affect him/her, until about a year of tolerating, where they verbalized discontinued use of their property.	2
53.	I have worked with individuals with mental health and intellectual disabilities for near 30 years. This is my specialty. I do very rare therapy (in an office setting) but provide training to others to be therapeutic when working with adults. I do assessment and evaluation on children. I worked at the dual diagnosis center doing therapy for clinical. I am an EMDR Therapist and if I had my own practice would absolutely serve this population. I am on a committee to formulate a certificate. This has been my career, my joy, my life's work. It has been extremely rewarding.	3
54.	My experience has been primarily providing therapy to people w/ borderline IQ. I do not have the experience in working w/ moderate or severe id. I have received no training in this area and will not feel comfortable treating this specialized population w/out training. I also have a limited understanding of the benefits of psychotherapy w/ severe or profound id.	0
55.	I grew up with an individual with Mild ID to borderline functioning. He would frequently get picked on and I often stood up for him and tried to understand his perspective on things. My sister also had some learning difficulties that made me more sensitive to the needs of individuals with disabilities.	3

Table 6

Clinician Exposure to People with ID, Question 20	Code
56. I have numerous experiences with people with intellectual disabilities. One individual who has a diagnosis of Fragile X Syndrome and is 15 years old. I base many of my decisions from what this individual has taught me and what I have taught him in the past 10 years.	2
57. I enjoyed my experiences with them. I can see and appreciate each individual's uniqueness and I learn from them as I do with my other clients.	2
58. Unless the person with intellectual disability is easily recognized (facial feature or additional physical disability) they are often not treated differently by others. When the person with ID has severely limitation, other people may seek to avoid them because of their discomfort with knowing what to say or do.	1
59. In previous settings have worked with ID and dual diagnosed ID clients.	2
60. I have worked in a group home with people who have ID. Working in inpatient and outpatient settings, I have also worked with some patients who have ID.	2
61. I have treated several people with intellectual disability and I have had positive experiences and have liked to be creative with ways of completing therapy with people with intellectual disabilities.	2
62. Have worked on clinical teams that served ID children in school, home, and hospital settings. Felt extremely challenged and gratified to see the therapeutic impact of music, art, and structured play	2
63. I enjoy working with any population and do not feel it is necessary to continue to label and re-label any person due to their cognitive abilities. I believe that I gain as much as my clients do from the interaction within the therapeutic process - regardless of the "IQ".	1
64. Limited interaction in the community and throughout school. From my limited experience the population is generally likable.	1
65. As part of a practicum, I assessed individuals with ID. I enjoyed the work with the population.	2
66. I stated people with ID make other patients feel uncomfortable because sometimes MH patients do not understand many of the behaviors they see from ID individuals and get upset.	1
67. I've had some very positive personal experiences with individuals, but no real experience treating DD folks.	1
68. Not much experience, just seen these clients in passing while working at Hall Mercer MH/MR. Have not worked with them directly.	1

Table 6

Clinician Exposure to People with ID	Code
69. It's hard to sum up a lifelong experience of being the sibling of a special needs child in a "brief list". I can say that I believe that my decision to become a clinician is informed by having been raised alongside a Down syndrome child. I think my compassion for others, attunement to suffering, and patience with slow learning are all directly related	3
70. I've worked as a teacher with students with borderline IQ's. I've enjoyed working with them but a lot of damage had to be undone.	2
71. I really enjoy my respite work with a teen male with autism and ID diagnoses, and am currently seeing great progress in functional skills with appropriate MH support for a large family with multi-generational ID (MR/Borderline CF). Some untrained professionals and caretakers can "misread" the psychiatric or medical issues of the person with ID as defiance, aggression or "attention-seeking behaviors". This saddens me, and I hope to see improved training and social tolerance for a wide range of needs expression.	2
72. My uncle has moderate MR and schizophrenia. I also know other individuals who have MR.	3
73. I have found that people with an intellectual disability (mild or borderline) are more open to behavioral therapy and can be treated successfully. Many people do not value their abilities. I am currently working with a gentleman that has exhibited the ability to recall models I have taught him in the past to use with current situations (i.e. crisis stages)	2
74. minimal to no experience	0
75. Very few, while in training I met with a few young clients with some mild intellectual deficits and I currently have a neighbor with very mild cognitive deficits due to brain surgery.	1
76. I did have experiences in which the work was more physically demanding, less interpersonal connection from the patients, and much more system work was involved to provide quality care but it was with autism which is very different from ID.	1
77. I have been treating people with intellectual and developmental disabilities for the last 12 years, providing individual and group therapy as well as behavior support plans and training for direct care staff and family members. I have worked to write behavior support plans and train staff to work with challenging people coming into community based care from institutions. My experience includes working with physically aggressive consumers, people with substance abuse and problematic sexual behavior. I have been attempting to become a network provider for Community Care Behavioral Health in Berks County for the past two years without success.	2
78. I had a family friend growing up with intellectual disability and it is one of the reason why I am in the field today	3
79. Primarily in my work with adolescents in residential treatment I have evaluated patients with ID.	2
80. I have had periodic clients with ID & in under graduate school I did a semester of a practicum at an agency that focus exclusively on this population.	2

Table 6

	Clinician Exposure to People with ID	Code
81.	Training and experiences with family members and patients have raised my tolerance level to accept the fact that most people are doing and living the very best they know how.	2
82.	I see patients with ID	2
83.	In an inpatient setting, people with ID seem to be more "accepted" on the adolescent unit rather than the adult units. The adolescents seem to take these patients under their wing. Adults seem to struggle with them more in group because it is very difficult to have such varying levels of functioning all within one group.	2
84.	Ran group homes for 2 years for adults with MH/MR Currently do behavior therapy for kids on the spectrum with additional MH diagnosis. Thoughts: I really dislike how sometimes people can talk about individuals with intellectual disabilities as a category or diagnosis, when if you get to know the individual their personality and their human experience is as rich as that of anyone else. If you don't work face to face with the people, you can tend to fall in line with the terms the insurance companies use to categorize them for services, and that can be very dehumanizing.	2
85.	I work w/ co-occurring pop. in residential treat facility- experiences have been positive-like any other client they are facing various challenges- of note, many have never accessed services- we try to get at least IQ testing if insurance allows	2
86.	I have been working with them clinically for years, and have enjoyed the experience. They are typically very emotionally honest - I like that.	2
87.	My psychoanalytic training has been very useful in helping me work with ID when I am on an inpatient unit. I am more able to understand behavior and less likely to mislabel people with ID as psychotic when they are actually upset and reacting non-verbally. I enjoy understanding non-verbal communication and devising ways to communicate non-verbally.	2
88.	I have close family members with autism and would rather not work clinically with this population.	2

Table 7a.

Willing to Provide therapy-CTQ-ID Q9

Test	Value	F	Hypothesis df	Error df	Sig.
Pillai's Trace	.269	2.177	8.000	112.000	.034
Wilks' Lambda	.748	2.151^b	8.000	110.000	.037
Hotelling's Trace	.315	2.124	8.000	108.000	.040
Roy's Largest Root	.203	2.837^c	4.000	56.000	.033

Wilks Lambda = .748, F (8, 110) = 2.15, p= .037 Those indicating that are willing to provide services showed significant difference from those who report undecided or from those who are unwilling to provide services to this population.

7b

MANOVA- Willingness to Provide Therapy and Attitudes

Source	Dependent Variable	Type III Sum of Squares	df	Mean of Squares	F	SIG	Partial Eta Squared
	INSE	8.160	2	4.080	.238	.789	.008
CTQ-ID9 Willing to provide Therapy	SDIS	78.576	2	39.288	2.377	.102	.076
	PRRT	89.119	2	44.560	2.195	.121	.070
	SUDB	33.555	2	16.777	1.141	.326	. 038

Follow-up tests found no significant differences for any of the 4 subscales on the independent variable in regards to clinicians willing to provide therapy compared to those not willing to provide therapy to the ID population.

Table 8a

Currently Provide therapy compared to No Therapy to ID

Test	Value	F	Hypothesis df	Error df	Sig.
Pillai's Trace	.067	1.621	6.000	136.000	.146
Wilks' Lambda	.933	1.621	6.000	136.000	.146
Hotelling's Trace	.071	1.621	6.000	136.000	.146
Roy's Largest Root	071	1.621	6.000	136.000	.146

A MANOVA was computed to determine whether those indicating that they currently provide therapy to ID differed significantly from people who do not provide therapy to people with ID on variables relating to exposure, education, or attitudes about patients with ID.
No differences were found on the initial analysis: Wilks Lambda = .933, F (6,106) = 1.62, p= - .146

Table 8b

MANOVA Provide Therapy and Attitudes

Source	Dependent Variable	Type III Sum of Squares	df	Mean of Squares	F	SIG	Partial Eta Squared
CTQ-ID2a Provide Therapy	INSE	156.471	1	156.471	10.021	**.002**	.064
	SDIS	149.619	1	149.619	10.125	**.002**	.065
	PRRT	105.584	1	105.584	6.320	**.013**	.041
	SUDB	121.256	1	121.256	9.016	**.003**	. 058

MANOVA comparing those who provided therapy to those who do not in regard to subscale and total scale scores for the MRAI-R indicated that the therapy group scored significantly higher on all subscales and on the total scale than the group that does not provide therapy.

Table 9

T-Test of Providing Therapy with Exposure

Measure	T	df	Significance (2-tailed)	Mean Difference	Std. Error differences
Q20 Equal variances assumed	-2.653	84	.010	-.37152	.14005
Q20 Equal variances not assumed	-2.540	60.084	.014	-.37152	.14629

Question 20 of CTQ-ID examines clinician exposure to people with MH-ID population. , $t = -2.54$, $p = .01$ Respondents with either some or substantial exposure to individuals with ID were significantly more likely to provide therapy than those indicating no exposure.

Table 10

Age Differences/Attitudes

		N	Mean	Std. Devi	Std. Error
INSE	24-34	46	21.6739	3.45803	.50986
	35-45	21	23.0000	3.39116	.74001
	46-56	20	23.7500	3.82340	.85494
	56-66	16	19.4375	7.03296	1.75824
	over 66	8	18.7500	5.03559	1.78035
	Total	111	21.7658	4.50849	.42793
SDIS	24-34	46	28.6739	2.80519	.41360
	35-45	21	27.1429	3.46822	.75683
	46-56	20	28.9000	2.88189	.64441
	56-66	16	24.6875	6.89656	1.72414
	over 66	8	23.5000	5.63154	1.99105
	Total	111	27.4775	4.31456	.40952
PRRT	24-34	46	22.2826	3.85090	.56778
	35-45	21	21.7619	2.84438	.62069
	46-56	20	23.2500	3.64005	.81394
	56-66	15	19.7333	5.78751	1.49433
	over 66	8	17.3750	3.73927	1.32203
	Total	110	21.6545	4.19575	.40005
SUDB	24-34	46	23.2174	2.58984	.38185
	35-45	21	23.2381	2.77317	.60516
	46-56	20	24.1000	2.67346	.59780
	56-66	15	19.5333	5.97455	1.54262
	over 66	8	19.1250	4.99821	1.76714
	Total	110	22.5818	3.80097	.36241

With the MRAI-R scales, the higher the score, the more positive are the attitudes.

Younger clinicians showed less bias to ID populations in comparison to clinicians 56 and over on all four of the attitude scales

Appendices

Appendix A: Solicitation letters

Philadelphia Coordinated Health Care
123 S. Broad Street, 22nd Floor • Philadelphia, PA 19109
(215) 546-0300 • Fax: (215) 790-4976
The Southeastern Pennsylvania Health Care Quality Unit

April 30, 2010

John Doe, PhD
Associate Director
We Do Good Inc.
1212 Saint Avenue
Philadelphia Pa. 19191

Dear Clinical Director Dr. Doe,

On behalf of Pennsylvania's citizens who cope with intellectual disabilities as well as mental illness (known for this project as people with dual diagnosis), we are requesting your assistance. In October of 2008, a coalition of eight Commonwealth funded Health Care Quality Units (HCQUs) undertook a grant project funded by the Pennsylvania Developmental Disabilities Council to look at ***Services and Supports for People with Dual Diagnosis***. Philadelphia Coordinated Health Care is the lead agency for this grant project. This project is supported by the Pennsylvania Developmental Disabilities Council, the Office of Mental Health and Substance Abuse Services, and the Office of Developmental Programs.

To identify the opinions of current clinicians about providing services to people with dual diagnosis the grant team has created a brief on-line survey. Additionally this information will be used as part of my doctoral dissertation toward requirements to becoming a psychologist. We would most appreciate for your assistance in forwarding this survey to all master and doctoral level psychotherapists/counselors and psychiatrists associated with your program. All responses will be kept strictly confidential, individual names or program identifiers will not be connected with any responses. The following link will direct respondents to the survey:

Thank you in advance for your support and assistance in this vital outreach project.

Sincerely,

Tim Barksdale

Tim Barksdale, MA
PCHC Behavior Health Specialist
Student, Philadelphia College of Osteopathic Medicine

Appendix B: Email Survey Introduction/Explanation

Dear Participant,

This is a request for you to take part in a research project to assess the experiences of psychotherapists in relation to people with intellectual disabilities (formerly referred to as having mental retardation). This project is being conducted by Tim Barksdale, M.A. Behavioral Health Specialist for Philadelphia Coordinated Health Care (PCHC) and Clinical Psychology Doctorate Student at the Philadelphia College of Osteopathic Medicine (PCOM).

This research, funded by the Developmental Disabilities Council (DDC) Grant, will be used by PCHC and the other Health Care Quality Units of Pennsylvania to support service delivery to people with intellectual disabilities. Mr. Barksdale will also use this data in support of his doctorate dissertation. Your participation in this project is greatly appreciated and will take approximately 20 minutes to complete the attached questionnaire.

To participate in this study, you must be a psychiatrist or a clinical therapist with a master's degree in psychology, Therapy or social work who is practicing and /or in training in a residency, practicum/externship or internship program. Your involvement in this project will be kept as confidential as legally possible. All data will be reported in the aggregate. You will not be asked any information that can lead back to your identity as a participant. Your participation is completely voluntary. You may skip any question that you do not wish to answer and you may discontinue at any time. Your employment or class standing will not be affected if you decide either not to participate or to withdraw. PCOM's Institutional Review Board (IRB) acknowledgement of this project is on file.

I hope that you will participate in this research project, as it could be beneficial to people with intellectual disabilities. Thank you very much for your time. Should you have any questions about this research project, please feel free to contact the research chair Petra Kottsieper, PhD at 215-871-6546 or by e-mail at PetraK@pcom.edu , Dina McFalls, Director of PCHC, Dmcfalls@pmhcc.org or Tim Barksdale MA, by e-mail at Timothyba@pcom.edu.

PLEASE FORWARD this email to as many other qualifying therapist, psychiatrists and psychologists as possible to further assist in this valuable research. Thank you for your time and help with this project.

Sincerely,

Tim Barksdale, MA,

Dina McFalls, MS, Director, PCHC

Petra Kottsieper, PhD, Dissertation Chair, PCOM

Appendix C: Survey-Therapist Demographic Information

Age range: 24 – 34 ☐35 – 45 ☐46 – 56 ☐56 – 66 ☐over 66

University of your clinical degree ________________ **Degree** _________________

Gender: ☐ Male ☐ Female

Race: ☐ White ☐ Black ☐ Hispanic ☐ Asian/Pacific Islander ☐ American Indian/Alaska Native ☐ Other ______________

County & State Where I Live: ____________________________ Country _____________

County Where I work: ________________________

I am a:
☐ Licensed psychiatrist
☐ Licensed psychologist
☐ Licensed Professional Counselor
☐ Licensed Social Worker
☐ Un-licensed therapist
☐ medical student
☐ Psychology Student
☐ Licensed Social Work Student
☐ Other (Please describe)
____________________________________)

Work Setting *(Check all that apply)*

☐ *Private practice*:
☐ *Day treatment facility*:
☐ Internship/ Practicum
☐ *Community Behavioral health/Outpatient facility*:
☐ *Inpatient setting*:
☐ Other __________________________________

Identify the setting/services you provide? ***(Check all that apply)***

☐ Inpatient Treatment
☐ Outpatient Treatment
☐ Therapy/Therapy
☐ Medications/Review
☐ Assessment /Evaluation
☐ Group Therapy
☐ Psych Testing

☐Other (***Please describe***) ____

Appendix D: Survey - Clinical Therapist Questionnaire on ID (CTQ-ID)

*In this survey "*** Dual Diagnosed ID*"or MH-ID** refers to people with Intellectual Disabilities**, (formerly identified as having been diagnosed with mental retardation.) who have at least one mental health diagnosis (depression, anxiety, schizophrenia ...etc.)*

---

1. Number of people **without** intellectual disabilities* (ID) for whom you currently provide therapy ___________
2. Do you **provide therapy** to people with a dual diagnosed ID ☐ Yes ☐ No Enter # of clients _______
3. Do you provide **assessments/ evaluations** for people with ID? ☐Yes ☐ No # in last year _____
4. If yes to 1 or 2 please check all groups treated: ☐Children ☐Teens ☐Adults ☐Adult over 65
5. Check **disabilities of clients you have treated:** ☐ intellectual disability ☐Autism ☐PDD ☐other ______
6. Check all ID **level of functions** treated ☐borderline IQ ☐mild ☐moderate ☐ severe ☐profound

7. In general what is **the main therapy orientation** that you provide? (Check all that apply)

☐Cognitive Behavioral ☐Behavior therapy ☐ Interpersonal ☐ Medication /Review
☐Person Centered ☐ DBT ☐ Psychodynamic/Analytic ☐Other (list) ______________

---

8. When obtaining your current degree did you receive **education/training** for working with people with an Intellectual disability. ☐ Yes ☐ No # of courses_____ name of courses ___________________________

School(s) where course were taken: ____

9. If you do not currently provide behavioral health services to people with dual diagnosed ID, Would you be **willing to provide services** to this population? ☐Yes ☐No ☐ undecided
10. My ability to treat people with ID would be : ☐Very good ☐Good ☐Fair ☐Poor ☐would not treat
11. If you **have no interest** in working with people with an intellectual disability please check all that apply:

☐ I Am too busy.	☐ I have never received training to work with Dual Diagnosed ID	☐ I have never been around this population	☐ I do not think this population would benefit /improve from therapy	☐ I am concerned that I will not be adequately compensated for services	☐ I am concerned about safety	☐ Our office staff would not work well with people with intellectual disabilities.

12. Please write in other reasons for not proving therapy to this population _________________________________

13. Are you **interested in training** for providing therapy to individuals with dual diagnosed ID? ☐Yes ☐No

14. I / we receive referrals to treat people with intellectual disabilities ☐Frequently ☐sometimes ☐ rarely ☐never

---

Please indicate if you agree with the following statements:

15. Behavior rather than psychiatric disorder is the primary issue with this population ☐Yes ☐ No ☐ undecided

16. People with Intellectual disabilities will make other **patients feel uncomfortable** ☐Yes ☐ No ☐ undecided

17. Providing therapy to people with intellectual disabilities will **hurt business**. ☐Yes ☐No ☐ undecided

18. I think treating people with dual diagnosed ID would increase **business**. ☐Yes ☐No ☐ undecided

19. If trained would you **add people with Dual Diagnosed ID to your practice**? ☐Yes ☐No ☐undecided

20. Please briefly list and explain any **experiences you may have had being around people with an intellectual disability (including family members or neighbors)** and thoughts/feelings about the experience(s).

____

Appendix E: Opinion Inventory

This inventory contains statements expressing opinions or ideas about people with **Intellectual Disabilities**. (The outdated term "mental retardation" was used when this inventory was created and remains in this inventory for consistency)

Directions: There are many differences of opinion; many people agree and many people disagree with each statement. We would like to know your honest opinion about each one. Put an **X** through the one response that best corresponds with how you feel about the statement. There is no time limit for the completion of this inventory, but you should work as rapidly as you can. All responses are kept strictly confidential and cannot be traced back to you.

Please Respond To Every Statement

KEY

SD: I Strongly Disagree
D: I Disagree
A: I Agree
SA: I Strongly Agree

SD D A SA 1. School officials should not place children who are mentally retarded and children who are not mentally retarded in the same classes.

SD D A SA 2. We should integrate people who are mentally retarded and who are not mentally retarded into the same neighborhoods.

SD D A SA 3. I would allow my child to accept an invitation to a birthday party given for a child with mental retardation.

SD D A SA 4. People who are mentally retarded are not yet ready to practice the self-control that goes with social equality with people who are not mentally retarded.

SD D A SA 5. I am willing for my child to have children who are mentally retarded as close personal friends.

SD D A SA 6. If I were a landlord, I would want to pick my tenants even if this meant only renting to people who are not mentally retarded.

SD D A SA. 7. It is a good idea to have separate after-school programs for children who are mentally retarded and children who are not mentally retarded.

SD D A SA 8. Regardless of his or her own views, a private nursery school director should be required to admit children with mental retardation.

SD D A SA 9. Even though children with mental retardation are in public school, it is doubtful whether they will gain much from it.

SD D A SA 10. Although social mixing of people who are mentally retarded and not mentally retarded may be right, it is impractical until people with mental retardation learn to accept limits in their relations with the opposite sex.

SD D A SA 11. I have no objection to attending the movies or a play in the company of people who are mentally retarded.

SD D A SA 12. Laws requiring employers not to discriminate against people with mental retardation violate the rights of the individual who does not want to associate with people who are mentally retarded.

SD D A SA 13. Integrating children who are mentally retarded and who are not into the same preschool classes should not be attempted because of the turmoil it would cause.

SD D A SA 14. Real estate agents should be required to show homes to families with children who are mentally retarded regardless of the desires of the homeowners.

SD D A SA 15. I would rather not have people with mental retardation as dinner guests with my friends who are not mentally retarded.

SD D A SA 16. Children who are mentally retarded waste time playing in class instead of trying to do better.

SD D A SA 17. Having people who are mentally retarded and not mentally retarded work at the same jobsites will be beneficial to both.

Over Please . . . .

Please Respond To Every Statement

KEY

SD: I Strongly Disagree
D: I Disagree
A: I Agree
SA: I Strongly Agree

SD	**D**	**A**	**SA**	18.	I would rather not have a person who is mentally retarded swim in the same pool that I swim in.
SD	**D**	**A**	**SA**	19.	I would be willing to introduce a person with mental retardation to friends and neighbors in my home town.
SD	**D**	**A**	**SA**	20.	Campground and amusement park owners have the right to refuse to serve anyone they please, even if it means refusing people with mental retardation.
SD	**D**	**A**	**SA**	21.	The problem of prejudice toward people with mental retardation has been exaggerated.
SD	**D**	**A**	**SA**	22.	If I were a barber or beauty shop owner I would not resent it if I were told that I had to serve people with mental retardation.
SD	**D**	**A**	**SA**	23.	Assigning high school students who are mentally retarded and who are not mentally retarded to the same classes is more trouble than it is worth.
SD	**D**	**A**	**SA**	24.	I would be willing to go to a competent barber or hairdresser who is mentally retarded.
SD	**D**	**A**	**SA**	25.	Even with equality of social opportunity, people who are mentally retarded could not show themselves equal in social situations to people who are not mentally retarded.
SD	**D**	**A**	**SA**	26.	Even though people with mental retardation have some cause for complaint, they would get what they want if they were more patient.
SD	**D**	**A**	**SA**	27.	I would rather not have people who are mentally retarded live in the same apartment building I live in.
SD	**D**	**A**	**SA**	28.	A person should not be permitted to run a day care center if he or she will not serve children who are mentally retarded.
SD	**D**	**A**	**SA**	29.	The child who is mentally retarded should be integrated into regular classes in school.

Please forward this to all the therapist you know to help ensure the success of this valuable project

Thank You for Your Assistance in Responding To This Opinionaire about People with Intellectual Disabilities.

Appendix F: MRAI-R Scoring Key

Mental Retardation Attitude Inventory – Form R

Item #	+/–	Scale	Scale Item #	Item #	+/–	Scale	Scale Item #
1	-	INSE	1	16	-	SUDB	4
2	+	INSE	2	17	+	INSE	5
3	+	SDIS	3	18	-	SDIS	5
4	-	SUDB	4	19	+	SDIS	6
5	+	SDIS	5	20	-	PRRT	5
6	-	PRRT	6	21	-	SUDB	5
7	-	INSE	7	22	+	PRRT	6
8	+	PRRT	8	23	-	INSE	6
9	-	SUDB	9	24	+	SDIS	7
10	-	SUDB	10	25	-	SUDB	6
11	+	SDIS	11	26	-	SUDB	7
12	_	PRRT	12	27	-	SDIS	8
13	_	INSE	13	28	+	PRRT	7
14	+	PPRT	14	29	+	INSE	7
15	-	SDIS	15				

To score the MRAI in the direction of a positive attitude, first score the items:

If the item is positive:	SD = 1	D = 2	A = 3	SA = 4
If the item is negative:	SD = 4	D = 3	A = 2	SA =1

The overall MRAI score is determined by summing the 29 item scores:

S	Number of Items	+	-	Score Range	Scale Title
MRAI	Ni =29	12	17	29 - 116	Overall Inventory

The four scale scores are determined by summing the item scores for those scales:

MRAI-R SCORING KEY:

Scale	No. of Items	# + / #–	Score Range	Scale Title
INSE	ni = 7	3+ / 4 –	7 to 28	Integration – Segregation
SDIS	ni = 7	5+ / 4-	8 to 32	Social Distance
PRRT	ni = 7	4+ / 3 –	7 to 28	Private Rights
SUDB	ni = 7	0+ / 7 -	7 to 28	Subtle Derogatory Believes

For more information on MRA-I refer to others:

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