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Therapeutic adaption : treatment of individuals with mental retardation and psychiatric disorders

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Thalia Ghazey Bates
Therapeutic Adaptation:
Treatment of Individuals with
Mental Retardation and
Psychiatric Disorders

ABSTRACT

This study was undertaken to describe the various methods clinicians employ to adapt their normal treatment strategies to best fit the special needs of a client who has both mental retardation and a psychiatric illness. The study also explores the availability of education and professional development trainings for this population.

A qualitative design was selected and a non-random sample of twelve clinicians who treat individuals with mental retardation was acquired. Interviews were conducted to ascertain their perceptions of the best ways to adapt assessment, diagnosis and treatment for this population, what modalities and theoretical frameworks they found to be most useful, and how they view clinical education and training opportunities in terms of informing and supporting therapeutic work with this population.

The major findings were that clients with mental retardation often have a tendency towards more concrete thinking, an increased level of daily frustrations, lack of choice and independence, language barriers, and a tendency to “act out” symptoms. Analysis of the data showed that to work with this population therapists must adapt how they perform the assessment, diagnosis, and treatment processes. Common treatment modalities were group work, narrative therapy, couples and family therapy, and art

therapy. Clinicians reported feeling very strongly that their clinical education, prior training, and opportunities for professional development poorly prepared and supported them in their work with this population.

**THERAPEUTIC ADAPTATION: TREATMENT OF INDIVIDUALS WITH
MENTAL RETARDATION AND PSYCHIATRIC DISORDERS**

A project based upon an independent investigation,
submitted in partial fulfillment of the requirements for the
degree of Master of Social Work.

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2009

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CHAPTER I

INTRODUCTION

The purpose of this study is to explore the various methods clinicians employ to adapt their normal treatment strategies to best fit the special needs and requirements of a client who has both mental retardation and a psychiatric illness. Mental retardation is classified as subnormal intellectual functioning or development resulting from congenital causes, disease, or brain injury. In the DSM-IV the American Psychiatric Association (2000) requires that a person have an IQ of below 70, deficits or impairments in adaptive functioning, and an onset before the age of 18. Some of the areas that are typically effected in a person with mental retardation include language ability, learning ability, general cognitive functioning, and social and vocational opportunities.

According to Silks and Hauser (1997), individuals with mental retardation represent about 1 to 3 percent of the total population of the United States. Within this disabled population it is estimated that about 40 to 70 percent have a diagnosable psychiatric disorder. This percentage is particularly striking when compared to the estimated overall 26.2 percent of Americans aged 18 and over who have a diagnosable psychiatric condition (National Institute of Mental Health, 2008). With so many individuals with mental retardation in need of psychiatric care it is important for individuals in the helping professions to be aware of the special needs and concerns that are inherent when working with this population.

In the past most people with mental retardation resided in treatment centers and care facilities of various kinds. However, over the course of the past decade more and more members of this population have begun to make their homes in the larger society and thus rely on community resources for their care. It is no longer the care center specialists that are mainly responsible for their mental health needs. This fact is made very clear by study results that show that between 1977 and 1991 the number of persons living in state run mental retardation facilities decreased by 51 percent. During the same time period the number of persons living in less restrictive semi-independent living and in supported living situations increased by 773 percent (Bruinicks, Olson, Larson, & Larkin, 1994).

Despite the fact that currently most of the mentally retarded population lives within the community and relies on community supports, very few clinicians are comfortable treating them. Matson and Sevin (1994) addressed this issue and claimed part of the current shortage of theoretical work, assessment and treatment approaches for this population comes as a result of the low status of mentally retarded individuals within the mental health field. They state that most clinicians have very little exposure to mentally retarded individuals, either through coursework or field experiences, and as such are uncomfortable treating them. Clay and Thomas (2005) agree with this idea and state that individuals diagnosed with both mental retardation and a psychiatric illness may constitute one of the most underserved populations in the United States.

Beasley (2004) calls for the importance of increased training for clinicians working with this population. She states that most mental health professionals who treat these individuals have little to no training in applying their specific treatment modalities

to people with mental retardation and psychiatric needs. She claims that the lack of formalized training approaches and training opportunities most likely negatively affects treatment outcomes and should be considered an obstacle to accurately testing the benefits of specific treatment outcomes. The need for a study such as this one is clear - we must look to how we can train our community social workers and other helping professionals to treat this population and their special needs and requirements.

Implications of the usefulness of such a study reside in social work practice, program development, policy, theory and social work education. Course listings for many schools of Social Work often lack content on disability awareness and educational opportunities. Deweaver and Kropf (1992) pointed out in their article that social work education does not have a standard for including the population of clients with mental retardation into their teaching curricula. Liese, Clevenger, and Hanley (1999) agree that this is a major deficit in social work education and suggest collaboration with outside partners who specialize in such teaching and training to remedy this void. Smart and Smart (2006) bring to light a related policy issue by pointing out that people with disabilities, like all individuals, have multiple identities, roles, and functions that could lead them to require the services of counselors in all specialty areas (aging and adult development, gay, lesbian, bi-sexual and transsexual issues, marriage and family counseling, career counseling, multicultural concerns, etc.). Therefore, to meet minimum standards of practice all counselors should be required to become proficient in disability issues; however, in spite of this need, very few university counseling programs provide adequate training about disability issues and concerns. By creating a study that explores the perceptions clinicians have of the overall state of needs and treatment modalities for

people with mental retardation, the educational requirements of our future social workers, areas in practice that need to be addressed, and adaptations to treatment theories and modalities when working with a population that may have difficulty with “normal” treatment approaches due to a lack of expressive language skills, decreased ability to tolerate strong emotions and stress, and similar cognitive difficulties may be identified.

The next chapter summarizes literature on whether psychotherapy is an appropriate treatment tool for people with mental retardation. I will review the major theoretical frameworks, specifically cognitive behavioral therapy and psychodynamic psychotherapy, which have been tested and used with this population. Finally, I will review the existing empirical literature of treatment interventions for people with mental retardation.

CHAPTER II

LITERATURE REVIEW

This chapter provides an assessment, based on the existing body of literature, of whether psychotherapy is an appropriate treatment tool for people with mental retardation. A review of the major theoretical frameworks, namely cognitive-behavioral therapy and psychodynamic psychotherapy, which have been implemented and tested for use with this population, follows. These frameworks will be compared in terms of their effectiveness, ease of use, and appropriateness for people with mental retardation. The next section of the chapter focuses on the prevalence of mental illness in people with mental retardation. Specific attention will be paid to the rates of mental illness in the general population as compared to the rates within the population of individuals with mental retardation. The chapter ends with a review of the existing empirical literature, focusing on usefulness and recommended adaptations in the assessment, diagnosis, and treatment processes.

Manny Sternlicht (1963) in one of the earlier articles relating directly to a theoretical model for the psychological treatment of individuals with mental retardation describes a theme that was emerging in the literature of the time, namely that psychotherapy and mental retardation were intrinsically incompatible. This sentiment was due in part to the belief that the client's cognitive and verbal deficits made psychological

interventions ineffective. Sternlicht however states that he thinks the belief that mental retardation precludes psychotherapy is based on “a provincial, if not lazy, concept of psychotherapy”. It is his belief that psychotherapy includes many different approaches to the mentally handicapped which do not require “normal verbal ability, insight, or self-reliance on the part of the client” (p. 622). In addition to this, authors such as Phillips (1966) suggested that people with mental retardation incur interpersonal difficulties as the result of organicity rather than psychopathology. These authors would then counter this argument by citing other clinicians who claimed that, based on the author’s own experience, psychotherapy was in fact helpful for those with mental retardation. Finally, the authors would lament that there was a lack of experimental research to conclusively decide the issue.

Though Sternlicht’s article was written close to 35 years ago, it still resonates loudly with modern complaints. Most of the authors who write within this field have commented on the lack of empirical research regarding treatment with this population (Beail, 2003; Lynch, 2004; Matson, 1984; Pfadt, 1991; Prout & Nowak-Drabik, 2003; Whitehouse, Tudway, Look, & Kroese, 2006; Willner, 2006). In an article that reviewed psychodynamic and cognitive-behavioral literature, Whitehouse *et al.* (2006) found that although in recent years barriers to individual psychotherapy for adults with mental retardation have become less restrictive, in comparison with the amount of empirical research and literature on psychotherapy approaches in general adult mental health, the number of studies remains minute.

Though the body of empirical research is small, there is a growing amount of anecdotal literature that describes how best to work with this population based on the

therapist's clinical experience. However, before one can even discuss various theoretical frameworks and which might be the most appropriate for this population, it must first be recognized that psychotherapy is indeed useful for people with mental illness and mental retardation. As was established through Sternlicht's article, this is an issue that has been debated on and off for decades. While there is still no unequivocal answer, most authors agree that psychotherapy is beneficial for this population. This belief is due in large part to a recent study done by Prout & Nowak-Drabik (2003). These men conducted a large-scale review of studies published from 1968 to 1998 in an attempt to determine the effectiveness of psychotherapy with individuals who have mental retardation. Ninety-two studies were identified and reviewed by an expert panel to determine the nature of the studies, the outcomes, and the effectiveness of treatment. Prout & Nowak-Drabik subsequently conducted a meta-analysis of a small number of the studies and found a wide range of research designs and types of interventions. They discovered that people with mental retardation often achieve an overall moderate degree of change and effectiveness with psychotherapy and thus they claim that psychotherapeutic interventions should be used in treatment with this population.

Prout & Nowak-Drabik's article has been very beneficial to the field as it has generated a lot of interest and discussion amongst authors and clinicians. The publication of their analysis prompted the production of what has become an incendiary article by Peter Sturmey (2005). Sturmey argues against psychotherapy for people with mental retardation. He refutes Prout & Nowak-Drabik's claim that psychotherapy with this population can be moderately effective and claims that social skills training and behavioral interventions are superior to traditional psychotherapy. Sturmey goes on to

claim that there is not enough research on the effectiveness, ineffectiveness or harmful effects of psychotherapy and therefore behavioral interventions and approaches should remain the preferred treatment option.

Sturmey's article is part of a large-scale debate over whether or not psychotherapy is a useful tool to use with this population. In terms of actual clinical practice, Bender (1993) pointed out what he described as the 'therapeutic disdain' of many mental health professionals towards conducting psychotherapy with these individuals. Other articles claim there is an over-reliance on behavioral interventions and modification work as well as an over-reliance on medications for this population (Antonacci & Attiah, 2008; Hurley, Tomasulo, & Pfadt, 1998; Stenfert Kroese, 1998).

In a direct reply to Sturmey, Beail (2005) stated that while there is available research on behavioral interventions, in recommending its use Sturmey overlooked some rather large drawbacks. One limit of the behavioral research is the fact that the majority of it was conducted on children with severe and profound levels of mental retardation who presented with high frequency internally maladaptive behaviors. Psychotherapy would probably not be the best choice for this population, whereas it could be much more productive in an adult with mild to moderate retardation who has the verbal and cognitive capabilities to participate. Further, Beail notes that over 25 percent of the behavioral interventions were aversive or punishment based. Importantly, Beail points out that while there is currently a lack of evidence for non-behavioral interventions, there is also very little evidence for the effectiveness of behavioral treatments for mental health problems, something for which psychotherapy can be helpful.

In addition to Beail, Hurley (2005), King (2005) and Taylor (2005) all published responses to Sturmey's article. These authors support Beail in his claim that behavioral treatment is not the best option for the majority of people with mental retardation. Taylor states that research shows behavioral interventions are most effective with individuals with moderate, severe, and profound mental illness who exhibit high frequency aggression and live in segregated environments with high staff ratios. He points out however that according to the American Psychiatric Association (2000) approximately 85% of people with mental retardation have mild retardation. Hurley, King and Taylor all claim that psychotherapy in the form of cognitive-behavioral work can be very useful with people who experience both mental illness and mental retardation as it approaches both the behavior component and the mental (cognitive) piece. Hurley refutes Sturmey's claim that assertiveness training, relaxation training, social skills training, and problem-solving training are not part of a psychotherapeutic treatment. Hurley claims that these techniques are often employed by cognitive-behavioral therapists and the fact that these treatments have documented success provides evidence that people with mild mental retardation can benefit from other forms of psychotherapy as well because they can use the interpersonal relationship format, follow advice, accept feedback, and learn new ways of thinking and behaving as a result of treatment (p. 446). These authors put voice to the majority belief that, in general, individuals with mild to moderate mental retardation can in fact benefit from various forms psychotherapeutic treatment.

Before the discussion turns to which theoretical framework is most appropriate to use with individuals with mental retardation it seems helpful to highlight a few common characteristics often seen in individuals with mental retardation and a psychiatric illness.

One of the most frequently seen characteristics of this population is language delays or impairments (Stavrakaki & Klein, 1986; Whitehouse *et al.*, 2006). These verbal difficulties often lead to difficulties in the individual's ability to communicate, not only in the therapeutic setting, but in their day to day lives (Antonacci & Attiah, 2008). Such daily frustrations in communication and self expression often lead to an individual acting out and having difficulty controlling their impulses (Butz & Bowling, 2000). This difficulty controlling impulses, along with increased levels of anger and aggression, is something that is very common and well documented in individuals with mental retardation and a psychiatric disorder (Smith, Branford, Collacott, Cooper, & McGrother, 1996; Willner, Jones, Tams, & Green, 2002).

Another common characteristic of individuals with mental retardation and a mental disorder, and one that therapists must be aware of, is a greater risk for overdependence than one would find in a more typical client (Lynch, 2004). Individuals with mental retardation are often prone to relying heavily on others to the point that their capacity and willingness to employ their own self-will and abilities is minimized. Paul Berry (2003) expanded on this idea by pointing out that many individuals with mental retardation exhibit a relative lack of internal awareness and understanding along with a sense of social uneasiness.

Theoretical Orientations

Most authors do agree that at least individuals with mild to moderate mental retardation can in fact benefit from some form of psychotherapy, the debate has turned to which theoretical framework is most appropriate to utilize in practice. Though the list of theoretical orientations is long some of the more common ones in the United States are

psychoanalytic, psychodynamic, interpersonal, psychodrama, cognitive-behavioral, behavioral therapy, and rational emotive behavioral psychotherapy (Hurley, 2005, p. 446). Cognitive-behavioral therapy and psychodynamic psychotherapy together represent the most frequently applied methods of psychotherapy in clinical practice with the general population (Leichsenring, Hiller, Weissberg, & Leibing, 2006). As such, it does not come as a surprise that these are the two frameworks that are being discussed the most for use with people who have mental retardation and psychiatric needs.

Cognitive-Behavioral Therapy (CBT) is an empirically supported treatment which focuses on specific patterns of thinking that are maladaptive to an individual and the beliefs that underlie such thinking (National Alliance on Mental Illness, 2008). CBT was first developed by Aaron Beck in 1967 to work with people experiencing symptoms of depression. Beck believed that people's negative representations of themselves caused low mood and depression. The development of cognitive therapy represented a movement away from both the restrictive nature of behavioral therapy and the perceived limitations of psychoanalytic work in which Beck was originally trained (Beck, 1967; Jahoda, Dagnan, Jarvie, & Kerr, 2006). Emerging CBT clinicians took the basic idea of cognitive work, using cognitive methods to modify dysfunctional beliefs, and combined it with the tradition of behavior therapy (Leichsenring *et al.*, 2006). Cognitive-behavioral treatment emphasizes the role of thinking in how we feel and in how we act. It is based on the idea that our thoughts are what cause our feelings and behaviors, not external things such as other people or life events. Given this basic tenet, CBT clinicians believe we can feel better and act better if we change the way we think, even if the situation that is causing us distress doesn't change (National Association of Cognitive-Behavioral

Therapists, 2008). CBT is generally very structured and directive and represents a collaborative effort between the clinician and the client. According to Leichsenring *et al.* the client and the therapist work together to identify and understand problems in terms of the relationship between thoughts, feelings, and behavior. The focus of CBT work is in the here and now and thus therapists generally don't venture excessively into the past lives of their clients in the same way a psychodynamically oriented therapist might. In treatment the therapist and client work together to formulate time-limited goals that directly target symptoms, reduce distress, and improve thinking and behavioral responses. Homework is an essential part of treatment and is one of the main reasons why CBT is one of the briefest psychotherapeutic models, usually lasting about 16 sessions.

Psychodynamic psychotherapy began to emerge in the late eighteen hundreds through Sigmund Freud and his followers. Over the ensuing years many clinicians such as Anna Freud, Melanie Klein, and Carl Jung, have built on, added to, and updated his ideas. In psychodynamic treatment therapists use their understanding of the client's ego-functions (or abilities) to create interventions that enhance a persons understanding of his or her functioning and to make them more aware of the unconscious roots of their feelings. Psychodynamic psychotherapy often employs a treatment process that uses an interpretive-supportive continuum. The goal of interpretive interventions is to enhance the client's insight about repetitive conflicts that are sustaining their problems. Supportive interventions try to strengthen abilities that are currently inaccessible because the client is experiencing acute stress, often caused by traumatic events, or that have not yet been fully developed. (Leichsenring *et al.*, 2006).

One of the main differences between CBT and psychodynamic work is the emphasis that psychodynamic psychotherapy places on the relational aspects of transference. Transference in treatment occurs when there is a displacement of feelings, emotions, and/or attitudes from their original object to a substitute for that object. In psychodynamic treatment transference is regarded as one of the most important sources of understanding and therapeutic change (Gabbard & Westen, 2003). Considering the importance of transference, it is not surprising that psychodynamic approaches rely more heavily on the interpersonal relationship between the therapist and client than most other forms of psychotherapy.

Current literature on the best theoretical orientation to use when conducting treatment of individuals with mental retardation and psychiatric needs almost always focuses on three different approaches; psychodynamic psychotherapy, cognitive behavioral therapy, and avoiding the exclusive use of any one theory at all. Nigel Beail, who is currently the chair of the British Psychological Society's Faculty for Learning Disabilities and a member of the executive committee of the European Association for Mental Health in Intellectual Disabilities, has published extensively on the benefits of psychodynamic work with individuals with mental retardation. His belief in the benefits and appropriateness of psychodynamic therapy for people with mental retardation has been supported and augmented by many other clinicians in the field (Beail & Warden, 1996; Berry, 2003; Frankish, 1989; Gaedt, 1995; Hassiotis, 1999; Levitas & Gilson, 1989; O'Hara, 1993).

In his article on the effectiveness of psychodynamic psychotherapy with adults who have mental retardation, Beail (2005) clearly illustrates reasons for the superiority of

psychodynamic work with this population. Within this theoretical framework the therapist's concern is of the client's mental representation of themselves within the world. They then seek to identify the origin, meaning and resolution of difficult feelings and inappropriate behaviors. This type of work is very applicable to people with mental retardation as they often have distorted views of themselves and how they fit into a world that is not designed to accommodate their needs and everyday lives. Another benefit of using this theoretical model for work with this population is that the therapist presents him or herself as a screen onto which the client can project their imagined perceptions of the therapist. This idea of providing the client with a "blank screen" to work with is particularly important for people with disabilities as many of these individuals present with a term that Lynch (2004) describes as "outerdirectedness". This term refers to a tendency to look to others for cues to solutions of difficult or ambiguous problems and situations. Considering this, one of the goals of treatment should be to teach these clients to perform these operations for himself or herself, based on their own understanding of their individual feelings and reactions and not those of another person. Berry (2003) supports this assumption that individuals with mental retardation often have a particularly difficult time understanding themselves. He believes that the ego functions of people with intellectual disabilities are especially vulnerable, particularly frustration tolerance, reality testing, and anticipation.

Another reason that psychodynamic work might be preferable to CBT is that the core cognitive capabilities required for CBT work might preclude a large portion of individuals with mental retardation. Several authors discuss the importance of a therapist, prior to utilizing a CBT model, assessing the client's ability to link antecedents, beliefs,

and consequences (Dagnan & Chadwick, 1997; Dagnan, Chadwick, & Proudlove, 2000). This is a skill that some people with mental disabilities might grasp on their own, others might be able to be taught, but still others will not be able to benefit from CBT methods even with introductory training. Psychodynamic work on the other hand, with its emphasis on the relationship between the therapist and the client and transferential work, might be able to reach a greater percentage of this population.

Psychodynamic work also benefits from having a longer tradition and provides clinicians working with this population greater resources to guide them in their treatment approach. CBT work with the mentally handicapped has in fact been gaining in popularity over recent years, however there is still a far larger body of literature supporting the use of psychodynamic and psychoanalytic therapy with clients who experience mental retardation and psychiatric illness (Beail, 2003; Whitehouse *et al.*, 2006).

Though psychodynamic work has been shown to be appropriate for people with mental retardation and a psychiatric illness, the literature does indicate some precautions that clinicians should be aware of before beginning a psychodynamic treatment with this population. As Beail, Warden, Morsley, and Newman (2005) point out, psychodynamic treatment entails making links between early life experiences and how these experiences influence unconscious and conscious expectations of relationships in the client's present life. However, making such connections may be difficult for individuals with more moderate or severe cognitive impairments. It is therefore important for the clinician to continually assess the client's ability to engage in this form of treatment.

Edwin Mikkelsen (1994) discusses another area that psychodynamic clinicians working with this population must be aware of and attune their treatment towards. Mikkelsen notes that many mentally retarded individuals who are not living with their families will have experienced repeated losses. Staff members, therapists, counselors, and residences may all have changed over time and this accumulation of losses and the fear of future similar losses can make such individuals hesitant to begin a new therapeutic relationship. If a clinician is not aware of these issues, he or she may wrongly consider the resulting reticence as the effect of limited cognitive capacity and thus incorrectly assess the individual and derive a faulty treatment plan. The clinician must be aware and allow for any needed additional time at the start of treatment for building trust and rapport with the client.

Stavarakaki & Klein (1986) caution clinicians working with this population about the heightened importance of countertransference. They believe that therapists must work very hard to be aware of any negative countertransferential feelings when working with individuals with mental retardation due to the client's sensitivity to non-verbal communication that often arises as a consequence of verbal language difficulties. Similarly, Hernandez-Halton, Hodges, Miller, & Simpson (2000) point out that the a clinician working with this population must be extremely careful when giving transference interpretations due to increased sensitivity which is common in client's with mental retardation and a psychiatric illness.

Cognitive-behavioral therapists argue that the use of this method with people with mental retardation is not only possible, but often preferable. However, prior to making the decision to utilize CBT with a mentally handicapped patient a therapist must first

assess whether their client is capable of participating in a cognitive treatment, which relies heavily on the ability to communicate. Therapists must perform an assessment of both their clients verbal and cognitive skills (Dagnan & Chadwick, 1997; Hurley *et al.*, 1998; Whitehouse *et al.*, 2006; Willner, 2006). Often this assessment screens out those with severe, profound, and at times even moderate forms of mental retardation as they do not have the skills necessary to participate in a cognitive-behavioral treatment approach.

Clinicians who argue for a cognitive-behavioral approach point out that it can be extremely useful for managing particular symptoms that are common in people with mental retardation. A prevalent problem amongst people with mental handicaps is anger management, which can lead to the aggressive behavior that is also common amongst this population (Smith *et al.*, 1996; Willner, *et al.*, 2002). Lindsay & Laws (1999) published a report showing that in the United Kingdom more than 60 percent of clients with learning disabilities referred to a community-based service for challenging or offending behaviors had clinically significant anger problems. As this is such a common and considerable issue amongst this population, it is necessary for therapeutic interventions to focus on decreasing both the symptoms of the anger as well as the inherent causes. Cognitive-behavioral work has been shown to be very useful in helping clients with mental disabilities manage their anger and behaviors (Taylor, 2002; Taylor & Novaco, 2005; Taylor, Novaco, Gillmer, Robertson, & Thorne, 2005).

Another benefit of CBT work is that it involves the caregivers of the clients. In treatment with individuals who have both mental retardation and mental illness it is important to work more closely with the caregivers than might be standard practice within the general population. Caregivers can provide important information about how

the client is functioning at home, help the client to continue to work on and remember the therapeutic goals in between sessions, and to provide support to the individual (Taylor, *et al.*, 2002; Willner, 2006). The use of homework, one of the hallmarks of CBT, is an excellent way to include caregivers in the treatment process while still keeping the focus on the individual with the disability.

Another benefit of CBT work with this population is that it is self-actualizing in nature (Taylor, 2005). The idea of treatment is to help clients develop control over their emotions and their behaviors. As noted above, individuals with mental retardation are particularly prone to difficulties controlling both their anger and at times aggressive or even violent outbursts (one of the behaviors that is linked to the anger emotion). Considering this difficulty, the focus of gaining control over these emotions and behaviors would be especially useful and necessary if such individuals desire positive interactions within a community setting. Though this framework is particularly useful in combating anger symptoms, more evidence is emerging that CBT approaches are beneficial for a wide range of both mental health and emotional problems experienced by people with mental retardation (Taylor, 2005; Willner, 2006).

Several authors have discussed areas of caution that a therapist utilizing CBT with a mentally retarded client should be familiar with. For instance, right from the start clinicians must be aware of the potential difficulties of obtaining full informed consent from a client with mental retardation (Arscott, Dagnan, & Kroese, 1999). Wong, Clare, Holland, Watson & Gunn (2000) suggest that the clinician develop procedures to simplify informed consent information to increase the likelihood that clients will be able to process the information.

As previously discussed, clinicians wishing to utilize CBT with mentally retarded clients must first perform an assessment of the client to determine whether CBT is a suitable form of psychological treatment for them. Some of the areas that a clinician must assess are whether the client has the needed receptive and expressive language skills; if they have the cognitive aptitude to participate such as the ability to self-monitor emotions; whether they have the capacity to identify and label their emotions; and if they have the capacity to understand the CBT model (Hatton, 2002). Once treatment has begun, it is important for the therapist to perform ongoing assessments to ensure their client is capable of participating in their own treatment.

Employing specific theoretical models is useful to therapists as it can give them an understanding of the client and helps to guide sessions; however, some clinicians are beginning to note that when treating individuals with mental retardation sticking with just one theory can become detrimental. Hurley *et al* (1998) note that no matter what treatment method a clinician is using, some adaptations to the original model will have to take place. The authors recognize that some of the recommended treatment modifications can be seen as somewhat specific to certain theoretical models and thus propose that success in working with individuals with mental retardation means not working within just one model such as CBT or psychodynamic techniques, but instead employing flexibility and innovation in their approach. This idea is seconded by a report published by the Royal College of Psychiatrists (2004) which notes that for psychotherapy to be effectively performed with this population the established models of therapy must be modified and clinicians must adopt a more flexible approach in their methods.

No matter what theoretical modality a clinician employs, there are several overarching cautions that must be attended to. Reports from Hatton (2002) and Jahoda *et al.* (2006) caution therapists about making diagnoses for this population using standard psychiatric classification models such as the International Classification of Diseases-10 (ICD-10) or the DSM-IV-TR. Jahoda *et al.* illustrate their caution by pointing out that to be diagnosed with depression these models both require individuals to be able to report on their mental state, something that is difficult for many individuals with mental retardation. Hatton (2002) points out that the applicability of these standard models remains untested for people with mental retardation, however based on his experience he claims that the standard diagnostic criteria needs to be modified to make it an appropriate tool for this population. Hatton also points out that there is no consensus amongst researchers or clinicians about which assessment instruments should be used to assess mental health problems in this population. Since the publication of these two studies, the National Association for the Dually Diagnosed (thenadd.org) in association with the American Psychiatric Association (APA) adapted current diagnostic criteria to fit the special diagnostic needs of individuals with mental retardation. The Diagnostic Manual – Intellectual Disability (DM-ID) was first published in 2007 and thus is only in its infancy in terms of being a common clinical tool; however, it is one of the first mainstream attempts at adapting standard diagnostic measures and is a large step forward for the field. However, in a study published a year after the DM-ID, Antonacci & Attiah (2008) still found that language and communication deficits, extremely common within this population, precluded the use of almost all standard diagnostic instruments and interviews.

Another caution that all therapists, regardless of theoretical orientation, need to be aware of is the potential hazard of relying on caregivers and second parties to gain information used in assessment, diagnosis, and choice of treatment approach. Though it is recognized that utilizing caregivers and other second parties is common and in fact adaptive for treatment with individuals who may have limited ability to accurately self-report, caregivers are rarely trained in the mental health field and an occurrence known as “diagnostic overshadowing” may occur (Antonacci & Attiah, 2008; Hatton, 2002; Reiss, Levitan & Szysko, 1982). This phenomenon occurs when caregivers, secondary parties, and even mental health professionals misattribute signs of a mental health problem as being due to a person’s intellectual disability. Emotional difficulties are incorrectly attributed to the mental retardation rather than a separate diagnostic category. Antonacci & Attiah also warn that it might be difficult for caregivers to report on internalizing symptoms, such as depression, as a person with mental retardation might not know how to vocalize and report on such symptoms.

As a final caution to clinicians who engage in therapeutic work with mentally retarded clients, Christopher Lynch (2004) states that no matter what framework and modality a therapist uses, some theoretical and conceptual issues always apply. First, the therapist must recognize the need to modify psychotherapy. Second, the therapist must be cognizant of the impact on the client of having a disabled identity. Thirdly, the therapist must always remain aware and attuned to dependency issues; and finally, the therapist needs to be aware of and open to the frequent need to involve others in the treatment process.

Prevalence

Individuals with mental handicaps can also suffer from mental illness. How prevalent are such emotional disorders amongst this population? Published reports vary slightly in their statistics, but what has been well established is that people with mental retardation have a greater likelihood of experiencing mental illness than individuals without an intellectual disability. In their report on psychiatric assessments in individuals with mental retardation, Silka & Hauser (1997) estimate that 40-70 percent of individuals with mental retardation also have diagnosable psychiatric disorders. However other researchers have found that about a third of all mentally disabled adults have psychiatric symptoms that require mental health care and treatment (Nezu, Nezu, & Gill-Weiss, 1992). Other estimates show that mentally disabled individuals are two to four times more likely than the general population to experience a psychiatric illness (Eaton & Menolascino, 1982).

The fact that mental illness is more prevalent in people with mental retardation has been well-documented, however there has not been as much attention paid to the type and prevalence of specific disorders. Clay & Thomas (2005) conducted a study using 179 mentally disabled individuals to determine the types of pathology amongst this population. The researchers found a relatively high rate of Axis I pathology, 31 percent as compared to 22 percent found in the general population (p. 81). Researchers grouped Axis I disorders into four categories, Anxiety Disorders (obsessive compulsive disorder, generalized anxiety disorder, post traumatic stress disorder, and anxiety disorder NOS), Mood Disorders (major depressive disorder, bipolar disorder and dysthymia), Psychotic

Disorders (schizophrenia, schizoaffective disorder, and psychotic disorder NOS), and Other (ADD, Tourett's syndrome, etc.). Through this categorization the researchers were able to discover that the mentally retarded exceeded the general population in every Axis I pathology except for generalized anxiety disorder. They also found that most of the difference between the general population and the mentally retarded lies in mood disorders where the mentally retarded sample was about 1.8 times as likely to have a diagnosis: 19 percent compared to 10.7 percent. That mood disorders are common amongst individuals with mental retardation was further supported by several studies that found very high rates of depression ranging from 44 percent of individuals with mental disabilities (Marston, Perry, & Roy, 1997) to 57 percent (Meins, 1993) in the general public. Antonacci & Attiah (2008) performed a review of the recent literature and found reported rates of mood disorders in adults with mental retardation varied widely, ranging from 7 to 97 percent. They account for this range by citing methodological problems, such as small sample sizes, lack of uniformity in screening and assessment instruments, broad and highly variable inclusion criteria, and a focus on higher functioning.

As the rate of mental illness is higher in people with mental retardation than the general population, there is a need for mental health professionals trained in the specific needs of this population. The Royal College of Psychiatrists (2004) published a report calling for increased specialized training. They found that a major barrier to people with intellectual disabilities receiving psychotherapeutic treatment was a lack of appropriately trained clinicians. In a recent article, Joan Beasley (2004) called for increased training and expertise for clinicians working with the mentally retarded. She states that most therapists who treat people with these disabilities have little to no training in applying

their specific modalities and theoretical frameworks to people with mental retardation and mental illness. She claims that individuals with these disabilities can benefit from treatment, but the clinicians must have training to be able to provide the treatment in the context of the individual's mental disability.

Empirical Literature

The final part of the literature focuses on the empirical literature and on the ways clinicians make adaptations in assessment, diagnosis, and treatment to work with this population. Though in recent years the amount of empirical literature has been increasing, authors and clinicians still repeatedly reference the scarcity of methodological studies on treatment with people with mental retardation (Antonacci & Attiah, 2008; Beail, 2003; Feldman, Atkinson, Foti-Gervais, & Condillac, 2004; Hurley, *et al.*, 1998; Lynch, 2004; Matson, 1984; Pfadt, 1991; Prout & Nowak-Drabik, 2003; Whitehouse *et al.*, 2006; Willner, 2006). One of the main reasons that most of the literature references anecdotal experiences as opposed to empirical studies is that it can be very difficult to receive permission to formally investigate this population. Ethical issues often prevent researchers from gaining approval to conduct studies on the mentally handicapped as they are considered a vulnerable population. Even when granted the right to begin their research, investigators often have problems obtaining informed consent as frequently the clients themselves can only provide their assent and instead it is their guardians, care givers, or state departments that have to provide the actual legal consent. Despite these

challenges more and more studies are being published, however a large percentage of them focus on treating offenders with intellectual disability (Allen, Lindsay, MacLeod, & Smith, 2001; Beail, 2001; Beail, 2002; Lindsay, Olley, Jack, Morrison, & Smith, 1998; Taylor, Thorne, Robertson, & Avery, 2002). While this research is helpful for understanding how such individuals fit within our community and how we must adapt our judicial system, they are beyond the scope of this study. The studies summarized below focus on treatment with non-offending, mentally retarded adults, and grouped into five overarching categories; CBT work, psychodynamic work, group treatment methods, treatment focused on anger, and treatment focused on psychosis.

Unlike studies utilizing cognitive-behavioral treatments, which have been increasing in frequency in recent years, there are very few studies utilizing psychodynamic approaches. Whitehouse *et al.* (2006) did a comprehensive review of all the published studies using psychodynamic treatment. Their findings suggest that the studies that are being conducted using psychodynamic approaches either relate to the treatment of offenders or are single-case studies.

One large study was conducted by Beail, Warden, Morsley, and Newman in 2005 to determine if psychodynamic psychotherapy would produce significant reductions in recipients' levels of psychological distress and improve their interpersonal functioning and self esteem. The study, an open-trial design with a three month follow up period used adaptations such as assistance in filling out general psychotherapy outcome measures and simplifying terms and descriptions. Potential participants were referred to therapy by family members or care providers for various reasons including aggressive behavior, sexually inappropriate behavior, depression, self-injury, bulimia, and obsessive-

compulsive disorder. A sample of 20 participants completed data collection on the treatment and the follow-up. Participants completed the Symptom Checklist 90-Revised, the Inventory of Interpersonal Problems-32 and the Rosenberg Self-Esteem Scales at intake, at the end of the study, and during a three month follow up. The results suggested that psychodynamic psychotherapy, provided in routine out-patient practice, can produce significant reductions in psychological distress, improve interpersonal functioning and increase self esteem in adults with mental retardation. The authors do however call for further research to determine the reliability and validity of psychodynamic psychotherapy with this population.

Studies of treatment using cognitive-behavioral therapy are much more prevalent and generally cover a greater number of treatment issues including the appropriateness of CBT for the mentally retarded and its effectiveness for anger management. In an early study, Cresswell (2001) used a flexible method, case-study design to show that CBT work was useful when working with an intellectually disabled adult. She employed an interesting treatment modification by using material from a soap opera to help the client understand complex relationships and behavioral consequences.

Joyce, Globe, and Moody (2006) conducted a fixed descriptive study to demonstrate the component skills (language and emotional vocabulary) necessary to undergo CBT. They wanted to figure out whether their participants had the needed language skills, ability to identify and to label emotions, and ability to link events, emotions and a cognitive mediation task. The study was conducted across 5 day services with 72 randomly selected people with mental retardation in an inner London borough. The authors found that it is possible to assess some of the skills needed to engage in CBT

work. Their results also indicate that people with mental retardation will need individualized supports from therapists to teach them the necessary skills.

McCabe, McGillivray, & Newton (2006) also found that CBT was an effective form of therapy to treat depression in adults with mental retardation. They used a fixed, experimental design to develop a group intervention utilizing CBT methods to treat depression in people with mild to moderate mental retardation. The participants of the study were all working in a supported employment program designed for people with mild to moderate mental retardation. The intervention ran for two hours for five weeks. At the start of the study the researchers administered the Beck Depression Inventory (BDI-II) to all participants. The participants who scored within the minimal depression range and above were eligible to take part in the study provided they had sufficient language skills to participate. The researchers used a total of 49 participants and divided them into two groups. The control group comprised 15 individuals while the intervention group comprised 34 individuals. They found that compared to the control group, the treatment group showed improvement in levels of depression, positive feelings about the self, and lower levels of automatic negative thoughts after the sessions; additionally, these changes were maintained at a three month follow-up. The researchers found that placing an emphasis on reshaping cognitive distortions, developing a more positive interpretation of events, and teaching the clients how to self-monitor their moods and thoughts and self-reinforce adaptive behaviors was beneficial to this population.

Sams, Collins, and Reynolds (2006) also wanted to assess whether CBT is a beneficial therapeutic tool for individuals with mental retardation. Researchers examined the performance of people with mental retardation on two cognitive therapy tasks,

emotion recognition and discrimination among thoughts, feelings, and behaviors, which are very important to the overall ability to engage in and achieve success with the CBT treatment model. The researchers also wanted to discover whether the provision of cues would aid in discrimination between thoughts, feelings, and behaviors. The researchers used 59 adults drawn from five day centers and a college in the east of England. Participants were included in the study if they had an IQ between 50 and 72 points. Participants were excluded if they had a current diagnosis of a mental illness or had received CBT in the prior six months. Researchers found that participants with higher IQ's and good receptive vocabulary were more likely to be able to identify various emotions and to discriminate amongst thoughts, feelings, and behaviors. The researchers determined that such individuals were more likely to be able to understand the cognitive model and benefit from such cognitive behavioral treatment. They also found that simplifying the cognitive therapy concepts and providing education about the cognitive model were required to better aid people with mental retardation in participation during cognitive treatment.

Esbensen & Benson (2007) conducted a fixed method, experimental design study to examine if Beck's cognitive theory of depression is appropriate for use with adults with mild to moderate intellectual disability. They also wanted to determine if this theory was associated with depressed mood in this population. Beck's theory of depression states that negative schemata (the stable organizing rules and procedures that guide the processing of information) in the face of stressors, lead to the development of cognitive distortions, a negative cognitive triad, and then subsequently to depression. Researchers recruited subjects from community residential agencies and divided them into a 'no

diagnosis' group and a 'depression group' members of whom all had diagnoses of major depression in their preexisting medical records. The authors found that the cognitive triad (negative views of the self, the world, and the future) is a construct that can be measured among adults with mental retardation and that the cognitive triad is associated with depressed mood in this population. Their findings partially support the use of Beck's theory.

Willner *et al.* (2002) and Taylor *et al.* (2005) both used fixed experimental designs to show that CBT could be used effectively with this group of individuals. Willner *et al.* (2002) conducted a study of the efficacy of CBT anger management groups for individuals with mental retardation. Using a randomized controlled trial involving two groups of seven clients, one a treatment group and the other a wait-list control group, pre and post treatment assessments were administered. The treatment consisted of nine, two hour groups using group brainstorming, role-playing, and homework. Clients in the treatment group improved on both self and care-giver ratings over their own pre-treatment scores and the control group. The clients in the treatment group also showed further improvement relative to their pre-treatment scores at a three-month check-up. The researchers found that the degree of improvement was strongly correlated with verbal IQ.

Taylor *et al.* (2005) focused on whether they could reduce anger in detained individuals with mild to borderline intellectual functioning. Therapists performed eighteen sessions of individual CBT work focusing on anger management. In this model the therapists performed an initial 6 sessions of psycho-education to prepare the intellectually disabled clients for treatment. They found that the group that received

treatment scored significantly lower on self-reported anger scores following therapy than did the control group, and these improvements were maintained at follow-up.

Willner & Tomlinson (2007), examined whether the use of CBT could increase anger coping skills in people with mental retardation and if so, could it be generalized across settings (day-service to residential). Eleven service users were assigned to one of two anger management groups. Treatment consisted of using a standard CBT package shown to be effective in earlier studies. Participants showed a decrease in anger and an increase in positive anger-coping skills. The therapeutic gains were maintained for at least six months and did generalize across settings.

The literature suggests that group therapy is an effective treatment modality for individuals with mental retardation. Several studies have examined treatment using this approach (Crowley, Rose, Smith, Hobster, & Ansell, 2008; Matson & Senatore, 1981; McCabe *et al.*, 2006; Willner *et al.*, 2002). Matson and Senatore (1981) conducted an experimental study where they randomly assigned thirty-five mild to moderately mentally retarded adults to a psychotherapy group, social skills training group, and a control group that received no treatment. The researchers were attempting to determine which treatment, psychotherapy or social skills training, was better at improving the interpersonal functioning of mentally handicapped adults. The two treatment groups both had three to five clients and met for one hour sessions twice a week. Both groups discussed the same topics, but the goal of the psychotherapy group was to establish group cohesion and express feelings. The social skills group was aimed at specific “target behaviors” such as decreasing complaining statements and increasing positive statements about others. Four different measures were used to determine the treatment outcome for

each subject. The first assessment was role play scenes where a narrator describes a scene to a participant and then the client interacts with a second staff member. The subject's responses were audio taped and rated retrospectively by trained students blind to the experimental conditions. The next measure was group meetings were therapists took assessments during informal group conversations of one hour duration. The third measure was the Social Performance Survey Schedule (SPSS) which is a 100 item Likert-like, five point scale that measures deficits and assets in interpersonal functions. The final measure was the Nurses' Observation Scale for Inpatient Evaluation (NOISE-30) which is a staff rating scale of general client performance. The researchers found that the social skills training group was significantly more effective than both of the other groups in improving interpersonal functioning. Haddock, Lobban, Hatton, and Carson (2004) used five case studies to illustrate CBT adaptations for individuals with mild mental retardation and psychosis. Their article shows how using treatment adaptations (simplifying their methods, using a directive approach, enhancing flexibility in the method, using pictures and audiotapes to better reach the client's language ability, performing psycho-education and teaching phases to ensure the clients understood the CBT approach, and involving caregivers) can increase the use and effectiveness of CBT with this population. McCabe *et al.*, (2006) described in the CBT section, found that the group format was extremely beneficial for individuals with mental retardation as participants were able to practice skills with peers and operate within a social environment where trust and respect for others could be experienced (p. 240).

Crowley *et al.* (2008) conducted a small pilot study to assess whether there was a way to increase the knowledge base of individuals with mental retardation and psychosis

about their illnesses. The study used a psycho-educational group attended by eight individuals with mild to borderline mental retardation and their care-givers to try to inform the clients of their illness and ways to care for themselves. Measures of self-esteem and knowledge of psychosis were administered before and after the intervention which consisted of two psychoeducational groups with four participants in each for six sessions. They found after treatment that the sampled individuals were better able to understand the concept of psychosis and the need for medication. They also found that the client's knowledge increased about the role that stress plays in psychosis and what early signs of relapse are.

Assessment and Treatment Adaptations

Though not empirical studies, several authors have performed reviews of the existing literature and compiled lists of some recommended diagnosis and treatment adaptations to use in therapeutic work with individuals with mental retardation. Matson (1984) reported that dynamically oriented therapists should modify their treatment methods to focus more on the expression and ventilation of emotions along with training in emotional control, reassurance and rapport building, release and catharsis, attainment of insight, and positive self-actualization. These adaptations help to guide treatment towards improving skills and levels of self awareness which are often problematic areas for individuals with mental retardation.

Hurley *et al.* (1998) recommended nine different adaptations to psychotherapy techniques; Simplification, used to reduce the usual technique in complexity and shorten

the sessions; Language adaptations including the use of shorter sentences and words to increase communication and cognitive understanding; Activities, such as drawing or homework assignments to increase learning; Developmental Level, integrating the developmental level of the client into the presentation of techniques; use of more Directive Methods; employing Flexible Methods to adjust the usual techniques and borrow as needed from other modalities; Involve Care Givers to help with change and homework; Transference/Countertransference since the attachments are stronger and quicker the therapist is urged to be stronger in boundaries and to ensure peer supervision; Disability/Rehabilitation approaches in which the issue of disability is addressed within treatment (p. 368).

Whitehouse *et al.* (2006) followed up by reviewing published case studies to understand which of the methods listed above were most widely used in treatment. Additionally, they broke down the information into which adaptations were most popular with CBT clinicians and which were most popular with psychodynamic clinicians. They found that all of the methods were used by the therapists utilizing a cognitive-behavioral approach, though transference/countertransference and disability/rehabilitation approaches were both only utilized in one case. None of the psychodynamic clinicians used directive methods with their clients and only one case showed use of simplification, though there was evidence of every other adaptation listed. CBT clinicians most frequently applied flexible methods, while psychodynamic clinicians most frequently utilized transference/countertransference approaches. Overall the most popular adaptation was flexible methods, and the least popular were directive methods and disability/rehabilitation approaches.

Willner (2006) agreed with many of Hurley *et al's*. ideas. He believes that it is important for clinicians to assess the client's readiness, willingness, and ability prior to beginning treatment. He notes that many clients with mental retardation come to therapy not of their own accord, but because a care-giver thought it would be a good idea. Thus, the client herself may not have the motivation or willingness to engage in therapy. Ability and readiness are also important to assess, for it is possible for a client to be willing but not have the ability or confidence to master the techniques and skills that are required for successful treatment. Matson (1984) suggested that clinicians increase the social relations between themselves and the client to a higher level than they would with a non-mentally retarded client. This treatment adaptation is geared toward teaching better social skills, something that many individuals with mental retardation struggle with. Matson also claimed that it was important for treatment with this population to involve both verbal and non-verbal behavior as many individuals with mental retardation experience verbal and language impairments.

Jahoda *et al.* (2006) found based on a review of CBT treatment for individuals with mental retardation and depression that it is helpful for CBT clinicians to help the client create and use narratives and life stories. Using narratives in therapy helps root the treatment in everyday experience and gives the process a more naturalistic and less abstract focus. Both Willner (2006) and Lynch (2004) make additional suggestions including that the therapist simplify language and use pictures where appropriate, proceed at a slower pace and use extensive rehearsals with the client, support the therapeutic work done in sessions by assigning homework, and by recruiting care-givers to provide assistance. Lynch (2004) goes on to state that no matter what theoretical framework and

modality the therapist is employing, they must remain cognizant of the impact that having a disabled identity has on their client and make sure they are attuned to the dependency issues that are inherent when working with this population.

As evidenced by a review of the current literature, psychotherapy is becoming more accessible for people with mental retardation. A few authors are beginning to publish studies and other reviews that suggest possible ways for therapists to work with this population; however, as of yet no one has conducted interviews with the actual therapists who work with this population. Currently all the literature is based off of pre-published case-studies or other empirical work. I feel that it is important for the field that the clinicians who work with this population be interviewed directly in order to best assess both what works, and what doesn't. My study will fill this gap as I intend to conduct 10 to 12 interviews with clinicians who have worked in a therapeutic setting with individuals with both mental retardation and a psychiatric illness.

CHAPTER II

METHODOLOGY

Research Design

This chapter describes the process of choosing a research design, recruiting subjects, the sampling procedures, data collection, and data analysis methods. The purpose of this study is to describe the various methods clinicians employ to adapt their normal treatment strategies to best fit the special needs and requirements of a client who has both mental retardation and a psychiatric illness. The research questions are: (1) how do therapists adapt assessment, diagnosis, and treatment when working with an individual who has a psychiatric disorder and mental retardation? (2) What does treatment with this population look like? (3) What are some specific areas that must be addressed when taking into account their special needs stemming from their dual diagnosis? As my goal was to collect narrative data from the clinicians I conducted a qualitative study utilizing flexible methods. This type of design is particularly helpful to the study goals as it enables me to vary my methods in response to emerging findings and my experiences in the field (Anastas, 1999). Qualitative methods are also appropriately used when there is little prior research in a particular area and little is known about the topic. The study sought to develop a better and more detailed understanding of how therapists work with individuals with mental retardation and mental illness. What does treatment with this

population look like? What are some of the specific areas that must be addressed when taking into account their special needs stemming from their dual diagnosis? Qualitative methods were used to create a more detailed description of the experiences of therapists who treat the mentally retarded and the ways they have adapted their practice approaches to meet the needs of this population. This study design also helped highlight areas of special concern that exist for practitioners who work with this population.

Sampling

Nonprobability sampling methods, specifically convenience and snowball sampling, were used to select a sample, thus creating a non-probability sample. I was able to identify agencies who specifically serve this population and using my community contacts gained access to their directors. Inclusion criteria for participants were: clinicians with a minimum of a master's degree in a clinical mental health field working with individuals with mental retardation and psychiatric diagnoses who are at least 18 years of age. Members of the clinical mental health field include master's level social workers, psychologists, marriage and family therapists, mental health counselors, and psychiatrists. I also included individuals who have advanced their degree holdings beyond a master's level. Eligible participants had to hold an individual license within their field (LSW, LICSW, Ph.D., Psy.D., LMFT, LMHC, MD) or have been working towards a license with the requirement that they have already completed all necessary clinical and supervisory hours. Originally, I had chosen to only include licensed master's level social workers, psychologists, and psychiatrists however I have since opted to

include licensed mental health counselors and licensed marriage and family counselors to my study. I chose to include individuals who held LMHC degrees after I investigated Service Net's staffing population and found that about half of the clinicians who work with this population have an LMHC.

The study's exclusion criteria were therapists who do not have at least a master's degree in one of the fields listed above, an unlicensed master's level or above clinician who has not finished his or her required hours of supervision and field work for licensure, or a clinician who has not worked with this population for at least a year. Additionally I excluded individuals who work only with children (clients under the age of 18). The desired sample size for this study was 10 to 12 clinicians.

The first step in the recruitment process was to research local agencies providing mental health care for individuals with mental retardation through the internet, phone book, and asking community contacts. The initial search produced four results. I continued investigations by calling their main numbers, or a person within the agency who had been identified by community contacts. After speaking with the contacts I found that two of the agencies would not fit the inclusion criteria of the study as they only worked with children under the age of eighteen. The third agency was also incompatible with the studies inclusion criteria as they did not provide clinical services by a licensed therapist to their population. The fourth agency, Service Net, was found to be compatible with the study.

I identified Service Net in Northampton, Massachusetts as an agency with whom I recruited subjects. Service Net is an agency aligned with the Department of Mental Retardation (DMR) that offers residential and support services to clients with mental

retardation. According to their website (www.servicenetinc.org, 2008) they are currently servicing 74 mentally retarded adults in Hampshire and Franklin Counties, through 9 group residences, 1 outreach program, and 1 shared living placement. They serve an additional 46 adults in Hamden County through eight group residences, 1 outreach program and 13 shared living placements. They also offer individual and group psychotherapy for these clients.

I met with the director of the Mental Retardation Clinical Team to discuss the study, including the study's purpose, design, aims, and goals. The director expressed interest in involving her agency and clinicians in the study. Eight licensed clinicians work with individuals with mental retardation and a psychiatric illness and meet the inclusion criteria in the Northampton office. Additional licensed therapists working out of the Greenfield office could be included if needed. After the study received HSR approval from the Smith College HSR Committee, I set up a time to attend a staff meeting where I proceeded to introduce myself, give the reasons for choosing this research area, introduce the study, outline what participation entails, and allow time for questions. At the end of the presentation I made a sign-up sheet available so that interested clinicians could provide their names, office telephone numbers, and good times to call. All the clinicians in attendance signed up to participate in the study. After I had collected names and information I began telephoning the potential participants at their offices to again review what participation in the study entailed and ensure that the participant was still interested. Every clinician expressed interest so I then went through a screening questionnaire with the candidate and set up a time to meet them for an interview in their office.

I was unable to gain the needed 10 to 12 participants required for the study from Service Net and was not able to reach any interested participants at their Greenfield or Holyoke offices. Additionally, I was not able to reach several other area contacts whom I had originally thought might be helpful. Instead I called NADD (the National Association for Developmental Disabilities) and was able to obtain some recommendations for clinicians and psychiatrists who work with this population from the director. Additionally, I utilized snowball sampling by asking several clinicians at Service Net as well as a few local social workers for recommendations of potential participants. Through these techniques I was able to find and recruit enough clinicians who fit the study's inclusion criteria and were willing to participate.

A total of four male and eight female clinicians participated in this study. All of the clinicians practice in Massachusetts. The participants' ages range from 29 to 67 years old with a mean age of 48. Five of the participants were licensed independent clinical social workers (LICSW), two were licensed clinical social workers (LCSW), four were licensed mental health counselors, and one participant held a medical degree in psychiatry.

Every effort was made to create a sample with as much gender balance as possible as well as a sample as ethnically and racially diverse as possible. Unfortunately, there was little opportunity for choice as the population of clinicians who work with individuals with mental retardation and a mental illness is still very small.

Data Collection

Data were collected through face-to-face interviews since this approach was the best fit for the qualitative research questions in this study that sought to explore how therapists work with individuals with mental retardation and mental illness. One of the advantages to using an interview format is that I was able to get more descriptive and in-depth information than would have been obtained from a survey or other collection method. Using this method gave the study participants greater options for elaboration. Interviewing also allowed the researcher to offer clarification if needed for any questions that might not be clear to the individual participant. Another benefit of conducting interviews using a flexible method is that I was able to focus more time on the specific questions and areas in which the participant had the most experience and/or the most insight to offer. The disadvantage to using individual interviews is that it could be interpreted as more intrusive than having a participant complete a survey on their own and send it back. The interview process is also not as anonymous as other methods, thus it was possible that the subject would not be as forthcoming as they would have been using a non-face to face approach. However, as this study did not ask for many personal or potentially embarrassing details the risks of performing an interview were greatly outweighed by the benefits to employing this format.

Once participants were identified, given information about the study through the recruitment speech, and gone through the screening process I set up individual interviews at the participant's office. This one-to-one interview lasted no longer than 90 minutes. I began by informing them of their rights as a participant and reviewing the informed

consent letter. After the participant signed the informed consent, I gave the clinician a duplicate copy of the letter for them to keep. After the consent form was signed I set up the audio recorder and the interview began according to the interview guide that had been created.

Instrument

A thirteen item interview guide was used. The questions in the guide focused on the areas of assessment, diagnosis, treatment, and professional training. The interview began by asking opening questions that were specifically designed to be less stressful and “warm-up” the participant, such as: What is it about the mentally retarded that drew you to work with this population? The most difficult and thought-provoking questions were posed in the middle of the interview, for example: How do you adapt or work with the DSM-IV criteria when developing a diagnosis for a person with mental retardation and a psychiatric illness? So as not to end the interview process with a difficult or potentially emotional question, demographic information was collected last. (See Appendix C).

Before each category of questioning the participant was informed about the general content of the next section (ex. “The next couple of questions will be about performing an assessment”). Occasionally, a participant asked for clarification, examples, or extra guidance when answering a specific question. At these times I used various probes that had been written into the interview guide for this purpose. After the final question about professional development I gathered a small amount of demographic data including age, gender, type of degree the clinician holds, how long ago they obtained it

and how long they have been working with this population in a clinical setting.

Additionally, I asked if they had been trained in, or currently use, any specific theoretical framework. At the end of the interview I reminded the participant of the withdrawal date and referred them to the contact information on the informed consent letter for any questions or concerns they might have. I closed the interview by thanking them for their participation. I personally did full, verbatim transcriptions of the interviews. I utilized my thesis advisor who provided peer debriefing, review, and consultation. Additionally, I performed basic descriptive statistics with the demographic data that I gathered.

It was very important for me to be aware of what my own biases were in order to be conscious of how they might have impacted my study. As Service Net offers treatment specifically for individuals with both mental retardation and psychiatric disorders I know it would be a very rich opportunity for my study; however in utilizing this source I had to be very aware and open about potential biases. My own brother has both Downs Syndrome and a psychiatric diagnosis and recently underwent individual therapy with one of Service Net's former clinicians. He was also part of their group therapy program. In working with this agency I had to be explicit and open from the first contact with the directors and clinicians about my relationship to him. As his individual therapist has left the agency I did not have to worry about potential contact with him, but I was concerned that I might have to avoid interviewing the clinician who facilitated the relationship group he engaged in. Due to the already small sampling pool I was particularly concerned about losing a potential interview subject; luckily, it turned out that the clinician was no longer employed at the agency. Additionally, I am very involved in the disability awareness and rights world, and as such have always wanted to guide my work towards

the benefit of that community. However, this project required that I take a close mental inventory of how this close-knit relationship could impact my research - would I be okay with reporting results if I did not view them as favorable? As I used narrative data it was important for me to maintain this self-awareness in order for my conclusions to be valid, reliable and replicable.

Considering the above, it was exceedingly important for me to protect my study against such biases, and assure others that my study is reliable and its validity is not questioned. To ensure the trustworthiness of my analysis I utilized prolonged engagement with my interview subjects, peer debriefing, review, and consultation, and full verbatim transcriptions of the interviews.

When taking into account the potential risks of the study to the participants, I thought about whom I was interviewing and what I was interviewing them about. I did choose to utilize participants who are licensed mental health clinicians, and inquired about professional and not necessarily personal information. In general, this is a low risk study though one potential risk was that the participant could have felt embarrassed by what he or she said or revealed in the interview. It was possible that they may have felt like they did not have the information I was looking for which might have made them uneasy. As with most studies, there was a risk that the participants would feel like they were being judged which might have provoked a sense of fear. Participants at an agency might have felt like they did not have enough time to participate, but think that they should because others in the agency were taking part in the study. This could have added stress to their working environment. With this study there was a potential legal risk if the clinicians mistakenly reveal specific client information. To avoid this risk I discouraged

subjects from saying anything about specific clients and instead asked them to give more general examples.

As the study utilized only licensed mental health workers, who are well informed of possible resources should they have needed them, I did not provide a referral list for mental health support. All the information and data will be kept confidential, though as I conducted the interviews in the participant's offices or agency setting I could not guarantee anonymity as it is possible that other clinicians saw me arrive or leave and deduced participation from that.

Through participating in the study, participants had the opportunity to gain personal benefits. One of those benefits was the opportunity to discuss their own ideas and thoughts about working with this population. Very few clinicians have worked with the mentally retarded, so this provided the chance for the participating clinicians to share their specific experiences and accumulated knowledge. As this is often an unrecognized population, these clinicians might achieve personal gain from the opportunity to be recognized for what they do and how they contribute to the broader mental health field. Participants may also achieve benefits from gaining a new perspective on their work with this population. At the end of my study I have offered to return to the agency and private clinicians and disseminate my findings so that they may gain from the perspectives of other clinicians who work with the mentally retarded who have a psychiatric diagnosis.

As psychotherapeutic work with the mentally retarded is an under researched area, participants might gain benefits from participating in the development of knowledge that might be helpful to others, both outside and within the field, or increase general understanding about this population and how to work therapeutically with them.

Data Analysis

I performed the transcriptions of the audio taped interviews myself and did not make use of an outside volunteer or professional transcriber. After I had completed the transcriptions I next performed a content analysis and counted the specific content of the transcriptions. I looked for phrases (such as “CBT”, “directive approach”, “labeling”, etc.) and themes that I could pull out from the data. As I had full transcriptions I was able to go through several summarizations of the material, each time looking at what is not as relevant to the overall picture and reducing the data appropriately. After this process I went back and categorized the similar relevant material for further analysis. Additionally, I performed basic descriptive statistics with the demographic data that I gathered. To increase the reliability and validity of my research I utilized prolonged engagement with my interview subjects as well as peer debriefing and review. My research advisor helped me analyze the data that I gathered, however she did not have access to any data until all identifying information was removed.

For my study I guaranteed confidentiality. In order to do this I had to safe guard all identifiable information I collected. At the start of the analysis I removed names from the written transcriptions. Instead of names I used a number code to identify the subject for my own purposes. The list with codes and names is kept in a separate file cabinet from the transcriptions. The list with the clinician’s names and phone numbers is kept separate as well. I also keep the signed informed consent forms separate from completed

interview tapes. No information stored on a computer (such as the transcriptions and my research paper) has identifiable information attached to it.

When I prepare the presentation and publication of my research I will present the information and data about the participants as a group and not as individuals. If there are any identifiable vignettes or quoted comments I will disguise the identity of the contributor by removing or disguising the individuals name and any other identifiable information.

CHAPTER IV

FINDINGS

The purpose of this study is to describe the various methods clinicians employ to adapt their normal treatment strategies to best fit the special needs and requirements of a client who has both mental retardation and a psychiatric illness. The research questions are: (1) how do therapists adapt assessment, diagnosis, and treatment when working with an individual who has a psychiatric disorder and mental retardation? (2) What does treatment with this population look like? (3) What are some specific areas that must be addressed when taking into account their special needs stemming from their dual diagnosis? This chapter will present a qualitative analysis of the data collected from clinicians who work with individuals with mental retardation.

Demographic information was collected as part of the interview process. Amongst the twelve clinicians who were interviewed the average number of years since they had obtained their graduate degree was seventeen with a range from two years to forty-one years. The average number of years spent working clinically with the mentally retarded was seven and ranged from two to twenty-five years. Finally, clinicians were asked if they were trained in using any specific theoretical frameworks and if they currently adhere to any specific frameworks. Out of the twelve respondents, four were trained in a psychodynamic approach and eight claimed they had a “generalist” training. Currently, four clinicians reported adhering mainly to a CBT framework, three clinicians claimed to

use a systems approach, another three stuck with the generalist framework they were trained in, and a final two clinicians mainly utilized psychodynamic principals.

The interview consisted of thirteen questions that covered the areas of assessment, diagnosis, and treatment as well as issues of professional development and training. I will present the results of the qualitative analysis by reporting on the main themes that emerged.

Working with the Mentally Retarded

To begin the interview the first question subjects were asked was “what is it about the mentally retarded that drew you to work with this population?” Across the board subjects responded that they had, through various means, fallen into the work accidentally. Ten of the twelve clinicians who were interviewed stated that they became involved with this population through a supervisor who recruited them due to their previous work with either children or families. According to one respondent:

One of the supervisors at the time who acted as a liaison between DMR and [the agency] asked me because I was doing a lot of child and family work and he thought some of the skills might be transferable. So I started with one client and just gradually started adding more and I got really into it.

Another clinician noted the benefits of working with this population in her reasoning for continuing with this work:

I had worked with children primarily before and I thought I might be able to apply some of that work to this population. Also the supervisor here really got me into it and it was appealing since it was a different kind of challenge and offered a different kind of work – different client population. I also thought somehow it would be less stressful and in some ways it makes me feel more relaxed. Practically speaking, most of this population has people transporting them and that is really helpful in getting people to show up regularly so on a financial and productivity level that was attractive.

Surprisingly, not one subject stated that they had intended to work with this population while they pursued their degree or when they chose this career path. However, several of the subjects did state that though they did not initially intend to work with the mentally retarded, once they began the work they found they derived an increased level of fulfillment and enjoyment from it. According to one subject, “I hadn’t had any experience working with this population and never thought I would - but it fits me like a three piece suit”.

Differences Between Clients With and Without Mental Retardation

Respondents were next asked about the differences between a client with mental retardation and a more typical client that they might see in their practice. A majority of the clinicians noted that one of the main differences between these two groups were the issues of control and dependence/independence that are so common for individuals with mental retardation. One respondent pointed out that there is “a huge lack of self determination in the developmentally disabled population and that absolutely must be taken into consideration during assessment and treatment”. During the interviews the

subjects discussed how most people with mental retardation do not have the same level of choice and control in their lives as a typical person usually does. While a “normal” adult typically is capable of living on their own and making decisions about what they eat, their schedule, and other aspects of their daily lives, many people with mental retardation, especially those who live in group homes, are not afforded such a high level of independence and choice. One respondent stated that:

A huge part of what you see with clients with mental retardation, especially those in the DMR system is how little control they have over their lives. Instead of personal choice being forefront, everything is done by team. For instance, I was at this meeting yesterday where team members were discussing moving a woman from one group home to another due to staffing issues. This woman is my client and I know she will not want to move – she lives with friends, is close to the bus stop, and is comfortable there, but because of a staffing change they are going to move her from the home she has lived in for seven years without even giving her a say in the matter! Can you imagine how terrible and scary it must feel to be told that and not be able to do anything about it?

Other respondents described how the lack of self-determination does not just refer to living situations but extends to almost all aspects of their client’s life:

The one thing that really strikes me the most about clients with mental retardation is just how much loss of choice and control is involved. Loss in terms of choice, friends, family, jobs, living situation. Loss of life opportunities because of their mental disabilities – it’s really important for therapists to think about all these limitations they experience and the impact it has on their lives and their own identity.

Similar to the theme of lack of choice was the amount of daily frustrations that individuals with mental retardation have to cope with. Three-fourths of the clinicians

interviewed discussed the difficulties their clients deal with that individuals without mental retardation do not often encounter on a daily basis. Some of these issues include not being able to choose where you live or what you eat, having to rely on others for transportation, coping with stereotypes, language barriers, not always being able to be understood, and managing their own identity as a “disabled” individual. One clinician reported being continually taken aback by how much her clients coped with:

You know, I find it really humbling to work with these clients – my perspective on learning what helps with these types of disabilities and what they have to deal with on a day to day basis can be just mind blowing. It was to me and initially I was really shocked at all the levels of challenge they have, mentally, physically, medically, socially, transportation, I mean – the gamut. And the level of frustration they have to deal with and still function – my hat goes off to them.

In discussing this theme another respondent noted that a lot of the work she has to do initially is around what these daily limitations mean for their lives:

One of the things I think is most different about this population is the collective frustration with some of the labels they get and the restrictions put on them because of really frustrating disabilities that they have. So a lot of what I do at first is working around and on that disabled identity and what that implies for their life – wanting to feel capable and like an adult but then being told that you have to be watched 24 hours a day or that you need help with this, this and that – I mean it can just be so frustrating and demoralizing for them.

Another difference between clients with and without mental retardation is the decreased ability for abstract thought. A majority of respondents noted that one of the

main clinical issues they face when working with individuals with mental retardation is that the clients often demonstrate very concrete thought processes:

I find this population often has more difficulty describing experiences or thoughts the same way that “normal” people do. They seem to understand things in a different way. There is more of a focus on the concrete and there are fewer abstract abilities. I think there is often a difference in their ability to be able to reflect on themselves, for instance sometimes it is about being able to think things through, like ‘if I do this, then this might happen’. For example, someone might go out to lunch without any money to pay for it – so less insight and ability to judge cause and effect.

Another clinician noted a difference in her client’s ability for self-reflection:

I often find clients with mental retardation struggle with the ability for self-analysis. For example, one of my clients becomes really nervous in specific situations, and while he realizes his reaction, he has not been able to grasp what that anxiety is about – it is just too amorphous for him, so we have to work on that together and go through it very slowly, step-by-step.

The difficulty with abstract thoughts and the tendency towards concrete thinking has implications for therapeutic practice with this population. Some clinicians noted that they often have to listen to the concrete scenarios or situations their clients describe and then try to interpret the emotional response with them. For instance, one respondent discussed a client who kept saying he absolutely hated his roommate because he sometimes shouted, and through several weeks of interpretation and discussion he discovered that the client had a trauma history that he had been unaware of, that was

prompting him to feel unsafe and respond in a hypervigilant manner whenever his roommate screamed.

Differences in the Assessment Process

When performing an assessment of a person with mental retardation respondents discussed how it was important to be aware of certain differences about this population and keep them in mind throughout the process. Two related themes that emerged during the analysis were the behavioral presentation of symptoms and the difference in symptomology between typical clients and those with mental retardation. Two-thirds of those interviewed noted that frequently a therapist must assess the client's behavioral presentation in order to gain a greater understanding of their mental state. Often times due to cognitive and language limitations a client with mental retardation might be unable to describe a symptom they are experiencing so the clinician must be experienced enough to recognize and assess the behavioral manifestations that arise from psychological issues. One respondent described how she performs an assessment of a client with cognitive delays:

Often I find the client cannot provide as much information as a typical client could and that they also have a lot of trouble linking thoughts and actions, so I wind up assessing behavior and basic life skills more than I would with a normal client...Assessing life skills gives me insight towards their ability to function on a day to day basis and by paying attention to how they are acting in the session – their mood, affect, and what they are doing while they are talking with me – I can gain a good deal of insight into their psychological state.

Four-fifths of respondents discussed the difference in presentation of certain disorders such as post traumatic stress disorder, depression, anxiety, and mania.

According to one clinician:

You have to be very careful and thorough in the assessment of people with mental retardation because symptoms are not always the same as you see in the general population. For instance, not only is trauma much more frequent with this population, but it can look very different. You might get someone in for an assessment for what the caregivers describe as an impulse problem but when you go past the behavioral presentation you realize that it is really trauma or depression or anxiety – they can just look so different that it is easy to miss if you aren't taking your time or really paying attention – especially as these clients often can't verbalize what is going on for them.

While four-fifths of the clinicians stated that disorders commonly present themselves differently, a majority of respondents also claimed that psychological illnesses often present themselves in behavioral disruptions more clearly than in mood disruptions. One clinician noted that among people with mild mental retardation most disorders manifest themselves in a very similar way with the exception being that “certain disorders, especially those surrounding trauma, depression, and anxiety become more acted out and you see more acting out behaviors”. In fact a majority of respondents stated that frequently clients are referred for therapy not because they seem depressed or sad but because they are acting out and creating disruptions in the home or work site and their caregivers don't understand what is causing the change in presentation. One respondent stated:

Being able to put into words what is bothering them is really, really a challenge so a lot of assessment is putting out hypotheses when someone is brought in by staff for being a behavior problem and causing disruptions and you have to figure out what is going on in their lives. Is that behavioral change because they are struggling with depression, or a psychotic episode, or do they have traumatic issues, or do they just not like what is going on where they are?

When performing an assessment respondents repeatedly referred to problems that arise from language limitations which are common with this clientele. While a typical client might be able to tell you how they are feeling, often times in assessing a client with mental retardation you must instead rely on the presentation of symptoms and other outside information. As one clinician put it, “How symptoms manifest themselves is different so you really have to think more about the context of the symptoms to get the whole picture”.

Another theme that eight out of twelve respondents discussed was the importance of assessing the accuracy of self-reporters. Particularly, it is very common for this population to struggle with issues of time and place. As one respondent pointed out “a lot of times these clients are not able to give any history – particularly dates, places, and chronology are really tough”.

Additionally, respondents acknowledged that there may be inaccuracies in self reporting as a result of the system in which many people with mental retardation live. Whether intentional or not it is common in many group homes for individuals with mental retardation to be rewarded for good behavior and punished for any acting out or poor behavior. This system presents difficulties for clients who, due to cognitive

limitations, often generalize this practice into the therapeutic setting. According to one respondent:

You have to be careful with self-reporting from this population – for instance I have a client whose staff will report that he is sleeping all the time but he won't report that. He'll say 'oh I had a good day. I did this, this and this' and it will just never come up for him. This is especially important to keep in mind when you have clients who live in programs where you get points or things for doing the right thing and you don't get rewarded if you don't do the right thing. That mentality can carry over to therapy and they feel like they have to say the *right* thing, do the *right* thing, and basically look good. They just have that mindset from their staff and living situation that they need to please and they don't always get that therapy is a confidential place where they can express their real feelings and emotions.

According to many respondents, the ability of therapists to understand this difficulty with time and inaccuracies in reporting that are common amongst this population is exceedingly important. Without the understanding of this limitation it would be incredibly hard to gain an accurate understanding of what the client is, and has been, experiencing.

Useful Assessment Adaptations

Interview subjects were next asked what adaptations, if any, they have found particularly useful when performing an assessment of a person with mental retardation. Analysis of their responses revealed several overarching themes including the use of outside sources, simplifying their language, and being more concrete and structured during the assessment.

The main theme that every one of the respondents claimed to employ in their practice is using outside sources. As previously discussed, most clients with mental retardation struggle with self-reporting and thus, despite the fact that these clients are adults, clinicians say it is crucial to gain additional information from individuals who know the client such as other providers, treatment records, or care-givers. One clinician described the process as:

Because I can't really totally rely on self report from a client, especially as they are brought here and usually do not ask to come, one of the most important adaptations I use is relying on their network to fill me in on what is going on and what the client is struggling with. I do like to include the client in that process but if I only have them individually with no one else around I wouldn't know a whole lot.

Another important aspect of using outside sources is that it allows the clinician to gain a greater perspective on what their client is experiencing in their life outside of therapy. One respondent stated:

I really have to rely on other people to give me the broader picture. I get only a limited piece here and you know something horrendous may have happened but it is not on their mind when they come in so I may have no clue unless someone else calls me or comes in to tell me and then the client will go "oh, yeah" cause they want to deal with it, it is just not in their consciousness. You know, that was yesterday and time is very difficult with this population so I have to use a lot of outside resources.

Another adaptation that every respondent claimed they used was simplifying their own use of language and at times repeating what they said several times to make sure the message was fully incorporated. According to one clinician:

It is crucially important for me to make sure what I am saying is understood. So I need to use language that is at a level that they can understand and also is not intimidating to the client. I have found if I take the time to give examples of what I am talking about that it really helps back up the verbal message.

Additionally the clinicians noted that it was very important for them to not assume what they were saying was being understood and thus check in with the client about whether or not they were using the appropriate language. One respondent stated: “I have to be very careful about how I say things so they are understood and get feedback so we’re on the same page”. Another clinician agreed, “I find I need to be very concrete in what I say, not be too wordy, and not go too fast”.

Three-quarters of respondents also noted that adapting the assessment and treatment process by being more concrete and structured with their approach was helpful for this population.

I find with this population that I have to be more directive in my assessment and treatment approach. It’s really about providing that structure for the sessions and keeping them on track because if I were to ask something like ‘what do you want to talk about’ I might get five hours of talk about their Aunt’s dog. I do like using the humanistic approach and letting clients lead the sessions, but you have to be careful of that with this population – especially during an assessment when you are more likely to need specific information.

In addition to using more concrete language and structuring the sessions, clinicians also noted that using concrete assessment modalities was appropriate and useful for this population:

I often have to use more concrete tools during assessments as it is very difficult for people with mental retardation to quantify for themselves how they are feeling. If they happen to be feeling badly at that point, then frequently everything becomes bad. So I use things like the feelings rating scale where I go through and ask them on a scale from 0 to 5 how happy or sad or nervous they are. And often I get clients who say either five or zero – there is no gray area, so then I structure it again by saying things like ‘five is like when your dad died, so are you at a five right usually?’ and usually they can begin to see some middle ground at that point.

Though most respondents cited using concrete tools and structure, there were a few clinicians who disagreed. Instead, they preferred a more ‘humanistic’ approach. Two clinicians noted that they were wary of being too directive in the treatment as it took away a certain amount of control and empowerment from the client.

Working with the DSM-IV

Formulating a diagnosis can be a difficult process with any client, but due to the fact that clients with mental retardation do not always manifest “typical” symptoms coming up with an accurate diagnosis can become even more challenging. In this section clinicians were asked how they work with or adapt the DSM-IV criteria when developing a diagnosis for a person with mental retardation. One theme that emerged in over half of

the interviews was clinicians having to do more hypothesizing and interpreting with this clientele. According to one respondent:

I don't follow it very strictly. I get a ballpark diagnosis based on gut impression – whether or not some of the symptoms might be spoken about in the DSM-IV....Everything, mental illness, cognitive issues, neurological issues, sort of blend together and so I have to try and tease out a little bit what is going on – it is long and hard and it is a lot of educated guess work and trial and error.

Another clinician not only agreed with this viewpoint but took it one step further by stating:

Because it is so easy to misinterpret symptoms with this population, for instance someone might just see anger when it is really an anxiety issue, and it does take so much interpretation on the part of the clinician that it becomes more likely that someone with mental retardation could be diagnosed ten different ways by ten different clinicians.

While most clinicians agreed with this theme, there were several respondents who claimed that they did not like the concept of a diagnosis for any population as it can be very subjective so they avoided paying any attention to diagnoses for people with mental retardation at all except for the purpose of billing insurance.

Another theme that four-fifths of respondents mentioned was the potential use of the recently published Diagnostic Manual for Intellectual Disabilities (DM-ID). While it is still too new for many clinicians to have adapted into their practice, most clinicians were aware of it and were looking forward to being able to utilize a tool specifically geared towards individuals with mental retardation and a mental illness. Already a few of

the sampled clinicians have begun to use it and find it helpful – according to one respondent:

I have been referring more and more to the DM-ID and trying to spread it around amongst the other clinicians who work with this population. I have used it in several cases and have found it really helpful in sorting through questions like, ‘is this a symptom of this disorder or that’ as well as in trying to figure out how various symptoms present themselves in people with mental retardation. I have found it the most useful as a reference and a way to support and interpret the DSM-IV for this population.

Another clinician agreed:

I just recently had some training with the DM-ID and have begun to use it. I find it helps sharpen my lens in terms of what might be driving some of the sort of behavioral and symptomatic presentations that are common with this population.

As the DM-ID is still very new it has not reached all clinicians working with this population yet. However, those who have worked with it have reported finding it useful in understanding how disorders present themselves in people with mental retardation.

Relevancy of Diagnoses

Though clinicians who want to bill insurance companies are required to formulate a diagnosis for each client they see the accuracy and usefulness of diagnoses for people with intellectual disabilities has not been broadly discussed in the existing body of literature. To address this topic interview subjects were asked how relevant they find

diagnoses for people with mental retardation. The main theme that emerged, with the majority of respondents, was that diagnoses are most useful in explaining behaviors to caregivers and helping caregivers better support the clients, but are not as relevant when it comes to discussing cases and clients with other trained therapists. As one clinician described it:

I find there is a relevancy in being able to use it to help better explain behaviors, especially for the people who are directly caring for the client. For example, I had this one non-verbal woman whose staff was reporting she was tearing apart her room and being very loud – they were extremely frustrated with her because they thought she was just destructive, so being able to say that it was actually a manifestation of depression and giving it a name really helped them understand what was going on and better support her. Also in terms of trauma work – being able to explain that this person is very traumatized and he or she is not doing this or acting this way because they want to make your life miserable. We had one client who would really just explode and it was extremely frustrating and anger producing for their staff, but we were able to explain that this was a trauma reaction and there was a connection where they act out the trauma but the more they act it out, the more traumatized they were by it and it was spinning out of control. So being able to show that the presentation was not just a behavior or a behavioral problem but it was actually a reaction to something traumatic helped the residential staff understand and work to prevent it instead of just getting more and more frustrated by it and elevating the situation. So the diagnosis often helps the residential staff and family members understand what is going on, but when talking to other therapists – I don't find them helpful or useful. They can be too black and white.

Though ten out of the twelve clinicians agreed with this description of the relevancy of diagnoses, the two other clinicians described utilizing a diagnosis as a flexible guideline for their treatment process. According to one respondent:

I find the diagnosis helpful in terms of being able to sort of categorize and guide the service so you have an idea of where to go – there is a direction. Really

though, you have to think about just how “good” are the diagnoses for this population anyway. Hopefully the DM-ID and further research will make it a bit more relevant in terms of knowing what direction to go in and what the issues are in terms of the mental retardation as well as the mental illness.

Another respondent agreed and stated that she often used the diagnosis as an indicator of where to start and in assessing which symptoms were the most salient at that particular point in treatment.

Theoretical Frameworks

Overall the use of theoretical frameworks varied widely amongst the sampled clinicians. Respondents discussed cognitive behavioral therapy, psychodynamic work, attachment theory, systems theory, object relations, and self psychology amongst others. The most frequently mentioned framework was CBT with three-fifths of respondents discussing it. Clinicians claimed the benefit of CBT work is that it is often less abstract and more easily adaptable than other frameworks. One respondent described how she utilized the theory in practice:

One thing I like about CBT is the main premise that our thoughts really determine how we feel and the belief that if we change our behavior we can change how we feel instead of waiting for someone else to help make us feel better. I think that is very applicable with this population. For example, I try to teach clients that if they are thinking their staff member is bad and they don't like him then they are going to feel angry, but if they are really wanting to ask the staff member to do something differently that they can practice trying that and find that they have some efficacy. They can in fact influence the outcome of the interaction and they are not helpless or powerless. Those are strong messages for this population to be receiving.

Another respondent discussed how she simplifies the method of CBT by reducing all the charts and modifying the homework assignments but that she finds the basic tenants very helpful:

I find useful the idea about schemas and core beliefs. You know a lot of folks who work with the MR population believe they often have bought a bill of goods about who they are because of their disabilities and if we can work on changing some of that they might be able to increase their sense of choice and work on dismantling their disabled identity. That yes, they have this disability AND that is not all of who they are AND they can be whole people and make changes and have values and want the same stuff that everyone else does. So I find that CBT work can be very helpful in changing those core beliefs.

Though most clinicians reported finding the CBT framework very helpful for this population, there was a minority of respondents who actually found that it was not appropriate for people with mental retardation. One clinician explained:

I found trying to use a cognitive behavioral framework a little too difficult for this population. A lot of my clients have a really hard time identifying their thoughts in the moment and separating out the thoughts, feelings, and emotions. I just found it very frustrating to try and even attempt any of that sort of work with this clientele.

The second most discussed theoretical framework was psychodynamic practice. Analysis revealed that the majority of respondents described using a psychodynamic framework, though some referred to it as client-centered therapy. One respondent described what was helpful about this model:

What I like about psychodynamic work – though nowadays I have heard it more often referred to as client centered work – is how much I get to use myself with the client. So checking in with myself all the time and thinking about what is going on for me, what is being prompted in me and that helps me better understand what they are feeling and experiencing and how they might be relating to other people.

Similarly, another therapist described her choice of psychodynamic work:

You know, over the years I have tried almost all the theoretical frameworks out there, but the thing I have found most helpful is the psychodynamic work. Using that inside voice that is always monitoring what I am thinking, what I am feeling, what part of me is activated. Thinking about what does what I am feeling right now mean about what is going on for this client. If I am feeling anxious or sad or if I am falling asleep, what does that mean? I think it is extremely helpful for this population – especially as using that transference and countertransference helps get around some of the language and expressive issues that are so common in people with mental retardation.

Though the majority of clinicians agreed that at least at times they utilized a psychodynamic framework in their practice, one therapist did note that she did not find it appropriate for this population, “I think that people’s ability to reflect is too weak for psychodynamic work. Perhaps for multiple reasons they have not developed that ability”.

The third treatment option that many clinicians discussed was utilizing a systems approach. Though most respondents described this as a theoretical framework all used it to support psychodynamic, CBT, or other theoretical frameworks they were already using. One clinician stated:

You have to use a systems approach with this clientele because you often get to work through many different systems who are hopefully, supposedly involved with the client in supporting the therapeutic work. You have the job site, the group home or the family home, perhaps a PCA [Personal Care Assistant] – there are so many opportunities to extend the therapeutic work if you utilize them.

Most clinicians stated that you must tailor your choice of theoretical framework to the needs of each particular client, but that sticking with one framework per client was the most helpful. There were two clinicians however who claimed that they did not stick with just one approach per client but instead used a more eclectic model. One respondent stated, “From all my trainings I find I mainly use a big bag of tricks taking parts from different frameworks that work for this population”.

Treatment Modalities

Analysis of the data showed that there was no singular treatment modality for people with mental retardation, but instead it seems that this population benefits from clinicians who specialize in a wide gamut of therapeutic treatment forms. Some of the more frequently mentioned themes were group, psychodrama, art therapy, and narrative therapy. Though clinicians varied in their treatment approaches, every single therapist stated that they would not accept a client for group, psychodrama, or other non-individualized modality without seeing them one on one as well. Group therapy, which included group work in the form of psychodrama, was the most frequently mentioned modality with all but one clinician saying they utilized the format with their clientele. According to one respondent:

When we started using psychodrama and group work it quickly became evident how useful it was for this population. Research shows that Dan Tomasulo's way of using psychodrama in a group modality is very effective. The clients are so involved by being with each other and learning from each other, where they can understand, express feelings, be heard, be respected, help each other and give each other support – that's what it is all about. Really developing the social intelligence, containing feelings, and modulating behavior. They learn to talk and express and not act out – and they learn to be connected and have relationships.

Another discussed why the socialization aspect of groups is so important for this population.

I think groups are actually huge. Unfortunately, I think this population gets really isolated sometimes and either they don't want to socialize with each other because they don't want to get lumped into being "retarded" or they just never learned how for whatever reason. I think that combining therapy and being in a group of people learning social skills naturally through that process is incredibly helpful. I really do think groups are amazing. I know there are some people who want just individual and that's fine, but I don't really have anyone in individual that I wouldn't at least recommend to a group as well.

Another clinician agreed with this concept of healing through experiencing peer support and guidance from people who deal with similar day to day issues:

Group work has been very successful with a lot of mentally retarded people. Now clinicians are doing more group work and you can see the power in that because clients can experience themselves interacting, being validated, and having the opportunity to not feel like they are so different. Realizing that there are shared troubles, challenges, and just experiencing that socialization – it's simply excellent.

Another treatment modality that three-fourths of clinicians discussed using with this population was art therapy. Some clinicians found it to be a useful way to access emotions while other therapists felt like it was most useful as it took the pressure of having to “know” what to say or do off the client. One respondent described the types of art therapy she uses:

I have found that expressive art therapy is really helpful. I have a sand tray here that a lot of clients really enjoy working with. Other types of art therapy I have used are drawing, painting, writing, plus I keep a stack of magazines to make emotion collages which is always very popular. Anything really that is hands on so they are able to hold something and bring something home – it makes it very cool and exciting for them.

Another therapist discussed the positive aspects of having something for the client to do, the empowerment in creating something, and the benefits of working collaboratively:

As much as I can I try to be active with the client and have something for them to do with their hands. For example we do a lot of stringing beads – I find that it helps them have something to do so they relax more. Plus because they are creating something there is some mastery and creativity in it. They are not just sitting here feeling like they are under a microscope – instead we are both working on something together so it is somewhat parallel and collaborative.

Three-fifths of clinicians described the use of narrative therapy or journaling as a helpful treatment modality for this population. As not all mentally retarded clients are able to write on their own, therapists described using computers, pictures as words, and at times scribing as the client gives an oral account. One respondent stated:

With a lot of clients I make books – books about their lives or “goodbye books” if someone dies, sometimes we write cards if the client is worried about someone or having a fight with someone – it helps to put it down on paper and get their thoughts out that way. With a lot of clients now I use the computer for journaling. Some of them know where the letters are on the keyboard and are a little familiar with using it and I help them spell. A lot of their thoughts come out that way rather than sitting down face to face and telling me what’s going on.

Another respondent discussed how she used this narrative therapy to create a tangible document that retold her client’s life in a completely new and very productive way:

Lately I have been doing a lot more narrative work with clients – though I have really done a lot with one client in particular...we wanted to retell the story of her life in a way that was a bit more balanced instead of just the negative stuff. We would do a normal session but for the last ten minutes of every session she would dictate and I would write. We made a list of all the topics she wanted to cover. We wanted it to be positive but still realistic so she’d dictate really exciting things and some more neutral things. It has been really helpful for her to create a story that is her life but told in such a different way then she had previously understood her experiences.

Though not every modality was mentioned by every therapist – analysis showed a very large variety of treatment forms being used with this population. Some of these included couples therapy, family therapy with both the family of origin and if the client lives a group home “family” therapy including their staff members, vocational therapy, and grief work. One therapist even described an LGTB group that he runs for the mentally retarded. Therapists discussed how this population, like all populations, needs

access to therapists trained in a multitude of modalities as their presenting issues are almost always not simply about their mental retardation or cognitive delays.

When clinicians were asked what was useful about the modalities mentioned above various themes emerged. Two-thirds of the clinicians mentioned each of three themes including helping the clients get around language barriers, the creative modalities accessing different areas of the brain, and the empowerment aspects of group work, art therapy, and narrative work.

One therapist described how she found creativity, specifically making life-story books particularly helpful for her clientele:

The great thing about creating these books of client's lives is that they can look at it whenever they like, it is so empowering and affirming for them. This one woman had to start another book because the notebook was so full...she'd bring in pictures, she'd do poetry, she'd write about events or things that were upsetting or that she was proud of. She had a lot of self-esteem issues so I was trying to integrate what things she was good at, what her strengths are, and what she really enjoyed so she could look at it and say 'wow! This is me!' She really got a lot out of it – she would take it around and say "look how big my book is! My life goes on and on! Look at this!" She was so proud...it has just been amazing for her self-esteem.

Another clinician discussed how using creative tools to access different parts of the brain has been very useful with this population:

I have noticed that with a good deal of my clients with mental retardation it seems that their artistic expression – whether it be through writing or drawing or working with clay – it seems almost normal to high IQ level in some sense. I have a number of clients in whom their creative abilities seem to be higher than all their other capacities, so tapping into that is very helpful. For instance, I have a client who often can't get words out but she can draw me these amazing pictures

that really represent her feelings whereas she couldn't explain it verbally. I have another client who uses clay to make things and then explains what everything represents and use them to work through her feelings about the objects or people – it is amazing how much these different creative tools really help.

Respondents also discussed how both creative modalities and group work can be very empowering for clients with mental retardation. One respondent noted:

One thing I have found useful about these modalities are the clients really seem to get a sense of achievement from them – like they have really accomplished something. I also think they get a feeling of independence – like they can write or draw whatever they want.

Clinicians also discussed how being in a group helps the clients feel a sense of sameness. Instead of always feeling like they are different from everyone else, suddenly the intellectually “normal” therapist is in the minority empowering them with the sense of control and comradery. One clinician even described a group she was running where a mentally retarded client who had always been extremely timid in individual therapy was able to find his voice when supported by a group of peers:

He had been in the group for awhile and he was still pretty quiet but one session I was saying something and he must have felt I was off the mark and he found the strength to turn to me and say ‘You know, you don't know what it is like to live with staff – you have no idea what we are going through so please don't even go there’. I mean, I really felt it at that moment, that kind of realism and opportunity to support each other who are going through it – that's really, really powerful.

While the majority of respondents stated they found it helpful to use various treatment modalities with their clientele, there was one therapist who claimed that he only

liked to use individual therapy as it added more structure to the client's life and didn't require that they constantly reinterpret what therapy is in a different formats.

Success of Treatment

Clinicians were next asked about the overall results of therapy for individuals with mental retardation. The majority of respondents claimed that the overall success rate of psychotherapy in clients with mental retardation was comparable or even equal to that of more typical clients. According to one respondent:

I think the success rate is really on par. In terms of the clients with mental retardation I think while there are still limitations that therapy will not really change – they won't become more intelligent perhaps, but will they become more content? Happier? Not as symptomatic in terms of their distress level or their abilities to get along in their work and home environment, and will they lead a more satisfying life – I think so.

Two overarching themes did arise when respondents were asked in general how successful they found treatment with this population. One of the main ideas, noted by five-sixths of respondents was that the clinician must modify his or her goals and expectations. This need for modification relates to all areas of therapeutic work including assessment, diagnosis, and treatment. According to one clinician:

I think it is important for the therapist not to expect too much...I often need to really back off from expecting that things are going to move quickly say during an assessment, or the treatment pace itself – you really have to learn to slow down the pace – the high expectations of the pace of progress and how much you can achieve. I have to do that with other folks too, but much more so with this population. You know it helps me to look for little steps of gains and progress; for

example, if someone is having multiple really horrendous tantrums not expecting those tantrums to completely disappear. It is more like reducing the intensity and frequency or maybe increasing the person's awareness about them.

Another respondent discussed how you have to modify your expectations based not only on the cognitive limitations but also as a result of traumatic life experiences that are unfortunately pretty common in people with mental retardation:

It is hard because I think one of the things you are up against with the majority of this population is long histories of trauma. In a normal population when you have long histories of trauma you are going to see chronic mental illness, so while I don't always see leaps and bounds of change, I don't think I would in somebody "normal" who has been raped as many times as some of these women. You know I have seen improvements but you are up against a lot of really difficult stuff so it is important as a therapist to remember that and not feel like the client isn't getting benefit from the treatment just because they aren't progressing at as fast of a rate as you would like.

Another theme that emerged in three-fourths of the interviews was that successful treatment with people with mental retardation often takes longer than with a more typical client. According to one respondent:

One of the things that I find most different about working successfully with this population is that because of a difference in their cognitive processing and their style of learning and understanding that the pace of treatment has to be much slower and longer. I think that is a big struggle with a lot of therapists who don't work with this population normally – it takes longer so you don't see the progression and the progress as quickly as you might in another client.

One clinician discussed the importance of continual repetition and practicing with their clientele:

You know, treatment really does take longer with this population so being able to sit with that and be okay with it as a therapist and not get frustrated is really important...So just knowing that it is going to take a longer time and be in it for the long haul verses feeling like you have to have instant progress and gratification. And the other piece is – often times this population doesn't understand something on the first go around so repeat, repeat, repeat and practice, practice, practice because eventually it does get incorporated.

Overall, the majority of respondents felt that, though the clinician needed to make modifications on the pace and length of therapy, the eventual outcome compared well with that of more typical clients. One respondent however did note some more substantial differences between the therapeutic course and outcome of these two populations:

When I am working with someone who is non-disabled you can sort of see their trajectory and where they are going, but with someone with a developmental disability it is not really clear and they also plateau in terms of what they can get from therapy.

A similar view was shared by one other respondent for a total of one-sixth of the overall sample.

Clinical Awareness and Education

The final part of this study investigated issues of clinical education and professional development opportunities for therapists who work with individuals with mental retardation. Respondents were first asked how well they felt their clinical

education prepared them for their work with this population. In an overwhelming response, every sampled clinician claimed to have had very little to no training during their graduate study years. One respondent described her educational experience with this population as:

Zilch! Just zilch! Now this was almost thirty years ago, but speaking to other therapists who graduated more recently, it is still zilch! I mean, just not all. It is so sad and such an oversight. I have been working with NADD who is trying to develop a program to get graduate schools to offer more classes, talk more about this population, develop certificate programs, etcetera, so I talked to one of the heads of this agency and he said “but why would anyone want to do that?!?” and that was the attitude of a man who heads an agency that devotes an entire department to this population!! The stigma of this population and those who work with this population is still overwhelming in the mental health field. So none. None. None. None. I think for me, finding NADD has been really important for even just being able to talk about this population. For feeling heard and getting that support – for not feeling my work with this population is invisible or not valuable, because I think in most places that don’t have a special department for this population you can really start to feel marginalized. I mean – our whole society says this population is not valuable. Think about it – the closer you work with people with mental retardation, the less money you make – the less valuable you yourself are seen as.

Another respondent agreed and discussed how receiving her training in the field of social work made the omission of this population even more disturbing:

Not at all! And I must say the fact that they’re not mentioned really disturbs me – there is that whole invisibility factor and you wonder why they don’t count here. It really speaks volumes – the omission of these people, especially when you consider that Social Work education is supposed to focus on the underserved.

Another respondent talked about how she felt ill prepared for work with this population because she didn't receive that much education and training tools that were focused on this population. Along with four-fifths of the clinicians sampled she also stated that the lack of education was a severe oversight as this population has multiple different psychological needs and therefore should not be treated only by clinicians whose sole focus is this field:

It is hard to be able to say, observe someone, which is something you usually get during your training, but most schools don't notice or really work with this population...and it is a big oversight because I have been really amazed since I started working with this population how much variety there is – there is as much variety of psychological needs as there is with a more typical population, and most clinicians just don't know how to work with this population or are too nervous to try.

Another clinician agreed stating:

It is not like we only need specialists to do this work – I believe all therapists need to be aware of how to work with this population – and they aren't – because again, it is not like people with developmental disabilities only need support around one or two aspects of their lives. Like all people they might need a therapist who does couples counseling, or someone who does marriage counseling...really anything.

Though from various psychological disciplines and educational backgrounds the sampled clinicians all described an overwhelming theme of omission and ignorance of the mentally retarded at institutes for training those in the helping professions. Sadly, though respondents varied in when they got their degrees from the late 1970's to several years ago, educational progress was not evident.

Professional Development and Continuing Education

Though graduate level education and training does not appear to focus enough on this population, this study also investigated both the strengths and weaknesses of the professional development and continuing educational opportunities that are currently available for clinicians who work with individuals with mental retardation. Data analysis shows that when respondents were asked about the strengths of the professional development opportunities the main theme that emerged in eleven of the twelve interviews was that awareness of this population in the general mental health field was slowly beginning to increase due in large part to very dedicated clinicians who work with the mentally retarded. According to one respondent:

Well lately the organization NADD [The National Association for Developmental Disabilities] has been doing a lot of work. However, of course they are just one organization and can only do so much – especially since they are still small. But I think because people who do this work are so dedicated to it we have been able to have many experts actually come to this agency to help train our clinicians and to talk to them – to think these experts are willing to do that! That is unusual I think – that commitment.

Another respondent agreed with this sentiment and described how getting the chance to be around other clinicians who work with this population was a really important experience for her:

There seems like there is a lot of really strong commitment and investment amongst some of the researchers and practitioners who work with the mentally retarded to really try to make a difference for this population and make clinicians

aware of the mental health needs of this population. There is an enthusiasm and zeal and a passion. I find that humbling aspect is there when I go to Boston for a NADD conference for a couple of days or something. When we went it was just so invigorating and nurturing because we don't usually get that recognition and it really nurtured us and broadened our outlook.

One respondent did not describe the high commitment level of clinicians who work with this population as a reason for the increasing awareness within the clinical field. However, the subject did state that he felt that the work that NADD is doing is beginning to have an impact on the mental health field, "through the efforts of NADD awareness is slowly increasing, but it's still very early and the broader mental health system is not there yet".

When asked about the weaknesses of the professional development opportunities available for clinicians who work with this population the majority of respondents stated that there were simply not enough trainings available forcing them to "self adapt" trainings geared towards children, clients with autism, and other populations. According to one respondent:

I think the lack of adaptation of trainings for the MR population is frustrating. Though I guess it could be considered cool cause it is so cutting edge...so it is kind of neat to be part of this developing field, but it can be really frustrating also because, for example, since trauma is such a huge issue for people with mental retardation I really want to know about EMDR for this population and it is not 'here is the workshop for that'! You know – I might have to wait another ten years for that or rely on figuring it out for myself, which tends to be what I end up doing most of the time.

Another respondent described what she felt were typical problems in applying the trainings that she has found that focus on this population to her practice with mentally retarded clients:

Most of the trainings currently around are more focused on things like autism so I have to take them with a grain of salt and sort of adapt them for my work. There aren't really any that are specifically for the mentally retarded – and ones that are tend to be less clinical. So most of it is not helpful since it tends to be more focused on teaching specific skills and stuff like that. Most of it really feels – it's hard to say it in a nice way – condescending or obnoxious. Like this one training had these films and I would be insulted if I watched them. They play down to the population, that sort of thing.

Analysis of the data revealed that amongst the clinicians who claimed that there were not enough training opportunities based on this population, one-half of them felt like more attention was being paid to working with clients who are on the autism spectrum. According to one respondent, “I think the strengths are mainly around the autism/Asperger's population, where more trainings and support systems are popping up”. In describing this phenomenon one clinician stated that she believed the extra attention from mental health professionals might be attributable to the fact that “autism is not always retardation” thus making such clients more attractive to work with in a therapeutic manner.

Another theme that emerged amongst four-fifths of the sampled clinicians was that there are not enough therapists who are trained in this work, which often causes clinicians who do work with this population to feel marginalized and lack peer support and understanding. One respondent stated:

I think that for people who work with this population outside of an agency where a lot of people do it, there is a lot less support and collaboration. I could see the clinicians themselves feeling very isolated by this work because not many other therapists, especially those in private practice do it.

Another clinician agreed and pointed out that not only might the therapist become more frustrated, but without the opportunity for peer review and consultation they are on their own as to how to adapt treatment methods and practices:

For clinicians who don't have [the support of an agency who specializes in this work] I think it would be a lot more difficult for them to on their own understand how to adapt treatment for this population – so I guess working with the developmentally disabled would be more frustrating for therapists because of that. I think that is why I saw all those really good, successful clinicians who were not successful with this population.

In thinking overall about the educational and professional development opportunities there was an extremely strong theme amongst the sampled clinicians that not enough attention is paid to the mentally retarded by the broader community of helping professionals. One respondent summarized this belief by stating:

You look at course listings in institutions where mental health workers are taught and trained and there is nothing about this population. It is not even that it is underrepresented – it's not represented at all. I mean this is probably the most unrecognized population there is in our country right now – at least that is my opinion. Autism is looked at a little bit more – perhaps because autism is not always retardation, but for the vast majority of clinicians don't want to work with this population or don't even know anything about it. It is really very sad. Even when we have experts in here, the clinicians in other departments won't come because they don't feel it is worthwhile. This population is very, very marginalized – and by social workers, therapists, mental health workers – people

who should be advocating for them and helping them are the same ones who are ignoring them and in effect, sending the message that they are not a worthy population! It's very sad.

Almost all clinicians who were interviewed felt very strongly that not enough attention was paid by the mental health field to the psychological needs of the mentally retarded. Clinicians reported that not only do their clients feel marginalized, but they themselves often feel ignored and devalued by their professional peers. Respondents reported a strong desire for more clinical attention for this population and greater recognition and training opportunities for the therapists who work with the mentally retarded.

This chapter has presented the findings from interviews with twelve clinicians who work with clients with mental retardation. Themes were drawn from a qualitative analysis of the thirteen interview questions. Throughout the interview clinicians described several issues and characteristics that they found to be common amongst their clients with mental retardation. These traits include a tendency towards concrete thinking, an increased level of daily frustrations, lack of choice and independence, language barriers, and the tendency to “act out” symptoms and frustrations. Overall analysis of the data showed that to work with this population therapists must adapt how they perform the assessment, diagnosis, and treatment processes. Clinicians must also adapt their own expectations, goals, and the pace with which they conduct treatment with this population. Common adaptations include simplifying language, being more concrete, working with outside sources, helping care-givers better support and understand the client, and using special tools such as the DM-ID to better understand symptom presentation. Common

treatment modalities were group work, narrative therapy, couples and family therapy, and art therapy. These specific modalities were particularly helpful as they were frequently creative in nature, potentially bypassed possible language barriers, and were empowering to the clients. Analysis showed almost all clinicians felt very strongly that their clinical education, prior training, and opportunities for professional development poorly prepared and supported them in their work with this population.

CHAPTER V

DISCUSSION

The purpose of this study is to describe the various methods clinicians employ to adapt their normal treatment strategies to best fit the special needs and requirements of a client who has both mental retardation and a psychiatric illness. The research questions are: (1) how do therapists adapt assessment, diagnosis, and treatment when working with an individual who has a psychiatric disorder and mental retardation? (2) What does treatment with this population look like? (3) What are some specific areas that must be addressed when taking into account their special needs stemming from their dual diagnosis? This chapter will present an analysis of the findings, limitations of the study, and the implications of the findings for practice, education and training, and continuing research.

Analysis of the data gathered during this study reveals that therapists who work with individuals with mental retardation find the use of cognitive behavioral therapy, psychodynamic psychoanalysis, and systems work to be the most appropriate frameworks for guiding their treatment with this population. Most of the clinicians reported finding CBT very useful for this clientele as it is more easily adaptable and often requires less abstract thought than other theoretical frameworks. Psychodynamic psychotherapy was also a popular framework, though several clinicians preferred to call it “client-centered

psychotherapy”. While most clinicians found their clients with mental retardation were able to benefit from this type of therapeutic work several respondents found it inappropriate for this population as it was too abstract and required a high level of cognitive processing that their clients were not able to engage in.

The use of psychodynamic psychotherapy with clients who have mental retardation is largely supported by the existing body of literature within the field. Beail (2005) discusses not only the appropriateness of this framework for people with mental retardation, but also highlights the effectiveness of such treatment in dealing with common issues such as negative and distorted self-perceptions and understanding of how they fit into a non-disabled world which people with mental retardation frequently experience. His findings are supported and enhanced by many other experts within the field (Beail & Warden, 1996; Berry, 2003; Frankish, 1989; Gaedt, 1995; Hassiotis, 1999; Levitas & Gilson, 1989; O’Hara, 1993).

Likewise, cognitive-behavioral therapy has been widely applied to individuals with mental retardation. Though the body of literature supporting CBT work with this population is still significantly smaller than that of psychodynamic work, in recent years CBT with individuals with mental retardation has been widely increasing in popularity (Beail, 2003; Whitehouse *et al.*, 2006). Adapting CBT has proven useful in such areas as anger management, reducing problem behaviors, increasing self-esteem, and including care-givers in the therapeutic process (Taylor, 2002; Taylor & Novaco, 2005; Taylor, Novaco, Gillmer, Robertson, & Thorne, 2005; Willner, 2006).

This study’s findings suggest that systems work is another very useful tool for working with this population. Clinicians noted that most adults with mental retardation

have many different agencies and individuals involved in their lives. Examples of this include the Department of Mental Retardation, group living homes, care-givers, family members, job placements, and personal care assistants just to name a few. As so many individuals and agencies are involved in the day to day lives of their clients many clinicians felt that utilizing a systemic treatment approach was a natural course and made the most logical sense. Clinicians described involving others in the treatment through various means including creating and maintaining contact with the care-givers, getting outside information during the assessment and treatment process, and at times bringing care-givers, family members, and residential staff members in for therapeutic sessions with the client.

While many clinicians in this study agreed that a systemic approach was very useful with individuals with mental retardation, the existing body of literature does not frequently discuss the utilization of this framework. Several reasons for this could include that the literature has not caught up to more recent practice trends, insurance companies as less likely to reimburse for all the outside work that often goes along with a systems approach, and involving so many outside sources might take the focus off the individual client and onto whatever issues the caregivers or staff may have.

This study also explored the assessment, diagnosis, and treatment adaptations clinicians found most useful when working with clients with mental retardation. Analysis of the data showed that using outside sources to gain more information, simplifying language, being more concrete and structured during sessions, and using active treatment modalities such as drawing, writing, play therapy, and psychodrama were the most appropriate ways to adapt the therapeutic process for this clientele. These findings are

supported in the broader literature. Hurley *et al.* (1998) and Whitehouse *et al.* (2006) mention all of these approaches and also include being aware of the developmental level of the particular client and structuring treatment accordingly and paying close attention to issues of transference, counter-transference, and the maintenance of appropriate boundaries.

Limitations of Study

Methodological Limitations

This was a qualitative study with twelve participating clinicians. Most of the clinicians were drawn from one agency, and the rest were all located within Western and Central Massachusetts. Clinicians were chosen based on their employment at the local agency or through connections made with other participating clinicians.

The non-random nature of the sample, the relatively small sample size, and the limited geographical area in which the respondents practiced create potential limitations for the applicability of the research. The sample itself could be considered somewhat biased and relatively small in size. Additionally, due to the nature of the local community the sample was not as ethnically or racially diverse as might be the case in other areas of the country or world.

Another limitation of this study was that it did not interview the actual clients with mental retardation and therefore they did not have the opportunity to discuss what works for them, what doesn't, and why. Though more and more studies are beginning to be done on working therapeutically with this population very few, if any, have

interviewed the actual clients. This is due in part to potential language limitations of the clients themselves, but more importantly due to restrictions from the Department of Mental Retardation and Human Subject Review Committees who are reluctant to give permission to interview such individuals based on concerns such as limited ability to provide informed consent.

As this was a qualitative study and not a survey the results may be more specific to the individual clinicians interviewed and potentially not as applicable as a more quantitative study that would have included a greater number of clinicians. However, the benefit of a qualitative study such as this one is that it provides very rich and in-depth data. Another benefit of this type of study is that it is able to look at the underlying social context which may not be clear in a larger study.

Substantive Limitations

One of the major substantive limitations of this study is that the definitions of mental retardation and mental illness that were used may be different than those used in other research. For the purposes of this study the definition of mental retardation being subnormal intellectual functioning or development resulting from congenital causes, disease, or brain injury came from the DSM-IV (2000). In addition it requires that a person have an IQ of below 70, deficits or impairments in adaptive functioning, and an onset before the age of 18. As the DSM-IV is only widely used in the United States of America, different countries may have a different understanding of what constitutes mental retardation. Moreover, because clinicians were not asked to specifically provide hard evidence to support their assessments of their clients IQ or psychiatric diagnosis it

was not possible to verify the degree to which the DSM-IV definition of mental retardation or psychiatric disorder was valid.

Mental retardation itself is also a very broad term that covers a wide range of individuals and disorders. The classifications of mild, moderate, and severe mental retardation exist within the broader definition. Due to the large nature of the term there can be no definitive assessment, diagnosis, or treatment procedures that would be appropriate for use with every single person with mental retardation.

The term psychiatric illness is also extremely broad and not always consistent across research. Mental illness itself is a huge category with many different diagnoses, treatment courses, duration, and outcomes. For the purposes of this study any individual who was in psychological treatment with a clinician who met the inclusion criteria of the study was considered as a person who met the definition of psychiatric illness.

Implications of Findings for Practice

This study's findings about the experience of working therapeutically with individuals with mental retardation can help other clinicians learn how to work with and provide psychological support for this population. The findings reveal a parallel process that is rather common between individuals with mental retardation and the therapists who work with them. All the clinicians sampled discussed their clients struggles to live in a world where having a disability often makes them an outsider. People with mental retardation often feel disenfranchised in society and overlooked by our culture as a whole. One clinician discussed how her clients struggle with feeling invisible within the

broader community and when they are “seen” they are seen as a disabled person, not simply a person.

The sampled clinicians verbalized similar feelings about their own work with this population. They indicated they felt their work was not seen as valuable by their colleagues and that they felt marginalized within the therapeutic community. In concrete terms clinicians who work with individuals with mental retardation are often paid less, which implies that their work is less valuable. By making this parallel process more explicit and coming to understand the implications of such feelings we are not only better able as helpers to understand what our clients go through on a daily basis, but also perhaps become better advocates for change within the broader system. If more clinicians become personally aware of the stigma that comes from not only being mentally disabled but also working with the mentally disabled than perhaps the way we practice with this population and value them as individuals will begin to change.

Another practice implication of this study is the growing awareness of the Diagnostic Manual for Intellectual Disabilities and its use in treatment with individuals with mental retardation. As the manual has only recently been published it is still not widely understood how to use it when working with clients with mental retardation, and many clinicians have not yet adopted it into their treatment regime. Several clinicians in this study have begun to work with the manual as well as train other clinicians in its use. Respondents discussed how they use it to gain a better understanding of what is going on for their clients as mental disorders do not always manifest themselves in the same ways as they do in more typical clients. Though the DM-ID will not replace the DSM-IV, nor is it intended to, this study has shown how therapists who work with individuals with

mental retardation can use it to support the work they are already doing with the DSM-IV to gain a deeper and more in depth understanding of what their clients are experiencing and how they are manifesting their symptoms.

Implications for Education and Training

One of the most crucial findings of this study was the intense need for education and increased training opportunities for clinicians who work with individuals with mental retardation. Every single clinician interviewed stated that they had not received training in their masters programs in how to work with the developmentally delayed. The sampled clinicians were trained in several different therapeutic fields including psychiatry, social work, and mental health counselors and had been educated anywhere from thirty years ago to three years ago. Despite all of this variety, not one of the educational programs they attended offered course material on the special needs of this population. The respondents all claimed they initially felt unprepared and ill-suited for this work as a result of their lack of training and education. Additionally, the clinicians stated there were very few continuing education and training opportunities available for therapists who work with the mentally retarded. This dearth of education and training represents a serious oversight and negligence on the part of the therapeutic field. Research has shown individuals with mental retardation are as high as three times as likely to develop a psychiatric disorder and therefore even more in need of our clinical expertise (Hauser & Silks, 1997). By not training our clinicians to work with this population we create a situation where many clinicians are reluctant to work with a population of which they have very little clinical knowledge or experience with, and those who do end up in the

work often feel undervalued and overlooked by the field as a whole. We must, therefore, look to increase the amount of attention given to this population both at graduate schools and within continuing education forums.

Implications for Research

It is clear that greater attention needs to be paid to the special needs of this population. Institutions that train helping professionals need to devote more time and class resources towards teaching future therapists to work with individuals with mental retardation. As such, there is a need for more research into the most effective methods of providing this education.

Data from this study showed that all but one clinician fell into this work either accidentally or because a supervisor asked them to. As this research suggests that very few clinicians attend school with an intention to work with this population it might be helpful for a future study to interview graduate level social work students to gain a better understanding about their thoughts on working with this population. Questions could include, what percentage of them would be open to the idea of working with the mentally retarded? If they were asked by a supervisor to take on clients with cognitive delays would they feel prepared? What do they feel would better prepare them in terms of education, course content, and/or trainings? A study of this sort could be helpful in developing the knowledge base for creating educational curricula that include this population.

Another area of future research could be duplicating a study such as this one in different environments. Would variables such as geographic area, race or ethnicity of the

respondents, clients, and surrounding community, agency, and socioeconomic status of the community change the outcome of the study? Would the findings on what adaptations were useful be similar? A study that changes such variables is another possibility for future research to broaden the overall field of knowledge.

Individuals with mental retardation make up such a small overall percentage of our population that it is not surprising that they have been an overlooked population in the past. Due to cognitive impairments and related problems these individuals have not always been able to be effective self-advocates to get their concerns and issues heard on a large enough stage. As such, it may not be surprising that academia has been somewhat slow to respond to the concerns and special treatment issues that are inherent when working with this population. Recent research has made great leaps in beginning to investigate how we can better adapt to their needs, and it is my hope that my own study will help continue this newly formed tradition. By interviewing the actual clinicians who work with this population this study has implications for how we as social workers conduct our practice, how we modify and develop programming and theory, and how we can improve our own clinical education to include more course work that addresses the needs of these special people.

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APPENDIX A

SMITH COLLEGE SSW HSRC APPROVAL LETTER

January 15, 2009

Thalia Ghazey Bates
88 Round Hill Road, #3
Northampton, MA 01060

Dear Thalia,

Your revised materials have been reviewed and all is now in order. We are glad to give final approval to your study.

Please note the following requirements:

Consent Forms: All subjects should be given a copy of the consent form.

Maintaining Data: You must retain all data and other documents for at least three (3) years past completion of the research activity.

In addition, these requirements may also be applicable:

Amendments: If you wish to change any aspect of the study (such as design, procedures, consent forms or subject population), please submit these changes to the Committee.

Renewal: You are required to apply for renewal of approval every year for as long as the study is active.

Completion: You are required to notify the Chair of the Human Subjects Review Committee when your study is completed (data collection finished). This requirement is met by completion of the thesis project during the Third Summer.

Good luck with your very useful project.

Sincerely,

Ann Hartman, D.S.W.
Chair, Human Subjects Review Committee

CC: Joyce Everett, Research Advisor

APPENDIX B
INFORMED CONSENT FORM

Dear Participant,

My name is Thalia Ghazey Bates and I am in my final year of the Smith College School for Social Work masters program. As part of the program I am writing a thesis that involves performing research. The purpose of my study is to describe how clinicians work with individuals who are dually diagnosed with both mental retardation and mental illness. The study pays particular attention to how clinicians adapt assessment, diagnosis, and treatment for this population. I am also investigating the opportunities for professional development within this field. The data I collect will be used for my MSW thesis and presentation.

Participation in this study requires a one time individual interview that will take place at your office. Participants are eligible for the study if you have obtained at least a masters level degree and state licensure in a mental health field (LSW, LICSW, Ph.D., Psy.D., LMFT, LMHC, MD). Additional requirements are that you have worked with individuals with mental retardation and a mental illness, aged 18 and over, for at least one year. Questions will be about your work in the field, specifically regarding your thoughts on assessment, diagnosis, and treatment adaptations and professional development. At the end of the interview I will collect a small amount of demographic information. This interview will last no longer than 90 minutes. The interview will be audio-recorded and I will personally be performing the transcriptions of the tapes.

Potential risks to participation in this study are negligible, though the possibility of minor professional discomfort does exist. Due to a potential legal risk, specific clients or examples that would reveal a client's identity cannot be discussed.

Benefits of the study include the opportunity and space for you to discuss your ideas and thoughts about working with this population. As not many clinicians are trained in working in this population, you will have the opportunity to provide others in the mental health field with your accumulated experiences and knowledge. Financial and other forms of concrete compensation are not provided.

As a participant you can expect that the interview content will be kept confidential. Identification numbers or codes will be assigned to all transcripts, interview guides and field notes, rather than names. While you may discuss your actual participation in the study with others, I will keep that information confidential. In addition to myself, my research advisor will have access to the data. No one, including the research advisor, will have access to the data until all identifiable information has been removed. After I remove names and other identifiable information I will transcribe all tapes. No one else will have access to the tapes except me. In any publications or presentations that result from this study I will present the data as a whole and carefully disguise all illustrative quotes and vignettes. All data, including notes, signed consent forms, tapes, and transcripts will be kept in a secure location for a period of three years as required by Federal guidelines. All data stored electronically will be protected. Should I need the materials beyond the three year period, I will continue to keep them in a secure location and destroy them as soon as they are no longer needed.

Participation in this study is voluntary. You may chose to withdraw from the study at any time during the data collection process and may refuse to answer any questions without penalty. If you later decide to withdraw from the study you may contact me by phone or email no later than March 1st 2009. Should you choose to withdraw all materials pertaining to you will be immediately destroyed. Should you have any additional questions or wish to withdraw you may contact me by email TGhazey@email.smith.edu or by phone (413-250-8061). Should you have concerns about your rights, or any aspect of the study you are encouraged to contact me or the Chair of the Smith College School for Social Work Human Subjects Review Committee at (413) 585-7974.

YOUR SIGNATURE INDICATES THAT YOU HAVE READ AND UNDERSTAND THE ABOVE INFORMATION AND THAT YOU HAVE HAD THE OPPORTUNITY TO ASK QUESTIONS ABOUT THE STUDY, YOUR PARTICIPATION, AND YOUR RIGHTS AND THAT YOU AGREE TO PARTICIPATE IN THE STUDY.

Signature: _____.

Date: _____.

APPENDIX C

Interview Guide

Opening questions:

What is it about the mentally retarded that drew you to work with this population?

Probe 1: Could you tell me a little bit more about that?

Probe 2: There are far more jobs working with the non-mentally retarded, so what led you down this specific path?

What is it about a person with mental retardation that is different from a more typical client?

Probe 1: Could you tell me a little bit more about that?

Probe 2: For example, anger or language issues.

Questions about assessment:

What are the differences between how you would make an assessment of a person without mental retardation vs. how you would do it for a person with mental retardation.

Probe 1: Could you tell me a little bit more about that?

Probe 2: What are some of the biggest differences you see? Does that make it harder?

What adaptation, if any, have you used or found particularly helpful when performing an assessment of a person with mental retardation?

Probe 1: Could you tell me a little bit more about that?

Probe 2: What are you likely to pay particular attention to when doing such an assessment? If asked for examples I can give the common adaptation of involving caregivers or parents in the process for background information.

Questions about diagnosis:

How do you adapt or work with the DSM-IV criteria when developing a diagnosis for a person with mental retardation and a psychiatric illness?

Probe 1: Could you tell me a little bit more about that?

Probe 2: What makes the existing diagnostic criteria difficult to apply to this population?

In general, how relevant do you find diagnoses for people with mental retardation?

Probe 1: Could you tell me a little bit more about that?

Probe 2: How much bearing does a specific diagnosis have on the course of treatment with a person who has mental retardation?

Questions about treatment:

Have you found working with any specific theoretical frameworks particularly appropriate for guiding your work with this population? (CBT, psychodynamic treatment, attachment, etc.)

Probe 1: Could you tell me a little bit more about that?

Probe 2: What is it about that framework that is useful?

What specific modalities have you found particularly appropriate for work with this population?

Probe 1: Could you tell me a little bit more about that?

Probe 2: For example - individual work, group work, psychodrama, or art therapy

Why have you found that modality to be successful?

Probe 1: Could you tell me a little bit more about that?

Probe 2: How is that modality more successful than other options?

Generally speaking, compared to non-MR clients, how successful do you find treatment with this population?

Probe 1: Could you tell me a little bit more about that?

Probe 2: Do you find that treatment generally takes a different path or course with this population?

Questions about professional development:

How well do you feel your clinical education and prior training prepared you for therapeutic work with this population?

Probe 1: Could you tell me a little bit more about that?

Probe 2: What do you feel would have been helpful to prepare you for this work?

How do you feel about the educational opportunities for clinicians who are interested in this field? What about this experience really helped support you in your work?

What do you think are some of the strengths of the professional development opportunities that are available in this field?

Probe 1: Could you tell me a little bit more about that?

Probe 2: What type of training has been useful? What, in particular, was helpful about it?

What do you think are some of the weaknesses of the professional development opportunities that are available in this field?

Probe 1: Could you tell me a little bit more about that?

Probe 2: What type of training would be more useful? What has been helpful about this training?

Ending Questions:

I will end by collecting demographic information using the demographic questionnaire I created.

Overall:

Before I begin the questions in each section, I will inform the participant about the general category of information I am seeking (ex. “In the following section I will be asking several questions about you adapt treatment when working with this population”).

Probe 1 will be used when I want to elicit more general information from the participant. I will be consistent throughout the interview with this probe, using the same general statement to encourage more information from the participant.

Probe 2 will be used when I want to get the participant to focus on a specific aspect of the question. Use of this probe will vary based on the specific area of the question that I would like the participant to focus more on. Some examples are given for each question.

APPENDIX D
DEMOGRAPHIC QUESTIONNAIRE

1. What is your identified gender?
2. What is your age?
3. What specific degrees do you hold?
4. How long ago did you obtain your clinical degree? (in years)
5. How long have you been working clinically with individuals with mental retardation and a psychiatric illness?
6. Were you trained in any specific theoretical frameworks?
7. Do you currently adhere to any specific theoretical framework?