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Lauren Rosenblum
Trauma in Adults with
Developmental Disabilities: An
Analysis of Trauma Theory and
Behavior Modification

Abstract

This theoretical study explored the phenomenon of trauma in adults with developmental disabilities. The study examined adults with developmental disabilities' vulnerabilities to abusive conditions and systemic oppression, increasing the populations' risk of traumatization. The study analyzed trauma theory and behavior modification, comparing the prevalence and treatment implications of each theory on adults with persons with developmental disabilities. Furthermore, findings indicated that there were limitations in research and access to trauma-based therapy, while behavior modification was predominantly used as a treatment remedy. This report concludes with recommendations for the social worker and mental health fields.

TRAUMA IN ADULTS WITH DEVELOPMENTAL DISABILITIES: AN ANALYSIS OF
TRAUMA THEORY AND BEHAVIOR MODIFICATION

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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2011

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Chapter I

Introduction

Individuals with developmental disabilities have historically been subjected to marginalization, institutionalization, and maltreatment. Today, adults with developmental disabilities (DD) continue to struggle with issues of poverty and autonomy. A significantly higher prevalence of trauma (Davis, 1989; Mansell, Sobsey, & Calder, 1992), including abuse, captivity, and control exists in persons with developmental disabilities compared to persons without DD. Additionally, due to current institutional structures such as residential and vocational programs, many adults with DD have limitations in decision-making and mobility, which can lead to dependency and oppressive conditions. Unfortunately, literature on treating traumatized adults with DD is sparse, as most of the available research is characterized by behavioral management, rather than trauma recovery. In the absence of such trauma-centered data, a challenge to adapt trauma-informed therapy to the population remains. Although clinical treatment predominately involves behavioral interventions (Griffiths, Stavrakaki, & Sommers, 2002; Harris, 2010; Winter, 2002), several studies and theorists have presented non-behavioral methods of treating adults with DD (Curen, 2009; Dosen, 2007; Lloyd, 2009; Schneider, 1986; Schuengel, 2009; Turk, Robbins, & Woodhead, 2005; Upton, 2009).

The purpose of this thesis is to examine the phenomenon of trauma in the population of adults with developmental disabilities. Using Judith Herman's (1992) *Trauma and Recovery model*, a widely recognized and implemented treatment option, in conjunction with *Behavior Modification*, the more predominant intervention in this field, I will introduce and explore a more integrated approach to trauma-informed care for adults with developmental disabilities.

Developmental disability is a long disputed term with varying international and national definitions. Most common definitions of developmental disability state that the onset of the disability is rooted in childhood, with limitations in functioning, adaptivity, and intelligence. In this context developmental disability will be addressed as stated in the American Psychiatric Association (2000)

significantly below average intellectual and adaptive functioning with onset before age 18 years (DSM-IV-TR, 2000). General intellectual functioning is measured by an individually administered standardized test of intelligence that results in an overall intelligence quotient (IQ) for the individual. Significantly subaverage functioning is defined as an IQ score of 70 or below. Adaptive behavior refers to the effectiveness with which an individual meets society's demands of daily living for individuals of his/her age and cultural group. The measurement of adaptive behavior may include an evaluation of an individual's skills in such areas as eating and dressing, communication, socialization and responsibility. (p. 41)

The term *developmental disability* has gradually begun to replace the term *mental retardation*. The stigmatizing nature of the word retardation was initially recognized by organizations in Canada and countries throughout Europe, only changing in the US over the last decade or so (Harris, 2010; Griffiths et al., 2002).

Trauma, and its psychological affect on an individual, varies in how it manifests, and the way it is defined. The American Psychiatric Association (2000) defined trauma as an individual being

exposed to a traumatic event in which both of the following have been present: 1. the person experienced, witnessed, or was confronted with an event or events that involve actual or threatened death or serious injury, or a threat to the physical integrity of oneself or others. 2. the person's response involved intense fear, helplessness, or horror. (American Psychiatric Association, 2000, p. 467)

Posttraumatic Stress Disorder has become a nationally known condition, which originated in response to war veterans returning from duty with symptoms of trauma. The increased awareness of PTSD has in some ways shaped the way society understands the symptomology of trauma. Herman (1992) expanded on widely known definitions of trauma by using the framework of complex trauma. Herman's theory went beyond a single traumatic event, as she studied the prolonged effects of trauma on one's ability to affectively self-regulate and optimally continue development. The notion of complex trauma, in many ways, is a counter to the symptoms and responses predictable in the earlier diagnosis of PTSD. For the purposes of this paper, trauma will be characterized by Herman's complex post-traumatic stress disorder definition. Complex PTSD is specified by Herman (1992) as a person being subject to

totalitarian control over a prolonged period, such as being taken hostage or domestic abuse; alterations in affect regulation, such as persistent dysphoria or inhibited anger; alterations in consciousness, such as dissociation or depersonalization; alterations in self-perception, such as shame or self-blame; alterations in perception of perpetrator, such as acceptance of belief system or rationalizations of the perpetrator; alterations in relations with others, such as isolation or persistent distrust; alterations in systems of meaning, such as a sense of hopelessness or loss of sustaining faith. (Herman, 1992, p. 121)

Experience of trauma in the population of adults with DD transpires in a variety of circumstances including systemic oppression, domestic and relational abuse, and many other forms of maltreatment and neglect. According to Blatt and Kaplan (1966), institutionalization of those with developmental disabilities was comprised of locked, overcrowded, and unsanitary facilities with abusive and neglectful conditions (Blatt & Kaplan, 1966). The majority of such institutions officially closed in the later part of the 1970s and early 1980s. Many adults with DD living today were subject to such traumatizing conditions, and many of those adults continue to live under the control of the government with no therapeutic support for their past or current traumas. A large percentage of adults with DD currently live in residential, group homes and have limited choice of housemates, inconsistent staffing, and income levels far below the poverty line (Emmett, 2008). Many adults with developmental disabilities have very little independence, limited choice in their day-to-day decisions, and few romantic, intimate, or trustworthy relationships. Today, most educational systems maintain the presence of special education class rooms which continue the stigmatization, unequal treatment, and segregation of the developmentally disabled (Emmett, 2008). Overtime such circumstances have generated conditions such as learned helplessness, diminished self-esteem and self-worth, and may deprive individuals in this population of optimal interrelational and personal development. Feelings of disempowerment and learned dependency can also contribute to mental health concerns and social isolation. Additionally, statistics measuring the rate of sexual and physical abuse towards individuals with DD are significantly high (Davis, 1989; Emmett, 2008; Mansell et al., 1992). Davis (1989) reported that 75-85% of women with developmental disabilities

living in community-based residential homes had experienced sexual assaults. Soon after, Mansell et al. (1992) found that varying forms of sexual and physical abuse towards individuals with DD were commonly perpetrated by the individual's family members or caregivers.

As communication and access to a trustworthy authority may be compromised, trauma responses in adults with developmental disabilities may manifest differently than one sees in other populations. The manifestation of trauma can take the form of aggression, social anxiety and isolation, public display of sexual arousal, and depending on frequency of the abuse, such symptoms may be consistent with Herman's definition of complex PTSD. Communication for some adults with DD can be appear as less verbal and more physical than persons without such disabilities, and caregivers and staffing may need to be informed about varying trauma responses in order to detect predictable behaviors and reactions.

Theoretical and clinical implications associated with the treatment of trauma have progressed enormously in the past few decades. Herman (1992) seemed to set the stage for the nuances of understanding trauma and its psychological impact. Continued use and practice of Herman's recovery model has shown that traumatized individuals can move past the debilitating effects of trauma through therapeutic intervention. Trauma-centered interventions have not been implemented in the population of adults with developmental disabilities, though rates of abuse and traumatization continue to be exceptionally high. Practice guides on psychodrama and adaptive psychotherapy (Upton, 2009) have been minimally provided in today's treatment for adults with DD; behavioral intervention continues to be the most predominant. Since Herman's 1992 statements, many

practitioners and theorists have modified ways of treating traumatized individuals, including a psychoeducation guide called Seeking Safety (Najavits, 2002). Behavioral interventions for adults with DD rarely focus on the individual's trauma, but rather their challenging behavior. Due to the pervasiveness of sexual abuse and vulnerabilities to trauma in the population, the mental health and social work fields have not seemed to progress in its adaptation of treating traumatized adults with developmental disabilities. In order to fully consider the clinical treatment of trauma in adults with developmental disabilities, further examination of behavioral-based theories and Herman's (1992) recovery model will be explored and addressed.

Chapter two expands on the intersections between trauma theory, behavior modification, and adults with developmental disabilities. Chapter three addresses trauma in adults with developmental disabilities, including the challenges in identifying and communicating abuse. Chapter four consists of Judith Herman's interpretation of trauma and recovery, including implications for practice. Chapter five presents the origins and use of behavior modification. Chapter six includes a discussion of how to facilitate integration of the treatments, with recommendations for the mental health and social work fields.

Chapter II

Conceptualization & Methodology

Researchers over the past few decades have studied adults with developmental disabilities, and forms of oppression that exist in the population. Most literature associated with trauma refers to abusive conditions that were present throughout the era of institutionalization; fewer studies consist of today's societal and institutional barriers in the population. The majority of clinical studies focus on behavioral challenges in adults with DD, and interventions to decrease or eliminate undesired behaviors. The phenomenon of trauma in adults with developmental disabilities has not been a clinical or theoretical focus in research, even though the population has greater vulnerability of abuse and traumatization. In order to exemplify psychological responses of trauma in this population, one must to understand the social and systemic conditions that increase vulnerability.

Marginalization has been unfortunate aspect of the lives of most adults with developmental disabilities. Beginning in early adolescence, children with DD are likely to be separated from their peers as they enter the educational system. Educational segregation sends the societal message that children with DD are incapable of succeeding in public academic constructs, and not worthy of social inclusion. Individuals with developmental disabilities become stigmatized at a very young age, lessening their self-esteem and optimal social development (Valas, 2001). For many adults with DD, issues of marginalization continue throughout their lifetimes. Due to inequities in public

education and living in a society that values academia, many adults with DD face occupational difficulties and live below poverty line. Social isolation and dependency on care providers are also common issues that adults with developmental disabilities face. These conditions limit the individual's access to meaningful relationships, intimacy, and self-expression.

Current governmental structures to support adults with DD consist primarily of residential facilities (group homes) and day habilitation or vocational programs. Group homes tend to have anywhere from few to several residents in each home, allowing minimal input and control to each resident. The intention of most day habilitation centers is to assist adults with community integration and socialization, as most adults with DD have been deprived of such rights. Vocational programs often consist of assembly-line work, providing very low wages. Both group homes and day habilitation centers tend to be underfunded, with segregating conditions, and little community integration. As reported by Mansell et al. (1992), most instances of abuse are committed by people in positions of support, such as caregivers or staff members. Sexual and physical abuse is most often attributed to former institutions, though continues to be present within today's institutional structures.

Trauma in adults with developmental disabilities can be experienced, and manifested, differently than other populations. Mansell et al. (1992) reported

most persons with developmental disabilities demonstrate negative effects following abuse. The experience of the negative effects following sexual abuse is idiosyncratic, and often related to pre-abuse history, the understanding of the abusive event, the nature of the abuse, the relationship with the abuser, and post abusive experience. Some individuals may experience the event as abusive and even traumatic; other individuals may experience the event with less negative overtones, or misinterpret it as love because of a lifetime of learned tolerance to an

institutionalized abuse or misunderstood intentions... In either case, the person with the disability is likely to demonstrate behavioral symptoms. These symptoms are often not acknowledged, as they are not understood as reactions of trauma. Instead, the behavioral symptoms of trauma are 'poorly managed through behavioural control and sedation... the symptoms may never be appropriately assessed or treated' (Mansell et al, 1992, p. 406)

Sedation through excessive use of prescription medication, and interventions consisting of behavioral plans are supported and widely used methods of treatment in the population of adults with developmental disabilities.

Behavioral interventions, such as applied behavioral analysis, consist of individualized assessments that seek to eliminate maladaptive behavior, and increase socially accepted, adaptive, behavior. Harris (2010) described behavioral techniques as the promotion of adaptive and appropriate behavior. Harris mentioned that behavioral plans are available to target undesired behavior, as well as to reinforce positive behavior. Treatment plans are often developed to enhance and reduce specified behaviors in adults with developmental disabilities.

Using these techniques, the individual is rewarded when he or she does not show a targeted maladapted behavior. If the undesirable behavior does not occur within a certain time period, then positive reinforcement or reward is applied, such as verbal praise, food, or another reward. The goal is to facilitate self-control. (Harris, 2010, p. 148)

Behaviorally based treatment plans are often used without consistent therapeutic support, and are documented by staff or caregiver(s) involved in the individual's life. If behavioral intervention is the only available clinical modality for a traumatized adult with DD, the plan could be ineffective and re-traumatizing. Herman's (1992) trauma recovery model in many ways contradicts the use of behavioral interventions. Rather than using methods of behavioral or therapeutic control, Herman (1992) has emphasized using

validation and collaboration in healing relationships. Herman brought attention to the therapeutic value of relationships by saying

renewed connection with other people, the survivor re-creates the psychological faculties that were damaged or deformed by the traumatic experience. These faculties include the basic capacities for trust, autonomy, initiative, competence, identity, and intimacy. Just as these capabilities are originally formed in relationships with other people, they must be reformed in such relationships. (Herman, 1992, p. 201)

The concept of habilitation in this population is not a new development, though does not seem to function in a reparative and habilitative fashion. Herman's (1992) trauma and recovery model specified therapeutic stages that an individual goes through in order to regain a sense of empowerment and relational connection.

Chapter III

Trauma and Adults with Developmental Disabilities

In this chapter the focus is on the phenomenon of trauma in the population of adults with developmental disabilities. Persons with developmental disabilities (DD) have been considered one of the most marginalized and vulnerable groups to trauma in our society. Adults with developmental disabilities are frequently subjected to lives of stigmatization, social isolation, and discrimination. The social vulnerabilities that adults with DD face creates an increased risk of abuse, neglect, and maltreatment (Davis, 1989; Lloyd, 2009; Mansell et al., 1992; Monsfils & Menolascino, 1984). Presently, many adults with developmental disabilities are infantilized, and provided little opportunity to live socially integrated and autonomous lives.

In a society that values ableism and intellect, living with a developmental disability can be an enormous challenge. Historically, persons with DD were labeled as incapable, lacking the ability to form emotional or meaningful relationships, and were frequently removed from their families and communities. Social segregation for persons with DD has been apparent in the last century. Former structures created to facilitate exclusionary conditions included asylums, hospitals, institutions, and currently have progressed to smaller, mostly government-funded, group homes. Each of the above structures generates themes of dependency, control, and social disconnection. Societal conditions for adults with developmental disabilities have advanced significantly, yet continue to be oppressive.

Overview of Institutionalization

In order to understand the gravity of stigma and inequities in the lives of persons with developmental disabilities, the history of deprivation and trauma in the population must be considered. Prior to the 1970s the majority of persons identified as having a disability would likely be sent to an institution. Institutions were intended to restructure past oppressive conditions, as they were meant to be safe and protective government-run, schools. The schools were created to provide a more humane level of support and better contain any potential self-inflicted or societal harm to persons with disabilities. Due to economic difficulties, partially associated with the great depression and World War II, institutions were left with reduced resources and funding. This loss resulted in a deduction of staff, activities, and the initial objective of schools; later giving explanation to the decades of abuse and negligence that took place in the lives of people institutionalized (Blatt & Kaplan, 1966).

Prior to the decline of institutionalization, caregivers of children with DD were frequently labeled responsible for the child's disability, and physicians recommended that institutions were the best treatment option (Griffiths et al., 2002). This time period preceded the oppressive circumstances found in asylums and hospitals, though were in similar neglectful and abusive states. After a span of 30 years from their origins, institutions were documented as having overcrowded wards, with naked and half-clothed residents, and barren rooms (Blatt & Kaplan, 1966). Most institutions had unmanageable staff to student ratios and led to markedly inhumane, overpopulated, and traumatizing facilities. Many of today's adults and elders with developmental disabilities spent

portions of their lives in institutional settings. A large percentage of those individuals were rejected by their families, and left alone to make meaning of their abandonment.

The social movement to deinstitutionalize persons with developmental disabilities only came to fruition in the mid 1970s. The movement was prompted by the media exposure of neglect and abuse occurring in a well-known State School in New York. The institution was one of the largest in the country, and first revealed through video tapings of unclothed residents, many whom were sitting in their own feces and urine. The recordings were appalling, and received the attention of the state and federal government. The prolonged exposure of abuse that many individuals had to endure led to systemic change, yet resulted in little focus on the treatment of the population's traumatizations. As institutions were being shut down, the US adopted the Scandinavian concept *normalization* (Nirje, 1969) as an effort to restructure and normalize the lives of those institutionalized. Specificities to this movement are discussed in chapter five.

Stigma and Psychotherapy

The lack of therapeutic support in response to the national exposure to institutional conditions may be understood by the extensive history of stigma in the psychodynamic field. The psychodynamic community had, historically, considered persons with developmental disabilities unfit for psychotherapy, due to their limitations in language, abstract thought, and reflective capacities (Monfils & Menolascino, 1984; Schneider, 2010). Lower intelligence has also been proposed as a determinant of the effectiveness of self-reflective and insight-oriented therapy, which seemed to be a central reason for excluding people with DDs from this practice.

For many years it was believed that people with intellectual disabilities could not make use of psychotherapy. If a client was not able to communicate their experiences well enough using words, and to think about their thoughts, feelings, and behavior, then they were considered unable to benefit from therapy... And while the belief that this group should have access to effective emotional and psychological therapies has perhaps changed over recent times, what has perhaps not changed sufficiently is the therapists' abilities to make the therapy itself appropriate and accessible. (Upton, 2009, p. 29)

Societal judgment of persons with limited IQ capacity has been influential in the evolution of medical and therapeutic language. O'Driscoll (2009) reflected on institutions throughout England, stating that prior to institutionalization persons with developmental disabilities were labeled as "idiots", and likely ended up "in the workhouse system where the best they could hope for was benign neglect" (p. 16). Much of the pathologizing language from European countries was used in the US, including term idiot. Medical and psychological terminology for persons with DD has contributed to stigma and marginalization of persons with disabilities. Pathologies created for the population has ranged from idiot and moron, to mentally retarded and currently, or as for now, intellectual or developmental disability (Harris, 2010; O'Driscoll, 2009).

Negative connotations have been associated with most diagnostic labels created to depict people with developmental disabilities. Each label seemed to reflect both the attitudes of the general public of the time, and the beliefs perpetuated by authorities in the medical and psychological fields. The degradation and dismissal of persons with developmental disabilities has been longstanding, and has provided some meaning to the neglect of research and minimal therapeutic treatment in the field today.

Similar to diagnostic challenges, efforts to socially integrate and deinstitutionalize persons with developmental disabilities have not been without flaws. The movement to

assimilate persons with DD into community-based settings involved transitioning those institutionalized into smaller residential group homes. In theory, the community integration movement was a national effort to mimic the lifestyles and homes of the norm. The formation of day habilitation and vocational programs were built in respect to providing persons with DD a sense of purpose, daily structure, and employment. Adults with DD living in government-supported residencies have received annual Individual Support Plans (ISP) to document their personal needs and desires. ISPs have been necessary to help facilitate choice and autonomy for residents, though are not legally bound, leaving little repercussion to government structures if the plans are not successfully met.

Since the normalization movement, many problems that arose in institutions have surfaced in today's services. Staffing within group homes are frequently under-supported and undertrained, with residents, predominantly living below poverty line.

Service providers are under funded with unrealistic staff/ client ratios. Providing service to someone with mental health needs in addition to his/her developmental disability is seen as time consuming, and may take resources away from other clients in need. Certainly, those with a dual diagnosis require more support, but a significant contributing factor is a lack of education. If the provider does not have trained staff to screen, assess, and plan interventions and integrated supports for the individual, then much more time is spent dealing with the inevitable crisis that will develop. Of course, these crises will tend to emotionally affect the entire client base that is in contact with the person in crisis, creating even more requirements for staff interventions. Education can be very effective in alleviating these crises, and in handling it in the most effective way possible. (Griffiths et al., 2002, p. 234)

Due to such challenges, residential facilities tend to provide minimal opportunity for residents to make their own decisions or preference over their day-to-day activities.

Morin, Cobigo, Rivard, and Lépine (2008) found that “1.2–27% of persons with ID have

unmet mental health needs, and that 6.2% are on waiting lists for mental health services, compared to 2.9% of the general population” (p. 185). Although the level of abuse and neglect has significantly decreased since institutionalization, elements of marginalization, dependency, and economic and social disparities remain.

Vulnerabilities to Trauma

Trauma in the population of adults with developmental disabilities has been difficult to identify, as limitations in research, communication, clinical awareness, and available treatment have all been factors in preventing the reporting of abuse. Clinicians and support staff often attribute behavioral concerns to the person’s disability, overshadowing their consideration of any trauma symptoms. Trauma commonly has manifested within interpersonal conflicts and emotional dysregulation, and is often labeled as challenging behavior. Prolonged neglect, emotional, physical, or sexual abuse, can all cause forms of traumatization. The lack of training provided for clinicians of trauma symptomology in adults with developmental disabilities likely contributes to the shortage of data and treatment tools in the population. Researchers studying the dual diagnoses of mental health and developmental disability have gained momentum (Griffiths et al., 2002), though remains insular in disability specializing clinics. Advances made in the clinical treatment of adults with DD are difficult to access, as treatment adaptations have not been integrated in mainstreamed mental health facilities.

Terminology presented in the following research may refer to persons with developmental disabilities as having an intellectual disability (ID). In this context, ID acts as an interchangeable term to the definition for developmental disability. Mansell et al. (1992) wrote about the increased likelihood of sexual and physical abuse towards

persons with development disabilities, and the aftermath of negative psychological symptoms due to trauma exposure. Mansell et al. described

the person with the disability is likely to demonstrate behaviour symptoms. These symptoms are often not understood, nor treated effectively as abuse reactions. Rather, symptoms can be poorly managed through behavioural control and sedation and the reason for the symptoms may never be appropriately assessed or treated. (pp. 425-426)

Since Mansell et al. many theorists and researchers have proposed the need to further explore risks of abuse and maltreatment in adults with developmental disabilities (Davis, 1989; Morin et al., 2008; Turk et al., 2005). Several clinicians indicated limitations in preventing the abuse of persons with DD due to the lack of research and clinical training (Llyod, 2009). A national report by the APA Council of Representatives in 2003 found that children with developmental disabilities are “two to three times more likely to be maltreated than are children without disabilities in their homes and in institutions” (APA, 2003). One recommendation in the 2003 report was for the inclusion of children with disabilities in annual federally funded research on child abuse, as children with developmental disabilities had been excluded from national research on child abuse. As of today, constraints exist in our understanding of trauma in adults with developmental disabilities. Possible reasons may be due to divisions in research and mental health arenas between those with and without disabilities, stigma within the psychotherapeutic field, economic challenges, and current behaviorally-based treatment modalities supported by government structures.

Davis (1989) found that children with developmental disabilities are over 3% more likely to experience physical or sexual abuse or neglect than children without disabilities. Most existing research (APA, 2003; Davis, 1989; Mansell et al., 1992) shows

similar increased risks for abuse in the DD population, mostly beginning in childhood. Researchers have also showed that there are not well-developed or implemented therapies for trauma recovery available to adults with developmental disabilities (Dosen, 2007; Monfils & Menolascino, 1984; Turk et al., 2005). Such implications may very well mean that a considerable amount of today's adults with developmental disabilities are living with histories of trauma, without receiving treatment or recognition of their suffering.

Craig, Withers, Craig, Hatton, and Limb (2002) referenced a study examining the reasons for mental health referrals among persons with developmental disabilities. Craig et al. stated that out of 92 participants, most of the people were referred for an assessment, behavioral issue, or mental health concern, with only one referral being about coming to terms with having a disability. Two of the suggested explanations for the absence of referrals based on identity were that service providers did not see identity conflicts as a concern or that providers refrained from the topic of identity to minimize their personal discomfort (Craig et al., 2002). "It is clear that stigma has a major impact on people with intellectual disabilities and that service-providers as 'significant others' can play a role in maintaining stigma either by collusion or denial" (Craig et al., p. 63). Craig et al. (2002) also referenced a study conducted by Jahoda et al (1988) to illustrate the affects of the DD label on a person's self-concept.

They found that all their participants showed an awareness of the stigma of this label. They found that there were two main ways of managing this stigma, either to distance oneself from the label and associated stigma by describing oneself as similar to people with non-intellectual disabilities or to do so by stating ones difference to more severely intellectually disabled individuals. (Craig et al., 2002, p. 62)

Turk et al. (2005) presented two case vignettes examining PTSD symptoms of a 13 year-old and 25-year-old with developmental disabilities. Both cases involved car accidents, with each person studied experiencing post-psychological symptoms. Both individuals showed signs of traumatization, including hypervigilance, reenactment of the event, feelings of unsafety, nightmares, and aggressive behavior. Turk et al. characterized both individuals as having PTSD, and spoke to the challenges of recognizing trauma-symptoms in persons with DD.

Usually diagnosis relies on detailed history of the event and experiences post-trauma, yet ID and communication difficulties hinder descriptions of thoughts and feelings. Hence PTSD will often go unrecognized with symptoms misattributed to other problems, or simply labeled as “challenging behavior.” (p. 873)

The process of diagnosing PTSD in those without disabilities would likely be to conduct a psychological assessment of the individual, obtaining a history of the client before and after the traumatic event occurred. Recommendations for diagnosing persons with DD are mostly congruent to those without disabilities, though involve a more detailed understanding of client’s specific disability. Turk et al. (2005) noted that individuals with Fragile X Syndrome tend to have increased anxiety and hand-flapping. Turk et al.’s recommendation demonstrates the importance of understanding the behavioral and psychological characteristics of a person’s disability, as those symptoms need to be differentiated from any behavioral responses to trauma. Currently, there are wide divisions between mental health centers that offer disability services, partially due to distinctions in government funding. The lack of integration in services limits the clinical knowledge of how to support persons with disabilities, and specifically how to

therapeutically treat those who have experienced trauma (Craig et al., 2002; Dosen, 2007).

Communication styles resulting from a disability may be another contributor to the lack of reporting, statistics, and acknowledgement of abuse in the population of adults with DD. Brackenridge (2010) found that self-reports of abuse of individuals with developmental disabilities revealed that the majority of reporting showed a lifetime of trauma. Several of the reports were found to lack details, and no information was found that suggested trauma-informed assessments or therapeutic interventions (Brackenridge, 2010). Since communication style and self-expression differ among individuals with developmental disabilities, therapeutic interventions will likely vary.

The communication of trauma from persons with developmental disabilities may appear different from persons without disabilities, and therefore go unnoticed. Communication may be expressed in the form of behavior such as increased aggression, avoidance of certain stimuli or places, unsoothable crying, or increased impulsivity and self-injury. Communication through behavioral expression requires attuned support staff and clinicians, trained to notice behavioral trends associated with trauma. For example, it is important to understand if behavioral changes occur when the individual goes to a specific place or sees a specific person, as these behaviors can indicate where the abuse may have originated. In many cases, behavioral responses to trauma are mislabeled as defiant, which likely leads to the implementation of a behavioral plan. In these circumstances, behavioral plans overshadow the only way survivors may know how to communicate that they have experienced trauma.

Survivors of trauma often internalize their abuse, holding their experiences in secrecy. Prolonged, or multiple instances of abuse can result in isolation, interpersonal distrust, diminished self-worth, and disempowerment. Because adults with developmental disabilities are vulnerable to a marginalized and oppressed position, lack of entitlement or self-worth may further inhibit them from seeking support. Sexual expression in adults with DD may be dismissed by residential-staff or caregivers, which may prevent victims of sexual violence from recognizing a sexual act as abusive. “Notions about asexuality have prevented many caregivers from acknowledging potential sexual abuse risk and have delayed the implementation of abuse prevention strategies, such as educating staff to be able to detect sexual abuse” (Mansell et al., 1992, p. 406).

Self-injurious behavior from survivors of trauma is a common way to express and cope with traumatization. Cutting or physically harming oneself often acts as a way to control, relieve, or communicate trauma, especially for those persons with DD who are non-verbal communicators. Because of the vulnerability to trauma in children (APA, 2003), with developmental disabilities, many self-injurious behaviors could originate from an early age in the person’s development. Attempts to cope and communicate trauma, therefore, may follow persons with DD throughout their adolescent and adult lives. Increased susceptibility to abuse or neglect in institutional settings may also signify that much of the adult population with developmental disabilities have been exposed to one or more traumatic events in their lifetime. Trauma-centered therapy for this population is necessary to alleviate symptoms of, and help treat, traumatization.

Prevalence of Research and Therapeutic Practices

The lack of available therapeutic support for adults with developmental disabilities may be attributed to discriminatory stereotypes about the population. Stigma towards persons with DD is present in most of today's social realms including educational, occupational, medical, and mental health systems. As previously mentioned, segregated conditions in mental health have historic roots within the psychodynamic field (O'Driscoll, 2009; Upton, 2009), suggesting that persons with DD were incapable of introspection and reflection, past criterion for psychotherapy. O'Driscoll (2009) offered the notion of *disability transference*, as the clinician's "over-identification with intellectual disability, ...a complex mix of shame, guilt, rage, and hatred" which tend to overpower "feelings of pride, joy, and love" (p.23). Clinicians' projections of shame or helplessness towards persons with DD may be another factor in the scarcity of trauma-based therapies. Clinicians' may also perceive their inability to cure a client's disability, or measure therapeutic progress, as clinical failures. O'Driscoll labeled the clinician's frustration and resistance to clinically treat persons with DD as the clinician's "narcissism being under attack" (p. 22). Many of today's clinicians' opposition to practice therapy with persons with DD may be due to O'Driscoll's interpretation of disability transference, and shortages in training and adaptations for such therapy. Although improvements had been made on therapeutic treatment for adults with developmental disabilities, adults with developmental disabilities remain underserved and given less clinical attention than mental health facilities for persons without disabilities.

Although limited, psychotherapeutic treatments had been studied and successfully implemented on a national and international level (Lloyd, 2009; Morin, 2008; Turk et al.,

2005; Upton; 2009). Research on adaptive therapeutic treatment, such as art therapy and psychodrama had shown to be effective in facilitating communication and trauma recovery.

Turk et al.'s (2005) cases (previously noted) illustrated examples of two individuals with developmental disabilities whom developed classic PTSD symptoms following a traumatic event. Lloyd (2009) presented a case of a woman with a developmental disability who endured a lifetime of abuse, abandonment, and pain. Lloyd described "Susie" as presenting to treatment with cloth-wrapped hands to protect her body from self-injurious behavior. Susie's mood fluctuated between having a smile that appeared "forced" and "blank" to crying inconsolably. Lloyd (2009) stated the client's history:

For Susie, her place in the world was a series of abusive fictions. She was abandoned by her birth mother and brought up by her aunt, whom she believed to be her mother. Her uncle, who she believed to be her father, abused her sexually and physically. She was reclaimed by her birth mother, who she thought was her sister, and abused by her stepfather, who she thought to be her brother-in-law: a nightmare tangle of lies and abuse. Eventually, when she told her mother of the sexual abuse by her stepfather she was disowned and thrown out, as her mother preferred to keep her allegiance to her abusing partner and not to her daughter.

When she began therapy she was in the habit of changing her name from week to week - both first and second names - so that neither she nor I would ever know who she would feel herself to be that day. (p. 65)

Throughout the therapeutic process, with time and consistency, Susie seemed to form a more defined and integrated self. Susie's self-injurious behavior, and prior way of communicating her pain, terminated. "Her recurrent sore throat and loss of voice, which has been extensively investigated, disappeared after she had, over many months and very haltingly, described how her stepfather would blow cigarette smoke into her mouth as he raped her" (Lloyd, 2009, p. 65).

In therapy, Susie began to journal all of the abuse that she had internalized and kept in secrecy, and decided on a permanent name. Eventually, she was able to move into her own living space.

On first moving into her flat she described, very movingly, going to buy a ‘teapot for one’: she had for so long been in institutions where all of life was communal – even the teapot – that having something of her own was miraculous. (Lloyd, 2010, p. 65)

Upton (2009) challenged past notions of persons with developmental disabilities being unfit candidates for psychotherapy. Upton acknowledged the clinical progress made for adults with DD in therapeutic field, though suggested that less progress has been made in “the therapists’ abilities to make the therapy itself appropriate and accessible” (p. 29). Upton recognized that self-reporting and narrative-based therapy might pose a challenge for many people with difficulties in language, memory, and forming cognitive connections. Upton stated that assisting clients with DD in self-expression, and alternative ways of communicating their feelings is an important therapeutic adaptation. Upton (2009) emphasized that

...one’s self-expression is deeply embedded in one’s relationships to other people. ...The therapist will encourage the client’s self-expression until these troubles reveal themselves and can be understood. Thus, the dialogue and the relationship to the therapist nurture the client’s self-expression, and in turn self-reflection. (p. 30)

Upton recommended the use of alternative therapeutic modalities to harness self-expression, and trauma recovery. Upton labeled two “creative approaches,” the first was “embodied expression,” such as whole-person movement, dancing, and role-playing; the second was “projected expression”, the act of projecting one’s feelings onto external objects, which includes painting, writing stories, and poetry (p.33). Each of the above

interventions are alternative therapies to direct communication, and helpful for persons with DD living with trauma.

The DD population is heterogeneous in nature, as biopsychosocial factors, levels of adaptation and functioning, and IQ capacity varies among individuals. For persons with severe developmental disabilities, social disparities and injustices significantly increase. Many of these individuals are dependent on caregivers and have more apparent communication impairments, which seem to exclude them from most therapeutic adaptations made for persons with moderate or mild DD.

...people with severe intellectual disabilities may still find themselves as a minority within a minority. Current research tools are not equipped for the challenge of analyzing the changes made through therapy with those whose verbal and receptive communication skills are severely impaired. The benefits of the therapeutic process are felt significantly by the patient but may be extremely difficult for a researcher—or, I suggest, an analyst—to discern. (Upton, 2009, pp. 45-46)

Isolated efforts in research and psychotherapeutic treatments for adults with developmental disabilities have been essential in dispelling stigmatization in the mental health field, though have not made enough progress to prevent the risk of traumatization. Researchers and clinicians have shown significantly higher risks of abuse and maltreatment in the population of persons with DD, while mental health options are largely nonexistent, or inaccessible. Social change, through the deinstitutionalization movement, was an important feat, while therapeutic adaptations and trainings for clinician's have not been adequately integrated to support persons with DD whom have experienced trauma.

Chapter IV

Trauma and Recovery Model

This chapter will cover Herman's (1992) definition of trauma, and treatment recommendations for how to best clinically support survivors of trauma. The most recognized diagnostic reference for trauma continues to be defined through the criterion of Post-Traumatic Stress Disorder (PTSD). PTSD most accurately represents victims of singular, traumatic events. Most often the victim is left with symptoms of hypersensitivity, sleep disturbance, flashbacks of the event(s), and various depressive indicators (APA, 2000). Herman (1992) identified three categories of symptoms common to PTSD: "Hyperarousal reflects the persistent expectation of danger; intrusion reflects the indelible imprint of the traumatic moment; constriction reflects the numbing response of surrender" (p. 35). For victims of multiple or prolonged traumatic events, it appears as if symptoms manifest in complicated and developmental ways.

Herman (1992) put forward an alternate view of how to diagnostically characterize trauma, than diagnoses previously defined by the American Psychiatric Association. Although singular traumatizing events occur and frequently have significant psychological repercussions, that type of trauma does not capture the range of traumatization that exists with prolonged victimization. The *trauma and recovery model* by Herman (1992) provides an enhanced illustration of traumatization-- one on a continuum that spans from a singular traumatic event to prolonged or repeated captivity and victimization. Whether trauma is perpetrated by someone personally known to the

victim, the result of a natural disaster, or an unpredictable tragedy, symptoms tend to manifest in an overall similar fashion. Most survivors of trauma experience a loss of power, autonomy, and sense of choice, which may result in altering their perception of safety and self-worth. Individuals affected by trauma most often possess feelings of hopelessness and worthlessness, and many confine their traumatic experience to secrecy. The symptoms of trauma are not glamorous, and can be highly stigmatizing in the mental health field. Behavioral disturbance, emotional dysregulation, and interpersonal difficulties are a few ways trauma can manifest. Traumatization often interrupts and challenges the formation of intimacy and trust within relationships. When trauma reoccurs in the form of chronic abuse or harm, characterological changes may begin to affect the survivor's personality development. In this examination, Herman's theory of Complex Post-Traumatic Stress Disorder, along with her treatment recommendations will be used to understand trauma in the population of adults with developmental disabilities.

Trauma and Recovery Model

Herman (1992) referenced stages of victimization that described the effects of trauma on one's psychological state. Such stages of psychological change were shown through various vignettes of survivors of trauma. Themes found in both stages that assist the victim in proceeding with life are acquiring the will to find a way out of captivity, and the removal of emotions or feelings associated with the trauma. Herman characterized the first element of traumatization as the scarification of the victim's interpersonal belief system and sense of power and safety.

Prisoners, even those who have successfully resisted, understand that under extreme duress anyone can be 'broken'. They generally distinguish two stages in this process. The first is reached when the victim relinquishes her inner autonomy,

world view, moral principles, or connection with others for the sake of survival. There is a shutting down of feelings, thoughts, initiative, and judgment. The psychiatrist Henry Krystal, who works with survivors of Nazi Holocaust, describes this state as 'robotization'. Prisoners who have lived through this psychological state often describe themselves as having been reduced to a nonhuman life form. (Herman, 1992, p. 84)

The latter process of the psychological effect of trauma is described as having a complete loss of will to live, an "attitude of absolute passivity" (p. 78). Just as prisoners of the Holocaust were described as "robotic," and "among the living dead" (Herman, 1992, p. 84), many people who have experienced trauma face the suppression of their emotions and degradation of their self-worth. Herman (1992) recounted an example of captivity and victimization through the story of Jacobo Timerman:

Although I cannot transmit the magnitude of that pain, I can perhaps offer some advice to those who will suffer torture in the future....In the year and a half I spent under house arrest I devoted much thought to my attitude during torture sessions and solitary confinement. I realized that, instinctively, I'd develop an attitude of absolute passivity....I felt I was becoming a vegetable, casting aside all logical emotions and sensations- fear, hatred, vengeance- for any emotion or sensation meant wasting useless energy. (Herman, 1992, p. 85)

The survivor's transition from emotional connectedness to utter emptiness is not exclusive to prisoners of war. Many people whom undergo a traumatic event begin to dissociate, "a disruption in the *usually integrated* functions of consciousness" (APA, 2000, p. 477). Numbness, or the disconnection to feeling, is a common tendency in survivors of trauma, as emotional memories attached to trauma are normally too intolerable to hold in a conscious state. Herman (1992) described the story of a woman forced into prostitution and pornography: "I had been degraded every possible way, stripped of all dignity, reduced to an animal and then to a vegetable" (p. 80). The vegetative state that the woman referred to is the removal and inaccessibility of her

emotions. Survivors of victimization are often left alone, in extremely fragile states, to make meaning of their violation. A concrete example of dissociation, and its function in periods of trauma, is exemplified through the poem of Alicia Partnoy, a disappeared woman in Argentina who was held hostage for a prolonged period of time:

“Take off your clothes.”

She stood in her underwear, her head up. She waited.

“All clothes off, I told you.”

She took off the rest of her clothes. She felt as if the guards did not exist, as if they were repulsive worms that she could erase from her mind by thinking of pleasant things. (Herman, 1992, p. 88)

The psychological ability to consciously leave an abusive circumstance is a common response to trauma, which comes with a significant cost. The repression of trauma, and emotions associated with it, allow for compartmentalization of memory and reality. The necessity to compartmentalize one’s self in response to trauma is a part of survival, and has great importance. If trauma is recurrent or prolonged, and the person being victimized is constantly forced to compartmentalize, considerable disruption can occur to the development of a cohesive and integrated self.

In order to adequately identify the full range of psychological disruption resulting from trauma, Herman (1992) expanded the diagnostic criterion for PTSD. Herman explained that chronic prolonged and repeated trauma affects one’s psychological state in complex and fragmented ways. Such distress may alter one’s perception of interpersonal connectedness and safety. Individuals who experience chronic trauma are also at a greater risk of being harmed again, either by another or due to self-inflicted harm, than persons whom have not experienced trauma. Alterations to one’s physiological makeup,

including hyperarousal and hypersensitivity may also remain permanently affected (Herman, 1992).

In general, the diagnostic categories of the existing psychiatric canon are simply not designed for survivors of extreme situations and do not fit them well. The persistent anxiety, phobias, and panic of survivors are not the same as ordinary anxiety disorders. The somatic symptoms of survivors are not the same as ordinary psychosomatic disorders. Their depression is not the same as ordinary depression. And the degradation of their identity and relational life is not the same as ordinary personality disorder. (p. 118)

Herman (1992) redefined the diagnosis as complex post-traumatic stress disorder, referring to trauma in the form of prolonged captivity and traumatization. Herman characterized people with Complex PTSD as having a

history of subjection to totalitarian control over a prolonged period (months to years), alterations in affect regulation, alteration in consciousness, alterations in self-perception, alteration of perception of perpetrator, alterations in relations with others, and alterations in systems of meaning. (p. 121)

Recovery from complex PTSD is extensive; the reparation and acceptance of a history of victimization is psychologically consuming and painful. Herman's redefinition of trauma questions the diagnostic implications of Post-Traumatic Stress Disorder, as its origin is mainly based on "combat, disaster, and rape" (p. 121). Characteristics of therapeutic interventions also differ for individuals with complex PTSD, as the symptoms of chronic victimization tend to be more invasive and enduring.

The lack of an accurate and comprehensive diagnostic concept has serious consequences for treatment, because the connection between the patient's present symptoms and the traumatic experience is frequently lost. Attempts to fit the patient into the mold of existing diagnostic constructs generally result, at best, in a partial understanding of the problem and a fragmented approach to treatment. All too commonly, chronically traumatized people suffer in silence; but if they complain at all their complaints are not well understood. They may collect a virtual pharmacopeia of remedies: one for headaches, another for insomnia; another for anxiety; another for depression. None of these tends to work very well, since the underlying issues of trauma are not addressed. (p. 119)

Herman (1992) was not the first in her profession to make a distinction between PTSD and chronic trauma, nor was she alone in creating a new framework of treatment and theory. Herman mentioned Lenore Term who used Type I and Type II syndrome, and Jean Goodwin who created the acronyms FEARS and BAD FEARS to define this continuum of trauma. Herman quoted Denise Gelinis, stating that disguised presentation was a problem that many traumatized individuals face. Patients often would arrive “reporting problems with intimacy, excessive responsiveness to the needs of others, and repeated victimization” (Herman, 1992, p. 123). According to Herman, Gelinis stated that most often, no connection between the patient’s presenting concerns and history of trauma was made.

Herman’s (1992) recommendation for the therapeutic treatment of trauma has predominant themes of empowerment, validation, and the restoration of safety. Herman’s progression of treatment is outlined in the form of three stages of recovery: safety, remembrance and mourning and reconnection. Herman brought attention to her linear nature of the model, stating that therapy will inevitably delineate, flexibility and attunement to the needs of the client are essential in guiding the survivor through the stages of recovery.

Safety

In therapeutic relationships an undeniable power differential exists between the client and therapist. Such power dynamics may have been present in a past victim-perpetrator relationship, creating vulnerability for potential reenactment, as they may remind the victim of his or her former depleted sense of control. Interpersonal difficulties and distrust are common challenges of survivors of chronic trauma. If one’s relational

development was based on abuse and isolation, the survivor's guardedness and mistrust may likely continue within adult relationships. Herman (1992) suggested that creating collaborative goals and parameters is imperative, as an attempt to equalize power and control within the therapeutic dyad. In turn, an essential component of the therapeutic relationship is to help build a more trusting and safe environment for the client.

The core experiences of psychological trauma are disempowerment and disconnection from others. Recovery, therefore, is based upon the empowerment of the survivor and the creation of new connections. Recovery can take place only within the context of relationships; it cannot occur in isolation. In her renewed connections with other people, the survivor re-creates the psychological faculties that were damaged or deformed by the traumatic experience. The faculties include the basic capacities for trust, autonomy, initiative, competence, identity, and intimacy. Just as these capabilities are originally formed in relationships with other people, they must be reformed in such relationships. (Herman, 1992, p. 133)

Herman viewed the therapy relationship as a triad, including not only the therapist and client but also the perpetrator, who will most likely be presented in moments of reenactment, distrust, or unsafety.

Remembrance and Mourning

Herman (1992) accentuated the therapeutic importance of the reconstruction of the survivor's history. This stage of treatment is named remembrance and mourning, a stage where trust and safety in the therapeutic alliance must have been established. Since cognitive and emotional fragmentation are common results of trauma, the therapeutic goal of this stage is for survivors to remember, restructure, and verbalize their narratives. As the individuals tell their histories, feelings attached to the trauma must be labeled and articulated. The cohesion of the survivors' chronologies, with the gradual identification of their emotions, will assist them to integrate their compartmentalized "selves." This

process is meant to reclaim the survivors' pasts, with the survivor no longer feeling they must suppress their trauma.

The conflict between the will to deny horrible events and the will to proclaim them aloud is the central dialectic of psychological trauma. People who have survived atrocities often tell their stories in a highly emotional, contradictory, and fragmented manner, which undermines their credibility and thereby serves the twin imperatives of truth telling and secrecy. When the truth is finally recognized, survivors can begin their recovery. But far too often secrecy prevails, and the story of the traumatic event surfaces not as a verbal narrative but as a symptom. (Herman, 1992, p. 158)

Throughout the reconstruction of the survivor's narrative, Herman emphasized the use of empowerment and validation to assist survivors in remembering their histories of trauma. Herman recommended that clients begin their narratives at times prior to periods of trauma, as acts as a reminder of life that existed before the abusive conditions occurred. Herman (1992) referred to therapeutic transference and countertransference, explaining that the content may contain themes specific to trauma. The potential for sexual attraction, sadness, and aggression transmitted through the therapist-client relationship, reflecting times of captivity and control, are common themes that may intrude upon on the therapy process. The therapist may be sensitive to the transference, and reflect similar countertransference themes.

As a defense against the unbearable feelings of helplessness, the therapist may try to assume the role of a rescuer. The therapist may take on more and more of an advocacy role for the patient. By doing so, she implies that the patient is not capable of acting for herself. The more the therapist accepts the idea that the patient is helpless, the more she perpetuates the traumatic transference and disempowers the patient. (Herman, 1992, p. 140)

The importance of boundaries is another focus of Herman's (1992) Trauma and Recovery Model. Establishing the parameters of therapy may offer predictability and containment to the victimized individual. Herman stressed the use of a therapy contract

that illustrates mutual boundaries and expectations of the therapy guidelines. One condition in the contract asked for survivors to agree to tell the truth, and fully to disclose details of their traumas that may have been withheld in secrecy. The agreement to verbalize traumatizing experiences helps to facilitate recovery, and to integrate suppressed memories and feelings into the survivor's reconstructed narrative.

Careful attention to the boundaries of the therapeutic relationship provides the best protection against excessive, unmanageable transference and countertransference reactions. Secure boundaries create a safe arena where the work of recovery can proceed. The therapist agrees to be available to the patient within limits that are clear, reasonable, and tolerable for both. The boundaries of therapy exist for the benefit and protection of both parties and are based upon a recognition of both the therapist's and the patient's legitimate needs. (Herman, 1992, p. 147)

After therapeutic boundaries and expectations are developed, empathic attunement and guidance are necessary. The reconstruction process may inevitably bring up overwhelming emotions and flashbacks of the survivor's trauma. For many survivors who lived with the secrecy of their trauma, victimization became ingrained in their identities. The process of reclaiming their narratives, and the potential for moving beyond victimization can be both empowering and extremely frightening. Continual attunement to the survivors' emotional stability, and adjusting the speed of therapy at times of disorientation, provides a safe and trustworthy atmosphere for the clients to move past atrocities that happened in their lifetimes. Awareness of the survivor's external world, including supportive or threatening conditions must also be understood prior to the reconstruction stage. Self-induced harm is a common occurrence in survivors of trauma, and must be acknowledged within the beginning stage of recovery.

With survivors of prolonged, repeated trauma, the initial stage of recovery may be protracted and difficult because of the degree to which the traumatized person has

become a danger to herself. The sources of danger may include active self-harm, passive failures of self-protection, and pathological dependency on the abuser. (Herman, 1992, p. 166)

Herman (1992) put great emphasis on clinicians to err on the side of safety, without rushing the beginning stage of treatment. The therapist's main objective after establishing a trustworthy and safe environment, in stage one, is to "rebuild the ego functions that are most severely damaged in captivity" (Herman, 1992, p. 166). Initial therapeutic goals within the remembrance and mourning stage focus on taking risks, regaining autonomy and choice, and rebuilding the self-worth lost through victimization.

The ultimate goal of stage two is for survivors to articulate their narratives, applying words to emotions suppressed and compartmentalized by trauma. The reconstruction of a survivor's chronology will most often elicit feelings of loss and grief, which can be mourned through this stage. Herman suggested drawing as a useful tool for times where the verbalization of the traumatic experience is too difficult. Questions regarding what the client was hearing, seeing, smelling, and feeling during inarticulate moments in their narrative acts as another tool to help reconstruct the survivor's narrative.

The survivor is called upon to articulate the values and beliefs that she once held and that trauma destroyed. She stands mute before the emptiness of evil, feeling the insufficiency of any known system of explanation. Survivors of atrocity of every age and every culture come to a point in their testimony where all questions are reduced to one: Why? The answer is beyond human understanding. (Herman, 1992, p. 178)

Reconnection

Herman (1992) named the third, and final, stage of recovery reconnection. The reconnection stage helps assist survivors in reestablishing their lives and desires that were lost through victimization. Reclaiming a life and new goals entails moving beyond the

role of a victim, and taking initiative to create goals outside of the trauma. The survivor is asked to endure the loss of an identity or fantasy of revenge and create newfound goals orientated towards the future. The tasks within the reconnection stage are challenging, as the victim is asked to move beyond the confines of the victimized identity. The aftermath of trauma is often all consuming, leaving little energy for the survivor to expend on self-repair or personal interests. Mastery of the first two therapeutic stages helps to free energy that was once consumed by traumatic memories. The survivor must begin to resume trust, form new relationships, and reconnect with his or her prior identity, previously overshadowed by trauma.

Contemporary Use of the Trauma and Recovery Model

Herman's *Trauma and Recovery Model*, published in 1992, continues to be referred to and modernized by current theorists and practitioners. Themes of safety, empowerment, and validation exemplified in Herman's trauma and recovery model continue to be utilized and referred to in contemporary approaches to trauma-informed treatment. The HEALTH and Seeking Safety models both demonstrate guidelines to treat trauma that expand on Herman's (1992) model.

The HEALTH model (Conner & Higgins, 2008) was formatted as a guideline to treat Complex PTSD, as defined by Herman (1992). The acronym HEALTH was designed to illustrate six stages of treatment, and remains one of the only treatment approaches studied to "implement and evaluate a guideline-based program for the treatment of CP symptoms over an extensive period" (Conner & Higgins, 2008, p. 302). The HEALTH guidelines go beyond safety and validation, accentuating the importance

of building the trauma survivor's ego-strength within the therapeutic context. The treatment modality is organized by six steps, including

(1) having a supportive therapist; (2) ensuring personal safety; (3) assisting with daily functioning; (4) self-regulation – learning to manage core PTSD symptoms; (5) treating Complex PTSD symptoms; and, finally, (6) having patience and persistence to enable “ego strengthening.” (Conner & Higgins, 2008, p. 304)

Conner and Higgins (2008) included Herman's criteria table for complex PTSD, and consider the diagnosis to be “the central component of the program” (Conner & Higgins, 2008, p. 293). The treatment model is primarily an individual process, though group therapy is recommended to reinforce the survivor's treatment. The experience of group therapy highlighted in the HEALTH model contains similarities to Herman's (1992) emphasis on rebuilding relational connections and on having others bear witness to the survivor's recovery process. The founders of the HEALTH model also share a similar concern described by Herman, stating that the symptomology found in survivors of chronic trauma does not capture the same diagnostic criterion found in PTSD, nor can it provide the same form of clinical treatment. The HEALTH model has a slightly lengthier and more detailed stage process than Herman's, though it seems to share similar emphases of the establishment of safety, patience, and the identification of complex PTSD symptoms.

Seeking Safety (Najavits, 2002) is another alternative treatment model used with individuals' with PTSD and substance dependency. The model was constructed in 1996 by Dr. Lisa Najavits, as a psycho-educational guide. Najavit's (1996) model is widely administered within the US, and is partially based on Herman's definition of complex PTSD. Seeking Safety can be facilitated in a group or an individual therapy environment,

covering specific examples of coping skills, grounding exercises, ways to regain power, and the development of safety. The Seeking Safety model includes 25 stages, which may be presented in any order. The stages include

Introduction/Case Management, Safety, PTSD: Taking Back Your Power, When Substances Control You, Honesty, Asking for Help, Setting Boundaries in Relationships, Getting Others to Support Your Recovery, Healthy Relationships, Community Resources, Compassion, Creating Meaning, Discovery, Integrating the Split Self, Recovery Thinking, Taking Good Care of Yourself, Commitment, Respecting Your Time, Coping with Triggers, Self-Nurturing, Red and Green Flags, Detaching from Emotional Pain (Grounding). Life Choices, and Termination. (Brown, Najavits, Cadiz, Finkelstein, Heckman, & Rechberger, 2007, p. 234)

Brown et al. (2007) conducted a multisite study to examine the adaptability of Seeking Safety for women with co-occurring disorders of substance use dependency (SUD) and histories of both physical and sexual abuse. A total of 157 clients and 32 clinicians reported on their satisfaction with various aspects of the model. Brown et al. (2007) conducted the research in four separate clinical sites, with a focus on

(1) What decisions did the different sites make in order to optimize the compatibility of Seeking Safety with the site's needs and experiences? (2) How satisfied were the clinicians/facilitators and consumers/clients with Seeking Safety, and were there differences between sites and between clinicians and consumers? and (3) What may be important factors that contribute to the adoption of new practices? (Brown et al., 2007, p. 235)

Consumer and clinician satisfaction were measured by using “The Seeking Safety Feedback Questionnaire” (Najavits, 2002) and the “Protocol Implementation

Questionnaire” (Najavits, 1996). All four sites showed significant scores of finding Seeking Safety helpful, including significant satisfaction with sections pertaining to “learning coping skills,” “safety as priority of treatment,” “structured approach,” “focus on behavioral skills,” “integrated treatment,” “patient session handouts,” “core concepts of treatment,” and “check in/checkout” (Brown et al., 2007, p. 237).

The study demonstrated that the Seeking Safety model could be adaptive and useful in populations that vary in treatment style, population, and range of diagnoses.

Brown et al. (2007) highlighted that

PTSD and SUD have consistently been found to co-occur (Ouimette & Brown 2003). Reports on rates of PTSD among women receiving treatment for substance abuse range from 20% to as much as 59% (Kessler 2000; Najavits, Weiss & Shaw 1997; Triffleman et al. 1995). Current research shows that 48% to 90% of women with co-occurring mental health and substance abuse disorders also have histories of interpersonal violence (Perkonigg et al. 2000; Lipschitz, Kaplan & Sorkenn 1996). Most clinical programs treat PTSD or SUD, but rarely both. Fewer than half of the women with co-occurring disorders and trauma will receive treatment that addresses all of these issues (Brown et al., 2007, p. 232).

The significant prevalence of SUD in people with complex PTSD is relevant to Herman’s (1992) recovery model, as Herman does not cater her treatment recommendations for survivors with issues of substance abuse.

Allen (2001), a psychologist and author of the text *Traumatic Relationships and Serious Mental Disorders*, made several references to Herman (1992) and her use of Complex PTSD. Allen used Herman’s comparison of prolonged trauma and personality development to expand his understanding of how chronic abusive and feelings of unsafety can cause a disruption of one’s personality development (Allen, 2001). Allen also wrote about sexual, verbal, and physical abuse as all contributing independently to the likelihood of a Borderline Personality Disorder (BPD) diagnosis. Allen considered

verbal and physical abuse and parental separation as contributors to the development of personality disorders, mainly BPD. Allen's (2001) suggestion of effective therapeutic intervention for individuals with histories of trauma and BPD stressed that therapy concentrate on specific fears and attachment styles that interfere with the survivor's ability to form new relationships. Such fears may include abandonment and loneliness. Allen (2001) linked the fears "to attachment disturbance and the inability 'to evoke a mental representation of a soothing (responsive, empathic, and reliable) other.' ...Accordingly, the client requires continual contact with the attachment figure, and anticipated separation may provoke frantic efforts to prevent abandonment" (Allen, 2001, p. 87).

The evaluation of trauma-focused psychotherapy brings attention to the large body of data and clinical practice that exists for persons that have survived trauma (Allen, 2001; Herman, 1992; Najavits, 2002). As noted in chapter three, persons with developmental disabilities are at great risk for being maltreated and abused (APA, 2003), including the experience of prolonged victimization. Herman's description of traumatization includes disruptions in behavior and self-perception, as well as interrelational difficulties. Such challenges are commonly labeled by researchers and behavior analysts as maladaptive behaviors (Carr, Dunlap, Horner, Koegel, Turnbull, Sailor, Anderson, Albin, & Koegel, 2002; Harris, 2010), rather than named as symptoms of trauma. Research on trauma-focused therapies for persons with developmental disabilities is often seen through the prism of the disability construct. The exploration and review of pre-existing, mainstreamed trauma treatments may provide a foundation for clinician's to more accessibly apply to persons with developmental disabilities.

Chapter V

Post-Institutionalization and Applied Behavior Analysis

The time period following institutionalization for persons with developmental disabilities was characterized by immense social and structural change. The US government was faced with the dilemma of how to humanely integrate institutionalized populations into communities throughout the nation. Efforts to deinstitutionalize persons with developmental disabilities led to challenges on how to support, integrate, and habilitate persons affected by institutional settings. Ideology on how to normalize the lives of institutionalized persons with DD set forth in Scandinavia (Nirje, 1969), and was soon after borrowed from US philosophers (Wolfensberger, 1983). Behavior modification theory, such as *applied behavior analysis* was popularized in the late 1960s, paralleling much of the deinstitutionalization movement. Many of the theorists' promoting the need to provide normalcy and inclusion to the lives of persons with developmental disabilities have been referenced by behavior analysts, and used to support the use of behavioral modification theories (Carr et al., 2002; Nirje, 1969; Wolfensberger, 1983). The first section of this chapter will describe the social conditions that occurred after the deinstitutionalization movement for persons with developmental disabilities. The second portion of the chapter will introduce the behavior modification theory, and address its relationship to persons with developmental disabilities.

Nirje (1969), the noted creator of the normalization principle, addressed how to best assist persons with developmental disabilities in leading socially integrated and normalized lives. Perrin (1999) described the normalization principle as promoting conditions where persons with disabilities have equal opportunity to circumstances commonly utilized by the majority (Perrin, 1999). The concept of the normalization principle was adapted within the US from Nirje (1969) in order to greater understand how to create a normalized and humane environment for persons with disabilities (Perrin, 1999). As noted in chapter three, most people with DDs living before the mid 1970s had been socially segregated and institutionalized, and therefore depriving individuals in this group from optimal social, educational, and cognitive development.

Adaptations of the normalization principle were influential to post-institutional conditions in the US. The concept of normalization was modernized and renamed as the *social role valorization* theory in the 1980s – focusing on the “enhancement of people’s ‘social image’ or perceived value in the eyes of others, and enhancement of their ‘competencies’” (Wolfensberger, 1983, p. 45). Wolfensberger’s (1983) social role valorization theory (SRV) examined the social role and value which persons with developmental disabilities historically obtained. Wolfensberger proposed that if a person with DD held a societally valued role, other desirable fortunes would follow that individual. Wolfensberger stated that the risk of being in a devalued social position would increase a person’s probability of maltreatment, being labeled and segregated, and being influenced by society’s negative stereotypes.

In fact, being seen as filling a valued social role may be the one thing which prevents a person from becoming devalued because of a characteristic which would automatically cast other people who do not have socially valued roles into

a devalued status. Even further, a characteristic which itself is devalued might become valued if it were displayed by a person in a valued social role. (p. 43)

Wolfensberger suggested that a way to protect persons with developmental disabilities from issues of marginalization would be to enhance their social images and social competencies. Therefore, a person's behavior deemed as socially inappropriate would need to be changed in order to bring that person a socially inclusive and respected societal position.

Wolfensberger's (1983) SRV theory was in response to social injustices within large institutional settings, and should be evaluated within that context. For many institutionalized persons, their development of social roles and norms were not fully formed. Wolfensberger, within the beginning of the community integration movement, brought attention to the fundamental need to socially habilitate persons with DD. In today's social climate, however, does SRV have the same implications? More so, should the ideals in SRV be used as a teaching tool to professionals, rather than focusing on how to change the social construction of disability services, and environments, which may inhibit the natural development of socialization? The implications to changing the environment may entail the restructuring of systems that segregate and deprive persons with DD of optimal development (i.e. the educational system and residential constructs).

The time period following institutionalization (late 1970s through the 1980s) was an era influenced by many theorists, civil rights leaders, and parental activist groups, as an infrastructure to support persons with DD was not yet developed (Blatt & Kaplan, 1966; Nussbaum, 2004; Segal, 2011). Nussbaum (2004) contributed theories associated with ethics and social development, including the capability approach, advocating for

persons with DD. Nussbaum wrote that “each human individual is profoundly valuable, spacious and deep, capable of separate life and imagination, of being more than just a continuer of a tradition or a family style” (p. 42). Advocacy groups and a changing political climate also contributed in reforming policies and initiatives to establish services for persons with developmental disabilities.

Behavior Modification

As social services for persons with developmental disabilities were in progress throughout the 1970s, theories concerning behavioral modification were becoming mainstreamed within agencies throughout the nation. Applied behavior analysis (ABA) was one of the initial behavior modification tools to be implemented in agencies for persons with DD, based on past principles outlined by B.F. Skinner and others behavioral scientists.

Baer et al. (1968) described the construction and rationale of the applied behavior analysis theory, formerly labeled as analytic behavior application, and its use within the population of persons with developmental disabilities.

Analytic behavior application is the process of applying sometimes tentative principles of behavior to the improvement of specific behaviors, and simultaneously evaluating whether or not any changes noted are indeed attributable to the process of application-and if so, to what parts of that process. In short, analytic behavioral application is a self-examining, self- evaluating, discovery-oriented research procedure for studying behavior. So is all experimental behavioral research (at least, according to the usual strictures of modern graduate training). The differences are matters of emphasis and of selection... Applied research is constrained to look at variables which can be effective in improving the behavior under study. (p. 91)

Baer et al. (1968) defined the meanings represented in the ABA acronym, and how the acronym related to overall outcomes of behavioral change. Baer et al. defined

application as the interest in which society showed the problem behavior being studied; *behavioral* being the confirmation and documentation of behavioral change; and *analytic* as when experimenters have the ability to exercise control and predictability over the targeted behavior. Baer et al. provided a standard example of such behavioral modification techniques, using a sample of how to change a problem behavior.

It may be reported, for example, that a certain patient rarely dressed himself upon awakening, and consequently would be dressed by his attendant. The experimental technique to be applied might consist of some penalty imposed unless the patient were dressed within half an hour after awakening. Recording of an increased probability of self-dressing under conditions might testify to the effectiveness of the penalty in changing the behavior; however, it might also testify to the fact that the patient would in fact probably dress himself within half an hour of arising, but previously was rarely left that long undressed before being clothed by his efficient attendant. (The attendant now is the penalty-imposing experimenter and therefore always gives the patient his full half-hour, in the interests of precise experimental technique, of course). (p. 93)

Baer et al. (1968) emphasized the experimenter's control and consistency within the facilitation of the behavioral plan. The ABA technique, above, exemplified the concept of reinforcement, a behavioral tool commonly found in behavioral plans, today. Baer et al. (1968) noted that if a behavior plan was easily replicable by professionals, and producing a predictable outcome, it would then constitute the validity of technique. "All components of social reinforcement must be specified (stimuli, contingency, and schedule) to qualify as a technological procedure" (p. 95).

Baer, Wolf, and Risley (1987) reviewed the theory and application of ABA close to two decades after their initial 1968 conceptualization. Baer et al. (1987) brought attention to both criticisms and praise that ABA had elicited from professionals since the 1960s. Baer et al. stated that some of the terminology used in ABA in the past had changed, including the meaning of the term *applied*. Applied was changed to social

problems manifesting as “behaviors of the subject or client that result in counteraction, sometimes by the client, but more often by nonclients, sufficient to generate something called a solution, or a least a program” (p. 314). Baer et al. (1987) regarded lobbyists and therapists as having contrasting agendas to ABA analysts, which seemed to be a common triad of supports for persons with developmental disabilities. Baer et al. mentioned that due to political agendas having little efficacy in structural or environmental change and the insular nature and short duration of therapy, made it difficult for those social supports to provide behavioral change among persons with DD (p. 314). Baer et al. predicted ABA would likely continue to evolve, though claimed that many of the original, fundamental principles found in ABA remained similar to those found in their 1987 review.

Carr et al. (2002) described a behavior modification technique with similar values to those found in applied behavior analysis. Carr et al. (2002) defined *positive behavioral support* (PBS) as a behavioral theory, identifying the ‘target population’ in PBS as persons with developmental disabilities (p. 9). Carr et al. (2002) discussed the historical and practical factors of the theory of positive behavior support, and its implications for adults with developmental disabilities.

The primary goal of PBS is to help an individual change his or her lifestyle in a direction that gives all relevant stakeholders (e.g. teachers, employers, parents, friends, and the target person him or herself) the opportunity to perceive and enjoy an improved quality of life. (p. 5)

Concepts of Wolfensberger’s (1983) social role valorization theory and past research on applied behavioral analysis seemed to have created a foundation for positive behavior support (Carr et al., 2002). Carr et al. (2002) provided several explanations of how to form natural and individual-centered environments for persons with DDs. Carr et

al.'s description of PBS emphasized the use of behavior modification to change devalued and socially unacceptable behaviors, possessed by persons with DDs. Carr et al. (2002) addressed that two focuses of PBS were using a "person-centered" approach and being conscious of environmental stimuli (p. 6), differentiating the theory from ABA. Carr et al. (2002) explained the time commitment of PBS as being "a life span perspective, which views intervention as a never-ending systemic process that evolves as different challenges arise during different stages of life" (p. 7).

Harris (2010) described current uses of behavior modification for persons with developmental disabilities. Harris defined target behaviors as those that were socially inappropriate or maladaptive, naming several examples of behavioral challenges exhibited by persons with DD. Such behavioral problems included, "self-injury, property destruction, screaming in public and other socially inappropriate behavior, lack of compliance with requests, and oppositional patterns of behavior" (pp. 122-123). Harris described the premise of behavioral plans, and the practicality of their use.

Using these techniques, the individual is rewarded when he or she does not show a targeted maladaptive behavior. If the undesirable behavior does not occur within a certain time period, then positive reinforcement or reward is applied, such as verbal praise, food, or another reward. The goal is to facilitate self-control. If this procedure is successful, the frequency of targeted maladaptive behavior decreases, and the frequency of the more adaptive behaviors that are reinforced increases. (p. 148)

Similar to some of the founding principles of applied behavior analysis, Harris (2010) referenced the use of reinforcement and facilitation. Harris understood behavior reduction through principles labeled as "extinction," "time out," "response cost," and "overcorrection" (pp.148-149). Harris referred to extinction as a "procedure in which a previous response is no longer reinforced" (p. 148), such as ignoring a person's

maladaptive behavior until the behavior decreases. Time-out was defined as removing a person “from a socially supportive setting until” a problem behavior “is back under control” (pp.148-149). Harris referred to response cost as the loss of a reward earned by the target person due to problem behavior, and overcorrection as a person “repeating the correct behavior until mastered...to overcorrect an inappropriate behavior” (pp.148-9). Harris described the use of a behavioral plan through a case example of a 16 year-old female, named Amy. Harris stated that Amy demonstrated aggressive behavior toward her father, though not to her peer group. Amy “becomes aggressive when her father comes too close” (p. 150), which was noted as disrupting Amy’s relationship to her father and the family’s dynamic. Harris’s recommendation was to apply a behavioral plan to decrease or eliminate the targeted behavior, in this case being Amy’s aggression. The case of Amy further exemplified that the emphasis of behavior modification does not seek to change or identify environmental provocations, but rather the individual’s behavioral response to such stimuli. The case of Amy, as described by Harris (2010), did not consist of any assessment to understand if Amy had experienced any trauma, even with the mention of her behaviors being specific to her father. This observation does not completely imply that Amy’s father was abusive towards her, though should bring suspicion to the origin of her behavior.

Behavioral modification as a practice appeared to be a widely accepted intervention by professionals working with adults with developmental disabilities (Baer et al., 1968; Carr et al., 2002; Harris, 2010; Wolfensberger, 1983). Whether defined as applied behavior analysis, positive behavior support, or another variation of behavior

modification, it seemed clear that such interventions have been researched and utilized within educational, vocational, and residential environments.

One could wonder if “a life span” (Carr et al., 2002, p. 7) of using behavioral plans to better a persons’ social capacity is a person-centered, or even effective, treatment? The notion of behavioral plans used in such a way brings concern to the ethics of implementing a plan that the recipient may not understand or agree to. Also, we need to consider how social norms and expectations are constructed, and if professionals have the right to enforce such norms on persons with different socialization styles. Herman’s (1992) approach to trauma recovery begins with the development of a safe and trustworthy environment, and only then will survivors be capable of moving beyond some of their debilitating trauma symptoms. Herman’s interpretation of recovery is within the context of safety, validation, and empowerment, using long-term, individual therapy. If persons with DD have experienced trauma, and then given behavioral plans that target their expression of the trauma, what psychological effects does the plan have on the survivors? Also, if professionals or caregivers label symptoms of trauma as maladaptive, what messages are we sending to the survivor? One can only imagine that using negative reinforcement techniques on the behavioral expression of trauma would cause re-traumatization to the survivor.

Criticism of behavior modification for persons with developmental disabilities had been present in the mental health field. Mansell et al. (1992) studied the occurrences of traumatization in persons with developmental disabilities, and noted that symptoms of trauma were often misattributed to challenging behaviors. Mansell et al. stated the inefficacy of behavioral plans, in saying they are “poorly managed through behavioural

control and sedation”, including that “the symptoms may never be appropriately assessed or treated” (Mansell et al, 1992, p. 406).

Dosen (2007) described the clinical treatment for persons with DD as having a “monodisciplinary treatment approach to behavioural and psychiatric problems” (p. 66). Dosen (2007) stated that the treatments offered to persons with DD were mostly through psychotropic medication or behavior modification, which have “yielded limited success” (p. 66), and deserving of a new treatment approach.

Chapter VI

Discussion

The purpose of this thesis was to examine the prevalence of trauma in adults with developmental disabilities, and to explore the availability and accessibility of trauma-focused treatment. This chapter starts with a review of social vulnerabilities that contribute to trauma in persons with developmental disabilities. The following section is an overview and comparison of trauma theory and behavior modification. The chapter ends with recommendations for trauma-informed treatment for people with developmental disabilities, and implications for the social work and mental health fields.

Trauma and Social Vulnerability

As noted, researchers showed that persons with developmental disabilities experienced trauma at a higher rate than persons without such disabilities (APA, 2003; Dosen, 2007; Mansell et al., 1992; Sullivan & Knutson, 2000). Within statistical findings of trauma among persons with DD, there was variation and challenges attributed to systemic oppression (APA, 2003). Traumatization in adults with DD was characterized on a spectrum of emotional, physical, and sexual abuse, social injustices, marginalization, and stigmatization. With reports showing that persons with DD were exposed to trauma two to three times more likely than are children without disabilities (Sullivan & Knutson, 2000), the gravity of traumatization that effect persons with DD in adulthood is really undetermined. Research on how to evaluate trauma in persons with DD proved to be a highly neglected area in the mental health and social work fields.

Current government and service structures for adults with developmental disabilities (i.e., group homes, vocational programs, and habilitation centers) contain issues associated with dependency, immobility, and control. Although social conditions have drastically improved from institutionalization in the 1960s, today's smaller residential facilities seem to have many of the obstacles that were present in past institutional settings. The lack of self-determination, self-expression, and individual freedom has remained a challenge within current support systems for persons with DD.

Behavior Modification and Trauma Theory

Behavior modification as a theory has been supported and implemented within the population of adults with developmental disabilities (Carr et al., 2002; Harris, 2010). Behavioral intervention for persons with developmental disabilities has made tremendous changes in self-injury, sexual deviancy, aggression, and other harmful behaviors exhibited by persons with DD. Considerable risks may exist, however, in applying behavior plans to adults with DD without conducting an extensive assessment for symptoms of trauma. One risk factor is the administrator of the plan overlooking any trauma completely, and attributing trauma symptoms to maladaptive behavior. Another risk factor is the potential of re-traumatization due to professionals' employing control over, or suppressing the communication of, a person that has been traumatized. The use of behavior modification without adjunct psychotherapy in settings that provoke maladaptive behavior, or overshadow the behavioral communication of trauma is a major flaw of the application of behavior modification (Mansell et al., 1992; Turk et al., 2005).

As seen in chapter four, Herman (1992) characterized the treatment of trauma as being between a therapeutic dyad, and encompassing themes of safety, validation, trust,

and the empowerment of the survivor. Behavioral interventions seem to directly contradict Herman's (1992) suggestions for the treatment of trauma. Behavior modification, such as ABA and PBS, do not create elements of empowerment, as the majority of interventions are created by "collaborators" (Carr et al., 2002, p. 8), such as parents, teachers, housing staff, etc., rather than created or chosen by clients themselves. Herman's trauma and recovery model and construction of complex PTSD has been a mainstream theory, and is under consideration as an addition to the next edition of the diagnostic statistical manual. If trauma-based therapies have been a progressing and accepted means of trauma recovery by the mental health profession for adults without disabilities, the question remains, why have the mental health and social work fields neglected to make it accessible for those with developmental disabilities? The long history of stigmatization, separation of government funding between mental health and disability services, and the social segregation of persons with DD may contribute to the answer. Ideology such as the normalization principle and social role valorization contained hope for the equality of persons with DD, though such ideologies did not include any questioning or deconstruction of how societal conditions oppress and psychologically affect persons with DD. The intention of this thesis was not to dismiss behavioral modification theories, but to explore how the social work community can intervene in developing clinical interventions to better support persons with DD whom have experienced trauma.

As mentioned in chapter three, the severity of traumatization in persons with developmental disabilities has been under-researched. Because of the increased risk of abuse and maltreatment in adults with DD, one would assume that such conditions might

lead to a significant degree of traumatization in the population. As discussed in chapter five, behavior modification and the use of behavioral plans to target “maladaptive behavior” (Carr et al., 2002; Harris, 2010) are widely used and accessible means of treatment. As proposed in chapter five, how can the mental health field competently treat survivors of trauma with DD with a behavioral plan? And, if a behavioral plan is the only accessible means of treatment for persons with DD, what psychological affect does that have on already traumatized recipients?

The case of Amy, presented by Harris (2010) in chapter five, may be a helpful way to illustrate the overshadowing of trauma by the mental health field. Amy exhibited aggressive behavior in the presence of her father (specifically in close proximity to her father), while aggression did not appear with members of her peer group or family. Hypothetically, if Amy had been victimized by her father or another man, and her family and professionals enforced a behavioral plan to target her aggression, what would that do to her pre-existing trauma? One can imagine that her experience would remain unknown and invalidated, her trauma might worsen, and her sense of safety would be severely compromised. If the plan was administered persistently, using negative reinforcement, her trauma might become so exacerbated that she would be complacent, or even experience a state of vegetation and compartmentalization as described by Herman (1992).

Recommendations for Trauma Treatment

As mentioned in Chapter three, Dosen (2007), Lloyd (2009), Mansell et al. (1992), Morin et al. (2008), and Upton (2009), to name a few, had developed and practiced psychotherapeutic treatments for adults with DD, and deemed the treatments

successful. Schuengel (2009) conducted a study examining the use of individual and family therapy in conjunction with behavior modification. Schuengel found that participants with therapy had significant improvement in following their behavioral plans compared to the participants without therapy. Schuengel's study was important, as it demonstrated the co-existence and efficacy among behavior modification and psychotherapy.

Schneider (1986) practiced psychotherapy with persons with dual diagnoses in DD and mental health, and suggested a variety of treatment techniques and adaptations.

Supportive psychotherapy or counseling techniques with the dually diagnosed are oriented toward more concrete demonstrations rather than verbal approaches. They should also focus on immediate and current life experiences rather than on historical review. Self-reflection becomes more meaningful with fresh observations and behaviors than with recall... Role playing can be a valuable activity, but, just as any other, it should be used in moderation. Higher functioning individuals who are capable of communicating feelings more directly require a variety of activities and techniques. Some examples of these techniques are working with pairs to promote cooperative behavior, and verbal exercises and interactions. The use of videotape is excellent for viewing behavior with minimal distortion and for analyzing nonverbal cues. (p. 155)

Such therapeutic suggestions appear progressive in the absence of mainstreamed therapy for persons with developmental disabilities. Therapeutic treatment for persons with DD seems to be confined to clinician's with specializations in disability. Government-funded structures for persons with DD commonly use behavior modification, while utilizing little consistent individual therapy.

Training on the prevalence and treatment of trauma in persons with developmental disabilities must be addressed in both licensed professionals and graduate institutions. I question whether today's clinicians and social workers would be competent in defining and diagnosing different developmental disabilities. Since many adults with

DDs have behavioral symptoms (Turk et al., 2005), clinicians will also need to be trained on typical symptom pictures that some people with disabilities possess. Conducting therapy with a client that has a developmental disability and non-verbal skills will likely have additional adaptations, which the mental health professionals need to be trained in.

Implications for Social Work Practice

The primary implications of this research for social work practice are for social workers and mental health professionals to heighten their awareness, and become active participants in, addressing traumatization in adults with developmental disabilities. Since vulnerabilities to trauma in this population appear to be partially due to systemic injustices, the mental health and social work fields must also address social structures that continue to perpetuate oppressive conditions. Recommendations for clinical social workers include the expansion of trainings and therapeutic adaptations on trauma for persons with DD. Also, assessment tools for mental health diagnoses, and symptoms of traumatization, must be developed and integrated into mainstreamed clinics and disability-funded services. Since therapeutic adaptations and suggestions for persons with DD exist (Dosen, 2002; Lloyd, 2009; Mansell et al.; Schneider, 1986; Schuengel, 2009; Upton, 2009), research may be done on the efficacy of existing therapeutic modalities and the implementation of treatments in the mental health field. If therapeutic support for persons with DD becomes a standard practice within mainstreamed clinics, our understanding of trauma, and its prevention in persons with DD will inevitably improve.

Accountability

The social work community must be cognizant of historical and current social vulnerabilities that affect persons with developmental disabilities. Reports of the significant risk and occurrence of trauma in persons with DD had been publicized, and even found in sources frequently viewed by mental health professionals (APA, 2003). Persons with developmental disabilities have been deemed to be at-risk for oppression and maltreatment by researchers and advocacy groups, which had been available to the social work community, since the 1950s. As social workers, we have the ethical responsibility to “pursue social change, particularly with and on behalf of vulnerable and oppressed individuals and groups of people” (National Association of Social Workers [NASW], 2008). The NASW noted the responsibilities of social workers in addressing issues of poverty, unemployment, and discrimination, all being forms of social injustices that affect adults with developmental disabilities.

In any therapeutic interaction with adults with developmental disabilities, social workers must take a person-centered approach. Like any competency training in other oppressed or labeled groups, it is imperative that we see persons with developmental disabilities outside of the confines of their diagnoses. Not all interactions will need therapeutic adaptations, focus on trauma, or address systemic oppression. As a field, we must remind ourselves that disabilities are constructed by society, and although affect, do not define the individual.

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