

DIFFERENCES BETWEEN INDIVIDUALS WITH DISSOCIATIVE IDENTITY  
DISORDER (DID) BASED ON RECEIPT OF GOVERNMENTAL  
DISABILITY BENEFITS

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## DEDICATION

I would like to thank the members of my Thesis Committee, my husband Glen, and my mother Susan for their support, encouragement, and time.

I would also like to thank the people who took part in this research, supported this project, and attempted to complete the survey but couldn't because it was too emotionally difficult.

Without their willingness and honesty this research could not have been done.

May this research and the research that may follow help improve public understanding of DID, therapy for DID, the lives of those who have DID, and the lives of those who love someone who has DID.

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by

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This study compared outpatient individuals who have Dissociative Identity Disorder (DID) and receive governmental disability benefits (n=42) to individuals who have DID and are not receiving governmental disability benefits (n=90). Internet peer support groups for DID were used to invite volunteers to answer an online questionnaire concerning past and current psychosocial aspects of their lives, abuse history, and psychological treatment history. The Dissociative Experiences Scale (DES) was also administered and scored.

While there were several similarities between the two groups, significant differences between the two groups were found. The disabled group had been in therapy for an average of 4.7 years longer than the non-disabled group, and had spent an average of 2.9 years longer in therapy prior to the DID diagnosis than the non-disabled group. Overall DES and DES-Taxon scores showed no significant differences between the two groups. However, two questions that are part of the DES-T and four questions that are not part of the DES-T were found to have significant differences between the two groups, indicating that the disabled group had more severe or more frequent occurrences of amnesia-related dissociative experiences.

Rehabilitation counseling could attempt to restore or improve functioning levels by focusing on the specific symptoms and experiences listed as reasons why the DID became disabling. The three most common reasons listed for why DID became disabling were losing time or memory difficulties (52.4%), rapid switching between alter personalities (35.7%), and depression (26.2%). The three most commonly reported ways in which DID negatively affected work or school tasks were concentration difficulties (34.4%), forgetting or not completing tasks (31.3%), and experiencing anxiety or panic attacks (11.1%). These common difficulties may be useful areas for treatment and intervention for individuals with DID who are not currently receiving disability benefits in an attempt to prevent disability benefits becoming a necessity. They may also be useful treatment areas for helping those who are receiving disability benefits successfully return to a vocation.

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## Introduction

Dissociative Identity Disorder (DID) is a psychological diagnosis that has been the center of many debates and controversies over the past century. In the past few decades much of the research pertaining to DID (formerly known as Multiple Personality Disorder, or MPD) has focused on proving its existence, providing diagnostic criteria, and suggesting treatment models and techniques (Ross, 1997). This study hopes that by utilizing the rehabilitation psychology framework as a new way of viewing DID and the difficulties individuals with DID face, the field can gain a new level of insight, thereby increasing the effectiveness of treatment for DID while providing research that is clinically important, personally useful, and therapeutically sound.

This research focuses on dissociation and disability. The following literature review shows that the role dissociation plays in long-term psychopathology, treatment and prognosis for other mental disorders, and in the individual's ability to return to work after an injury has been studied in populations dealing with anxiety disorders, brain injury, chronic pain, and substance abuse. Clinicians often use dissociation measurements as a screening instrument or diagnostic tool when evaluating a person for dissociative disorders, but to date, no research has looked at what correlation these measurements may have in relationship with the long-term difficulties individuals with DID may experience.

*Statement of Research Design Bias and Beliefs*

Every researcher strives to find the perfect sample population. This research utilized the Internet to gather data from participants. This offered some potential benefits, and some potential drawbacks. The following beliefs or biases were accepted for this pilot study:

1. The Internet was used to gather the research data. This allowed for a large pool of participants who were not limited to a specific geographical area, an inpatient treatment program, or being treated by the same therapist/treatment model. The American Psychological Association has not set up any specific guidelines for using Internet participants in research. They have recently published an article stating the usefulness of the Internet for research, and how the current research guidelines apply to research done on the Internet (APA, 2004). The APA standards for research were used for this study, including informed consent, and handling data in such a way to maintain confidentiality.
2. Participants were not currently inpatient and some were not currently in treatment. Most DID research utilizes inpatient populations. This study maintains the belief that the most effective way to measure psychosocial factors affecting vocational ability, or disability, occurs when a person is stable enough to be treated in an outpatient setting.
3. Diagnostic and treatment histories were not verified by outside sources. Participants in this study believed that DID was the proper diagnosis for them, stated that they have received the diagnosis from someone they sought psychological treatment from, and stated that they have had psychological therapy which focused specifically on

DID. Some individuals reported that they either had not been diagnosed by a mental health professional, or that they had never received psychological treatment for DID. These individuals were not included in the study.

4. Disability status for this study was based upon the current receipt of governmental disability benefits (typically referred to as Social Security Insurance or Social Security Disability Insurance in the United States). Participants were included in the government disability group if their government disability was granted based on one or more diagnoses that included DID. This division is based on the belief that the governmental disability status was the best objective indicator available for ability to function in a vocation. It is an imperfect system, and this study used this indicator with the assumption that an equal number of individuals are either erroneously denied or granted governmental disability. The implication of using this as a measurement of disability is that this study may not be able to find significant differences or the same differences that may be found if a different indicator of disability was used.

## *Disability and Rehabilitation*

### *Disability Facts and Figures*

According to the World Health Organization, psychological disorders account for 5 of the top 10 causes of disability in established market economies worldwide. These top five disorders are schizophrenia, bipolar disorder, major depression, substance abuse, and obsessive-compulsive disorder. Worldwide, it is estimated that more than 400 million people suffer from mental disorders or intellectual disabilities (WHO, 2001).

In the United States the President's New Freedom Commission on Mental Health submitted a report called "Achieving the Promise: Transforming Mental Health Care in America" in July 2003. In this report they stated that a fundamental shift is needed in treatment expectations to include getting individuals the treatment they need with a focus of integrating individuals back into community life and vocational opportunities. This report stated that the annual bill for treating mental illness in the United States is currently \$71 billion. In addition, they estimated that the cost of untreated mental illness is approximately \$300 billion each year in criminal justice and social welfare spending. Of this amount, \$20 to \$25 billion a year is spent on Social Security Disability payments to people the study described as "people who would rather work." People with mental illness now represent the largest and fastest growing group receiving Social Security Disability benefits. The Commission also estimated that approximately 90% of adults with serious mental illness are unemployed, and may want to work and could return to work with modest assistance.

### *Psychiatric and Vocational Rehabilitation*

The Rehabilitation Model of treatment can be described as an interdisciplinary, biopsychosocial approach that focuses on empowering individuals with a disability to act in a responsible manner, achieve maximum independence, and adjust to their disability with necessary accommodations in order to decrease limitations. It is a strength- and ability-focused model, which uses comprehensive case-management to assist individuals in all areas of their lives. Therefore, the goal of rehabilitation is to restore the highest level of functioning possible, not to cure or eliminate the disorder (Rubin & Roessler, 1995).

Vocational rehabilitation is not a new concept. There are several federal acts or laws that have been established over the past century to help reaffirm the need for vocational rehabilitation programs, as well as provide the financial support to keep these programs functioning. The first federal act was the Smith-Hughes Act of 1917, which offered federal financial matching for state vocational education programs. In 1918 the Soldier's Rehabilitation Act created vocational rehabilitation programs for the disabled veterans of World War I. The Smith-Fess Act of 1920, also known as the Civilian Vocational Rehabilitation Act, established vocational rehabilitation programs for civilians with a 50%-50% financial match guideline. The Social Security Act was passed in 1935, which gave vocational rehabilitation programs a permanent place among yearly federal funded programs. The scope of vocational rehabilitation continued to develop and in 1943 the Barden-Lafollette Act opened the way for mentally and psychiatrically disabled person to benefit from vocational rehabilitation programs. Training for vocational rehabilitation professionals was supported by government grants that were part of the 1954 Vocational

Rehabilitation Act. The Rehabilitation Act of 1973 advanced the civil rights of individuals with disabilities and stressed that recipients of rehabilitation services must be personally involved and approve of the treatment goals set up for their personal vocational rehabilitation plan. The Americans with Disabilities Act, which was passed in 1990, furthered and antidiscrimination provisions of the Rehabilitation Act of 1973 most notably in employment concerns.

According to Pratt, Gill, Barrett, and Roberts (1999) rehabilitation is important with any mental disease for three main reasons: the prevalence of mental illness, the cost of untreated and under-treated mental illness, and the impact mental illness has in all aspects of the individual's life. It is estimated that in the United States as many as 20 to 32 million people have a mental illness. Approximately 10% of that population experiences a long-term reduction in their capacity to perform age-appropriate activities, such as self-care, keeping house, and maintaining employment. Unemployment for the mentally ill who are experiencing difficulty performing these kinds of tasks is estimated to be as high as 85%. The impact of a mental illness is widespread due to the long lasting and severe nature of mental illness. Normal intellectual, social, and vocational development is often stunted, and previously acquired skills can be lost due to disuse (Pratt, Gill, Barrett, & Roberts, 1999).

There have been studies that have tried to determine how best to evaluate a individual with psychiatric disorders for vocational rehabilitation services, with a specific emphasis on return-to-work as a goal of treatment. One study investigated whether the impairing diagnosis was related to the outcome of vocational rehabilitation services, because as a group people with psychiatric disabilities have lower employment rates than other disability populations. This study

reported that a weak relationship existed between these two variables and called for more research to be done for predictors of successful work functioning (MacDonald-Wilson, Rogers, & Anthony, 2001). Another study noted that participation in a vocational rehabilitation readiness program and not individual characteristics including diagnosis was an important predictor of positive vocational outcomes (Blankertz & Robinson, 1996).

### *Psychiatric Disability Defined for This Study*

Disability is both a medical and a social concept. There are several possible definitions of disability. This study uses the Social Security Administration's definition, which outlines four major areas that must display impairment continuously present for at least 12 months:

1. Activities of daily living (e.g., grooming, hygiene, maintaining a household, managing finances),
2. Social functioning (with family, friends, community, and in the workplace),
3. Concentration, pace, and task persistence (ability to function for 6 to 8 hours without supervision), and
4. Ability to tolerate competitive work.

Iezzoni (2002) studied the advantages of using administrative data, specifically Social Security Disability determinations, for research. She stated that administrative data offered important advantages of allowing large populations to be accessible for research over various lengths of time with minimal costs. Administrative data is also easier to access, categorize, and interpret compared to typical research data options such as service utilization, claims payment, cost and quality of care, and other health service dependent data.

*Rehabilitation Research and DID*

Turkus (1991) described DID as:

A chronic dissociative disorder characterized by disturbances in memory and identity. The dissociative symptomatology is admixed with the numbing and intrusive symptoms of posttraumatic stress disorder. This leads to a chaotic lifestyle that includes acting out behaviors including self-destructive acts, substance abuse, and eating disorders; lack of goal direction; difficulties with relationships and intimacy; and lack of support system (p. 649).

Turkus discussed clinical case management as part of comprehensive treatment for chronically mentally ill patients, such as those with DID. She stated, “As a concept, case management is the antithesis of the [DID] lifestyle, because it strives to bring order out of chaos, to stabilize the patient in the community, and to encourage the highest level of functioning during treatment” (p. 649). She pinpointed the need for rehabilitation and case management because “despite the presence of intelligent and social alters, many patients with [DID] are woefully naive about living skills. Childhood abuse disrupts normal developmental steps and created cognitive distortions” (p. 655).

Turkus’ description of a person with DID and the “DID lifestyle” can be discouraging for a person or a clinician. Turkus is one of the few who have even broached the subject of rehabilitation for individuals with DID. Many researchers and clinicians continue to believe that this diagnosis is so severe and long-term in nature that permanent disability is a natural outcome. Turkus and others, such as Colin Ross and Steve Gold, have clinically commented on deficits in adaptive functioning skills, impaired or hindered psychological developmental stages, and



impaired social skills, but there has been no research to support these clinical observations (Ross, 2000; Gold, 2000).

Stewart Wakeman (2002) produced a descriptive review paper which applauded the benefits of psychiatric rehabilitation, viewed it as useful in a broad range of mental disorders, and believed that this approach needed to be utilized and studied for individuals who have survived severe trauma and who may dissociate. Wakeman firmly believed that this population could benefit from rehabilitation, and that rehabilitation would produce successful results. Judith Cook (2003) focused on the specific relationship between major depression, disability, and rehabilitation services for women. She found that rehabilitation programs failed to meet the specific needs of women with mental illness, especially women who suffered from major depression. Since research on DID indicates that a majority of people with the disorder will be female and will have depression, this research indicates that while rehabilitation can be useful for the individuals with dissociative disorders, specific techniques and research will need to be created for this population in order to maximize the benefits of the rehabilitation treatment model for DID.

## *Dissociative Identity Disorder*

### *Brief History of DID*

In the late 1800's, three leading theorists in psychology began to focus on dissociation and DID: the functionalist, William James, the psychoanalyst Sigmund Freud, and an early experimental psychologist, Alfred Binet. Binet, Freud, and James often mention Morton Prince's work, which will also be discussed..

William James believed that psychology should study the mental life, which he said included the stream of consciousness brought forth by experiences. To him, studying dissociation and DID provided key information concerning mental life in the rest of the population. James believed that all people had 'selves' who had different functions, desires, and activities. He often referred to examples such as the social self, the spiritual self, and the family self. What unified all these selves, who he stated were often in conflict, was the feeling of ownership in regard to the stream of consciousness. James explained that normal people have a stream of consciousness that links together the memories and separate parts of the self. James believed that in people affected by DID dissociation of ideas created different streams of consciousness that did not span across these different parts. He further stated in *The Principles of Psychology* (1890), that in order for the states of personality to change so thoroughly, so abruptly, and with different memories that the well-organized association paths in the brain must change and develop along with the alter states. He proposed that this physiologically-affected neurological path model explained how different alters could be present at the same events, or be unaware of events that were occurring to other alters.

Sigmund Freud and Josef Breuer co-authored *Studies on Hysteria* (1895), in which they addressed dissociation and DID as subsets of hysteria. Breuer's infamous patient, Anna O, was diagnosed as having DID and her case sparked Freud's interest in the workings of DID. Breuer and Freud stated that trauma which involved extreme emotional content was the cause of DID and dissociation. Unlike James, they believed that dissociation of ideas that were inadmissible to the consciousness of the primary self created a splitting of the mind. Freud believed this because he thought that splitting of the consciousness was impossible. He pointed to the fact that an alter self could recall the information that was inaccessible to the primary self to prove that the information was still in the consciousness somewhere. Freud proposed that the alters were defined by the memories they held that were inadmissible to the complete consciousness. He called for abreaction done with the assistance of hypnosis in order to bring those memories back into complete consciousness as the cure for DID and dissociation. Breuer and Freud also brought forth the idea that alters could affect other alters without direct contact or co-consciousness, such as through emotion and memory leakage.

In *Alterations of a Personality* (1896), Alfred Binet focused solely on DID and dissociation. Binet witnessed and tested patients who had DID or who dissociated, including tests of memory, hypnotizability, autonomic writing, and differences between alters' handwriting, speech, and intelligence. From this research he noted that there was a stable base of symptoms that linked DID patients. First, he noted that each alter had characteristics that differentiated them from another alter. These included: memory recall; their state or disposition; and their state of sensibility, movement, mental capacity, and physical differences or problems.

Some similarities he found in early cases were: headaches, loss/shift in appetite, body pains from psychological sources, highly hypnotizable, loss of time and memory, and different pain thresholds for different alters. Binet felt that studying people with DID and dissociation provided much information because "they magnify the phenomena that must necessarily be found to some degree in the case of many persons who have never shown hysterical symptoms" (p. 89). Binet agreed with Freud and Breuer on the belief that different alter states could affect and interact with each other, either directly or indirectly. He felt that something more "profound" than associationism must be working in the mind due to dissociation occurring even with frequently recurring memories or memories with strong affect/emotional content (p. 269). According to Binet, the process of dissociation was creating different consciousnesses, which could be identified by character and memory.

*The Dissociation of a Personality* (1905), by Morton Prince, provides case studies that are important because they offer much information about DID and dissociation, and they also offer an early cross-cultural study of these phenomena. Prince was much like James in his belief that studying cases of DID offered knowledge about the normal functioning of the human mind. Prince noted that the alters had distinct characteristics, including different trains of thought, views, tastes, habits, memories, ideals, and temperaments. He argued that the term double or multiple personality should be changed to "disintegrated" personalities. For Prince, each of the alters merely made up the whole, normal self, which had undergone a process of the personal ego breaking apart. Prince stressed that this was a process of disintegration and separation, and not degeneration or destruction. Furthermore, he made the distinction that patients with DID were

not insane, but "functionally dissociative" with their "elementary psychical processes" remaining normal. In addition, he said that since nothing was being destroyed in the process of dissociation, that the alters were "capable of being reassociated into a normal whole" (p. 3).

Ross (1989, 1997) and Duncan (1994) traced the history of DID from 1910 through 1980. Both authors describe this as a period of time in which dissociation and DID fell from interest and research due to several concurrent factors. Duncan referred to this time as when the field reached its full maturity and then experienced an unfortunate decline, so severe that dissociation and DID were eliminated almost completely from the field.

Ross (1989, 1997) and Duncan (1994) also described theoretical changes within psychology as one cause of decreased interest in DID. Research and theories based upon on learning and conditioning ushered the behavioral movement to the foreground. This school of psychology suppressed the study of dissociation and DID as being irrelevant and unnecessary. Furthermore, Freud broke away from Breuer and repudiated their earlier theory that childhood sexual trauma was the foundation and cause of hysteria. He insisted that the reports of incest and child abuse were really incestuous dreams and desires that women were having, which fit in to his theory of psychosexual development.

Another cause of decline in interest was attributed to the rise in attention given to schizophrenia. As Ross (1997) cited Rosenbaum's research on the history of DID, from 1914 to 1926 there were more diagnoses of DID than schizophrenia. In the late 20's and early 30's, Rosenbaum says that the diagnosis of schizophrenia "caught on." He said this was due to the field becoming more physiological and biological in focus. A sign of this pattern was also found

by Hilgard, as cited by Ross (1997). Hilgard found that 20 abstracts concerning dissociation and DID appeared in Psychological Abstracts from 1927 to 1936, eight from 1937 to 1946, two from 1947 to 1956, and only three abstracts from 1957 to 1966. Duncan (1994) stated that patients with DID would most likely be diagnosed schizophrenic or hysteric during this time frame.

Ross (1997) also cited an article published by Taylor and Martin in which 76 patients with DID from the US, France, Britain, Germany, and Switzerland were analyzed. They found that 49 of the patients had dual personalities, and that only six had five or more alters. They claimed that the causes of DID could be head injury, fatigue, intoxication, unbalanced urges, and excessive learning and forgetting. At that time, no mention of trauma surfaced in their study.

The next major time period ranged from the 1970's to the 1990's in which dissociation and DID began to be studied and taken seriously as their own entities once again. This period was marked by the publication of Hilgard's *Divided Consciousness* (1977). This book brought dissociation back to the research forefront. Two social influences that helped the resurgence were the attention to Post Traumatic Stress Disorder (PTSD) after the Vietnam War, and the attention to child abuse that the Women's Movement brought forth. The American Psychiatric Association's *Diagnostic and Statistical Manual of Mental Disorders, third edition* (DSM-III; 1980), officially adopted Multiple Personality Disorder as a diagnosis in the field of Psychiatry and Psychology. The DSM-IV (1994) changed the name of Multiple Personality Disorder to Dissociative Identity Disorder (DID).

War in the United States has provided the rehabilitation field with much of its support, legislation, funding, and early research. War also allowed major strides in the psychological field

because there were thousands of veterans with similar experiences of war, and yet very different outcomes of how they handled the trauma of war. After each war a different group of symptoms surfaced, each related to what we now call posttraumatic stress disorder (see Table 1).

Table 1: Symptoms of Post Traumatic Stress Disorder in Various U.S. Wars

Name & Symptoms:	<i>Civil War</i> “Irritable Heart”	<i>WWI</i> “Effort Syndrome”	<i>WWII</i> “Combat Stress Reaction”	<i>Vietnam War</i> “PTSD”	<i>Gulf War</i> “Gulf War Syndrome”
Fatigue	X	X	X	X	X
Shortness of Breath	X	X	X	X	X
Palpitations	X	X	X	X	
Headache	X	X	X	X	X
Excessive Sweating	X	X	X		
Dizziness	X	X	X	X	X
Disturbed Sleep	X	X	X	X	X
Fainting	X	X	X	X	X
Difficulty Concentrating		X	X	X	X
Forgetfulness			X	X	X
Muscle/Joint Pain				X	X

Adapted from Kaplan & Sadock’s (1998) *Kaplan and Sadock’s Synopsis of Psychiatry*. (p. 620)

It is not surprising that war is listed by Hilgard as one of the reasons for bringing dissociation and dissociative disorders back to mainstream psychology. But in the current climate of skepticism and fear, it is important for individuals and clinicians to remember that DID, dissociation, and even rehabilitation are not new ideas, or fads, but rather important concepts that have passed the test of time.

### *Criteria for DID*

The diagnostic criteria for Multiple Personality Disorder were first established in the DSM-III (1980). The DSM-IV (1994) changed the name of Multiple Personality Disorder to Dissociative Identity Disorder (DID). The current diagnostic criteria for Dissociative Identity Disorder are:

1. The presence of two or more distinct identities or personality states (each with its own relatively enduring pattern of perceiving, relating to, and thinking about the environment and self).
2. At least two of these identities or personality states recurrently take control of the person's behavior.
3. Inability to recall important personal information that is too extensive to be explained by ordinary forgetfulness.
4. The disturbance is not due to the direct physiological effects of a substance (e.g., blackouts or chaotic behavior during alcohol intoxication) or a general medical condition (e.g., complex partial seizures). Note: In children, the symptoms are not attributable to imaginary playmates or other fantasy play. (DSM-IV; 1994)

The most frequent precursor to DID is extreme physical, emotional, and sexual abuse in childhood, but survivors of other kinds of trauma in childhood (such as natural disasters, invasive medical procedures, war, and torture) have also reacted by developing DID. The most commonly reported secondary clinical features of DID are childhood abuse, previous clinical history, self-destructive behaviors, comorbidity, and headaches. The epidemiology of DID is estimated to be



between 1% and 3% of the general population, with women 3 to 9 times more likely than men to be diagnosed with DID (Ross, 1997).

### *Symptomatology of DID*

In a study done by Ross et al. (1991), sexual abuse was reported by 90.2% of the subjects, physical abuse by 82.4% subjects, and of those reporting abuse 95.1% stated that both physical and sexual abuse had occurred. Over 50% said the abuse started before the age of five, and the average duration was ten years, with several perpetrators (Ross et al., 1991). Ross (1997) stated that the average number of years spent in therapeutic treatment prior to diagnosis averaged 6.8 years. He also stated that the average number of previous diagnoses is 3.1.

Further research by Ross (1997) showed that an average of 45% of the DID patients interviewed had received a previous diagnosis of schizophrenia, 68.2% had previous schizophrenia or schizoaffective disorder diagnosis, and 74.3% had previous diagnosis of a psychotic disorder. One of the reasons for the high incident of inaccurate diagnoses of schizophrenic and schizoaffective disorder may be the tests used for diagnosis (Ross, 1997). Ellason and Ross (1995) compared 108 DID patients with 240 schizophrenic patients with the Positive and Negative Syndrome Scale, which was developed to differentiate schizophrenic subtypes. They found that the positive symptom scores were more severe in the group with DID while the negative symptom scores were more severe in the group with schizophrenia. Consequently, depending on which end of the scale is being focused on by the diagnosing professional, misdiagnosis can occur for either diagnosis. Schneiderian first rank symptoms (such as the experience of hearing thoughts as if externally audible, hearing voices arguing,

discussing, or commenting, believing thoughts are being withdrawn or influenced by outside forces, etc.) are also used to diagnose schizophrenia, but research has shown that individuals with DID present more Schneiderian symptoms than individuals with schizophrenia. A comparison of 1739 patients with schizophrenia and 368 patients with DID found that patients with schizophrenia averaged 1.3 symptoms, while patients with DID averaged 4.9 (Ross et al., 1990).

Self-destructive behaviors range from self-harm (such as self-inflicted wounds caused by cutting, burning, or puncturing the skin or breaking bones) to completion of suicide. Ross (1997) found that 92% of patients with DID had recurrent suicidal thoughts, while 72.5% attempted suicide. A history of self-inflicted injuries or drug overdoses were reported by 23.5% of patients with DID. Another common feature found is the experience of frequent and severe headaches, occurring in 78.7% of DID patients. Comorbidity rates for meeting other diagnostic criteria in the lifetime are: 98.1% for mood disorder, with most qualifying for depression; 79.2% for Post Traumatic Stress Disorder; 65.4% for substance abuse; 41.4% somatization disorder; and 38.3% for eating disorder (Ross, 1997).

## *Dissociation and Other Disorders*

### *What is Dissociation*

Dissociation is sometimes confused with the psychoanalytical idea of repression. Repression is defined in Kaplan and Sadock's *Synopsis of Psychiatry* (1998) as a "defense mechanism characterized by unconscious forgetting of unacceptable ideas or impulses" (p. 285). Dissociation is defined as an "unconscious defense mechanism involving the segregation of any group of mental or behavioral processes from the rest of the person's psychic activity" (p. 285). In this case, it's not hard to see why there is confusion, since both are described as unconscious defense mechanisms.

Jon Allen defined dissociation in his book *Coping With Trauma* (1995) as a concept that is being overused to describe a broad range of different ideas and experiences. He narrowed down the key difference between dissociation and repression by defining dissociation as "an emergency defense" that is used when the consciousness of a person is being overwhelmed by incoming stimuli that is often seen as threatening and is often in a situation where physical flight from the stimuli is not an option. Therefore, mental flight occurs, and the brain compensates by altering consciousness through dissociation so the experience is excluded from normal perception. Allen explains that this alteration may take the form of splitting memory apart into pieces (such as the BASK Model which is an acronym for behavior, affect, sensation, and knowledge splits in memory) or by splitting the memory into an altered consciousness (which in DID would be an alternate personality state).

It is important to know that dissociation is seen as a normal skill, occurrence, or ability that can be used to pathological and nonpathological levels. Many in the field believe that dissociative experiences fall along a continuum from normal (such as day dreaming) to pathological levels and types dissociation (such as dissociative disorders). This ability or skill is thought to be stronger in some people than others. Research has been done on twins to determine the influence of genetics on dissociative capacity. The correlation between genetics and dissociative capacity was .91, suggesting that dissociation is more than just an environmentally caused phenomena (Jang, Paris, Zweig-Frank, & Livesley, 1998).

It is also believed that repeated trauma, or repeated need to use dissociation, makes it easier for the brain to shift into dissociative modes, thus creating a learned response that may make dissociation overused as a coping mechanism. This learned response may also account for why dissociation continues to be used as the main coping mechanism even after the trauma ends, and even in less-threatening less-traumatic situations that arise after the initial dissociative response.

#### *Research on Dissociation in Other Disorders*

Many of the disorders frequently seen as comorbid with DID have utilized dissociative scales in research to predict treatment outcome and long-term prognosis. These studies often use the Dissociative Experience Scale (DES), which is also used in this present study. The DES is a 28-item self-report scale that measures the frequency of experiencing certain types of dissociative experiences. This test was originally designed to help diagnose dissociative

disorders, but has commonly been used to try to assess severity of dissociative experiences in individuals who do not have a dissociative disorder.

The relationship between dissociative experiences and childhood or adulthood abuse, as well as the differences between physical and sexual abuse incidents, was evaluated using the DES. Higher rates of dissociation were significantly correlated to multiple episodes of abuse and combined types of abuse in both childhood and adulthood. For childhood abuse the presence of physical abuse and father-perpetrated sexual abuse were also significantly correlated (Lipschitz, Kaplan, Sorkenn, Chorney, & Asnis, 1996). Research done in Japan with female outpatients with eating disorders and a history of childhood abuse showed a stronger correlation between physical abuse and high rates of dissociation than between sexual abuse and dissociation (Berger et al., 1994). Borderline personality disorder, another disorder group that often has experienced childhood abuse, has also been studied with the DES. Shearer (1994) found that DES scores were correlated to adult sexual assault, behavior dyscontrol, and combined abuse in childhood. Furthermore, individuals who were diagnosed with borderline personality disorder and had high levels of dissociative phenomena tended to self-report more traumatic experiences, more post traumatic symptoms, a higher incidence of behavior dyscontrol and self-injury, as well as alcoholism.

Individuals with panic disorders have been compared to individuals with nonpanic anxiety disorders using the DES by Ball, Robinson, Shekhar, and Walsh (1997). It showed no difference in the rates of dissociation between the groups, but noticed that individual correlates of dissociation were depression severity, social anxiety, and the presence of comorbid

personality disorders. Schimmel (2003) used the DES to compare adults with panic disorder versus adults with generalized anxiety disorder, and found that individuals with panic disorder dissociate significantly more. One study done with the DES and individuals with chronic pain disorders found that this group had a higher frequency of dissociation than populations of normal adults, adults with alcohol use disorder, and adults with specific phobias or agoraphobic disorders. In addition to this frequent dissociation, those individuals who had also experienced trauma in their life had a markedly higher level of dissociation (Duckworth, Iezzi, Archibald, Haertlein, & Klink, 2000).

These studies are of interest because they show that dissociation occurs in more than just individuals with dissociative disorders and may be currently overlooked in treatment of individuals who do not have a diagnosed dissociative disorder. There has also been research that has attempted to predict treatment outcome and long-term prognosis using measurements of dissociation. These studies can help play a major role in reshaping treatment and rehabilitation services. For instance, a three month study carried out immediately following a traumatic event measured peritraumatic dissociation, acute stress, and PTSD, and found that dissociative experiences were a strong predictor of developing PTSD. The researchers of this study firmly believed that these predictors could be used to identify individuals at early stages of distress and disordered behavior in an attempt to reduce their risk of remaining symptomatic over a long period of time (Birmes et al., 2003). Another study done by Bremner and Brett (1997) measured dissociative and flashback experiences in veterans and found that higher levels of dissociation were predictive of long-term psychopathology.

Other groups that have been studied using the DES to help evaluate a correlation between dissociation levels and treatment outcome include brain injury and substance abuse populations. Mooney and Speed (2001) found that recovery outcomes dropped for individuals with mild traumatic brain injuries who experienced a comorbid psychiatric disorder following the brain injury. Common disorders included depression, anxiety, and conversion disorders. Overall, DES scores predicted treatment outcome 77% of the time. Wenzel et al. (1996) found that the DES scores were significantly correlated to the overall length of time alcohol or cocaine was abused. A study done in Israel by Somer (2003) found higher levels of dissociation were predictive of substance abuse relapse following treatment.

There are two critical research projects using the DES that must not be ignored by clinicians in the rehabilitation field. First, Michaels et al. (1998) discovered that dissociation scores taken at admission were able to predict return-to-work outcomes following a trauma in that higher DES scores indicated a less likely return to work status. Criteria that were not useful as predictors included previous employment history, previous psychological diagnoses, the severity of the injury, or the level of ambulation. Walker et al. (1992) found that women with chronic pain were not only more inclined to dissociate, but also exhibited more psychological distress, labeled themselves as “disabled”, and reported functional impairment in vocational and social arenas when compared to women who did not have a history of chronic pain. Individuals with higher levels of dissociation viewed themselves as more functionally and physically impaired.

While the DES is often used when evaluating a person for the presence of dissociative disorders, no research studies to date have examined its potential usefulness in predicting treatment outcome, long-term prognosis, or potential for rehabilitation in individuals with DID. If other disorders, both psychological and physical in nature, are finding the DES information useful, why is the dissociative disorder field not evaluating it? One assumption would be that treatment for dissociative disorders treats the underlying dissociative experiences. Research by Ross and Ellason (2001) demonstrated that inpatient DID treatment produced lowered scores on the Beck Depression Inventory, the Beck Scale for Suicidal Ideation, the Beck Hopelessness Scale, and the Symptom Checklist-90-Revised, but no change was seen on the DES scores. This could be an indication that the types or severity of dissociation being measured by the DES is more stable over time and that treatment may need to specifically address dissociation processes in order to produce measurable improvement in this area.

There are many aspects of how DID affects people's lives that have not yet been studied, although some have been covered in case studies and anecdotal information. These include how DID affects personal and family relationships, vocational choices and performance, marriage, parenting, and other issues that affect the individual who has DID and the people who are a part of their lives. The immediate goal of this study is to determine if there are differences between people who have been diagnosed with DID and receive governmental disability benefits based on their DID diagnosis versus those who have been diagnosed with DID but do not receive benefits. If specific differences can be found between these two groups, then there may be a difference in severity of DID or a difference in how the DID affects the individuals in both



groups, with the assumption that those receiving benefits would display a higher level of severity or complexity of DID symptoms. By understanding these differences, rehabilitation therapy can then attempt to restore and maintain the highest possible level of functioning in these areas to minimize the negative impact DID can cause in a person's life.

### *Hypotheses*

This study will attempt to look at factors other than the presence of DID to assist clinicians in identifying individuals who are at risk for disability. The hypotheses for this study are:

- Hypothesis 1: The disability group will show an overall pattern of more previous diagnoses, more years spent in treatment prior to DID diagnosis, and more inpatient hospitalizations.
- Hypothesis 2: The disability group will show an overall pattern of a later age of diagnosis or awareness of DID.
- Hypothesis 3: The disability group will show an overall pattern of a higher incidence of childhood abuse and adult revictimization.
- Hypothesis 4: The disability group will show differences on the DES reflecting a higher level of overall dissociation or differences in specific types of dissociative experiences reported.

## Methods

### *Participants*

There were 132 total participants, with 90 in the non-disability group and 42 in the disability group (Table 2). The participants were predominantly women, with only 3 males in the each group. Eighteen participants reside in countries other than the United States. In the disability group there were two participants from the United Kingdom, and one from each of the following countries: Australia, Canada, and the Netherlands. In the non-disability group there were nine participants from Canada, and one from each of the following countries: Australia, Belgium, the Netherlands, and the United Kingdom. The majority of the participants were Caucasian. In the disability group there were three individuals who reported they were Native American, and one African American. In the non-disability there were five reported Native Americans, and one from each of the following ethnic descriptions: African American, Asian, Hispanic, and Multi-Ethnic.

The difference in age of the respondent at the time that they completed the questionnaire was found to be statistically significant between the two groups. The mean age for the disabled group was 39.0 ( $\pm 8.7$ ), and the mean age for the non-disabled group was 35.1 ( $\pm 8.9$ ). Based on the results of the independent t-test, the disabled group had a significantly higher age at time of completing the questionnaire ( $t(130) = 2.3$ ,  $p = .02$ ). Since age was found statistically different between the groups, the remaining interval data was evaluated with age as a covariate to ensure that age was not the cause of the differences found.

Table 2: Demographics:

	<u>Disability Group</u>	<u>Non-Disability Group</u>
<i>General Information:</i>		
Average Age <sup>1</sup>	38.98 ( $\pm$ 8.7)	35.11 ( $\pm$ 8.9)
Female	39 (92.9%)	87 (96.7%)
Male	3 (7.1%)	3 (3.3%)
Total	42 (31.8% of all participants)	90 (68.2% of all participants)
<i>Ethnicity:</i>		
African American	1 (2.4%)	1 (1.1%)
Asian	0 (0.0%)	1 (1.1%)
Caucasian	38 (90.5%)	81 (90.0%)
Hispanic	0 (0.0%)	1 (1.1%)
Multi-Ethnic	0 (0.0%)	1 (1.1%)
Native American	3 (7.1%)	5 (5.6%)
<i>Location:</i>		
Australia	1 (2.4%)	1 (1.1%)
Belgium	0 (0.0%)	1 (1.1%)
Canada	1 (2.4%)	9 (10.0%)
Netherlands	1 (2.4%)	1 (1.1%)
United Kingdom	2 (2.4%)	1 (1.1%)
United States	37 (88.1%)	77 (85.6%)

<sup>1</sup>  $t(130)=2.3, p = .02$ *Inclusion/Exclusion Criteria**Inclusion:*

- Nickname recognized as group member
- Completed questionnaire within two week time frame
- Responded that they had received a diagnosis of DID and had been in therapy for DID
- Included in Disabled group if currently receiving governmental disability benefits related to DID diagnosis

*Exclusion:*

- Responded that they had never been diagnosed or treated for DID
- Did not complete the DES at all or left more than 5 questions blank
- Left more than 10 questions blank, excluding DES, abuse, and optional Disability or Employment sections
- Excluded from both groups if receiving governmental disability benefits related to physical impairment

*Procedure*

All participants were actively involved with Internet-based peer support and discussion groups for people with DID. Participants in these support groups were asked to volunteer their time in order to complete a questionnaire and a copy of the DES, which was posted on a private web page on the Internet and could only be accessed by group participants. The web site

remained accessible for two weeks and then was closed to prevent search engines from making the site public knowledge.

Participants were asked to provide their nickname, which was checked against the known support group members. If a nickname was not recognizable as a group member, they were deleted to prevent possible duplications or people possibly filling out the form who were not members of the group. This was to help limit erroneous or false information in the data because it was assumed that only people who believed they had DID would be participating in the support groups that had been invited to join the study. Email addresses were collected on an optional basis as a way of contacting participants who wished to know when the final research was available for their review.

Data from the web site was sent in an email form to a private email account set up solely for the purpose of receiving the data. Data was then imported directly into Microsoft Excel. This ensured that no data would be lost, mistyped, or attributed to the wrong respondent. Each data file was given a number for tracking, and the nickname and optional email information was removed to prevent bias when dealing with the data and to protect confidentiality. Data was only handled by the researcher, who created the web site, received the emailed data, imported the data, and then performed the statistical analysis of the data.

Questionnaires were considered incomplete and unacceptable for inclusion in this study if the respondent had not been diagnosed with DID, did not complete the DES, or left more than 10 questions blank excluding the optional sections and the abuse history section. Participants were then split into groups according to receipt or non-receipt of government disability benefits.

Individuals were included in the disability group if their government disability status was based on mental illness diagnoses that included MPD or DID. Three females who were in the disability group were removed from the study because their disability status also included significant disability diagnoses that were not related to DID or related psychiatric disabilities (one was legally blind, had severe deafness, and had Klippel Feil Syndrome; one had Cerebral Palsy and epilepsy; and the third female had a traumatic brain injury history and was currently quadriplegic as a result of her injuries).

Data from close-ended questions required no modification. The answers for open-ended questions were used to create a list of possible answers, allowing each person's response to become an endorsed versus not endorsed nominal value on which statistical analysis could be performed. No response was left unnoted or unaccounted for. Some open-ended questions were not analyzed because they were frequently skipped, incomplete, or answered in ways that did not provide enough information for meaningful statistical analysis.

### *Materials*

Each participant completed a copy of the Dissociative Experiences Scale (DES) (Appendix A). The DES is a 28-item visual-analog self-report rating scale. On the web form, this was presented as a check box that allowed participants to pick only one value per question, in the same increments of 10 used on the standard DES.

The DES was developed to be a screening instrument for dissociative disorders, and has been found to reliably discriminate patients with DID from other diagnostic groups and normal controls. The DES has also been shown to have a test-retest reliability of 0.84 (Bernstein &

Putnam 1986; Ross, Norton & Anderson 1988). Each question has a possible score of 0 to 100, in increments of 10, based on frequency of occurrence in the respondent's experiences. The scores are then summed, divided by the total number of questions, and a final score of 0 to 100 is reached. Scores above 30 are correlated with a high likelihood of a dissociative disorder.

The remainder of the questionnaire was created using materials including the DSM-IV criteria and clinical features for DID, research concerning clinical features and comorbidity for DID, and research concerning the role of past history of abuse in DID.

#### *Institutional Review Board*

The University of Texas Southwestern Medical Center's Institutional Review Board was presented a copy of the questionnaire and disclosure statement that participants received, an overview of the purpose of this study, and an overview of the methods used for finding participants and handling participant data. It was decided that since the participants were not seeking services (treatment, research, therapy, etc.) from the University of Texas Southwestern Medical Center that the data did not need to be reviewed and accepted by the Institutional Review Board as it was deemed to be my personal data instead of property of the University of Texas Southwestern Medical Center.

#### *Statistical Analysis*

Pearson's Chi-Square and Fisher's Exact Tests were used to interpret nominal data. Since age was determined to be statistically significant based on the independent t-test, age was treated as a covariate and Univariate Analysis of Variance tests were run to evaluate all interval data. All statistical analyses were done with SPSS.

## Results

### *Demographics*

Demographics were previously presented as Table 2 in the methods section. The difference in age of the respondent at the time that they completed the questionnaire was found to be statistically significant between the two groups ( $t(130) = 2.3$   $p = .02$ ). The mean age for the disabled group was  $39.0 (\pm 8.7)$ , and the mean age for the non-disabled group was  $35.1 (\pm 8.9)$ . No statistical differences were found based on gender, ethnicity, or geographical location.

### *Therapy & Treatment History*

Two significant differences were found in therapy and treatment history (Table 3). First, the disabled group was found to have spent a longer time in therapy for DID and non-DID related issues, averaging  $13.4 (\pm 8.6)$  years compared to  $8.7 (\pm 5.3)$  years for the non-disabled group ( $F(2, 130) = 10.1$ ,  $p = .00$ ). In addition, the disabled group had significantly more time in therapy prior to being diagnosed with DID ( $F(2, 130) = 5.5$ ,  $p = .02$ ), averaging  $7.4 (\pm 7.8)$  years compared to  $4.5 (\pm 4.0)$  years for the non-disabled group. Potential causes for this difference may be the presence of a more complicated clinical presentation or a failure to be properly diagnosed by mental health professionals causing an extended duration of therapy.

Significant differences were not found between the two groups based on the age DID was diagnosed or became common knowledge, the age therapy began, or the duration of therapy for DID. Furthermore, the past history of a psychiatric hospitalization, the age of the first psychiatric hospitalization, and the number of psychiatric hospitalizations were not significantly different. Data from the question concerning present medications were not analyzed.



Therefore, Hypothesis 1 is partially accepted because the disabled group had spent significantly more years in therapy prior to the DID diagnosis compared to the non-disabled group. Hypothesis 1 is also partially rejected because there was no difference found in the number of previous diagnoses or in the number of previous inpatient hospitalizations between the two groups. Hypothesis 2 is rejected because no difference in age at diagnosis or DID awareness was found between the disabled and non-disabled group.

Table 3: Therapy/Treatment History:

Description	Disabled	Mean $\pm$ SD	ANCOVA
Age DID was diagnosed or became common knowledge among majority of dominant personalities	Yes (n=42)	31.6 $\pm$ 9.3	N.S. <sup>1</sup>
	No (n=90)	29.7 $\pm$ 9.0	
Age first entered therapy	Yes (n=42)	24.2 $\pm$ 9.2	N.S.
	No (n=90)	22.3 $\pm$ 10.2	
<b>Total duration of therapy (years)</b>	<b>Yes (n=42)</b>	<b>13.4 <math>\pm</math> 8.6</b>	<b>F(2, 130) = 10.1</b> <b>p = .00</b>
	<b>No (n=90)</b>	<b>8.7 <math>\pm</math> 5.3</b>	
Duration of therapy prior to DID diagnosis (years)	Yes (n=42)	7.4 $\pm$ 7.8	F = 5.5 p = .02
	No (n=90)	4.5 $\pm$ 4.0	
Duration of therapy for DID (years)	Yes (n=42)	4.3 $\pm$ 1.8	N.S.
	No (n=90)	4.7 $\pm$ 1.8	
Age of first psychiatric hospitalization	Yes (n=42)	26.5 $\pm$ 9.9	N.S.
	No (n=90)	23.6 $\pm$ 9.1	
Number of psychiatric hospitalizations	Yes (n=42)	5.7 $\pm$ 5.1	N.S.
	No (n=90)	3.8 $\pm$ 3.8	

Description <sup>2</sup>		Non-Disabled (n=90)	Disabled (n=42)
History of Psychiatric Hospitalization	Yes	57 (63.3%)	32 (76.2%)
	No	33 (36.7%)	10 (23.8%)

<sup>1</sup> N.S. = Not Statistically Significant

<sup>2</sup> Pearson's Chi-Square and Fisher's Exact showed no significant differences unless otherwise noted

### Other Diagnoses

Common comorbid conditions that affect individuals with DID were used to create the conditions listed for Table 4: Other Diagnoses. An open-ended question asking for other psychiatric diagnoses was used to create the list of psychiatric conditions listed as Table 5: Other

Diagnoses – Psychiatric. No significant differences were found between the two groups in either of these tables except for Borderline Personality Disorder

Tables 4 and 5 reflect similarities to research on DID completed by Ross (1997). Ross found that 79.2% of people with DID also had a diagnosis of PTSD, and this current study found an overall average of 80.3%. Ross found 72.5% had attempted suicide, and this study found 74.2%. Frequent headaches were reported 78.7% in Ross' study, and 75.0% in this study. The average duration of therapy prior to the DID diagnosis was 6.8 years in Ross' research, and 6.0 years to be the average of the two groups of this study.

Table 4: Other Diagnoses:

Description	Disabled	Mean $\pm$ SD	ANCOVA
Sum of Common Comorbid Problems	Yes (n=42)	6.3 $\pm$ 1.9	N.S. <sup>1</sup>
	No (n=90)	5.8 $\pm$ 1.9	

Description <sup>2</sup>		Non-Disabled (n=90)	Disabled (n=42)
Asthma	Yes	31 (34.3%)	19 (45.2%)
	No	59 (65.6%)	23 (54.8%)
Irritable Bowel Syndrome	Yes	33 (36.7%)	16 (38.1%)
	No	57 (63.3%)	26 (61.9%)
Depression	Yes	88 (97.8%)	40 (95.2%)
	No	2 (2.2%)	2 (4.8%)
Substance Abuse	Yes	31 (34.4%)	19 (45.2%)
	No	59 (65.6%)	23 (54.8%)
Post Traumatic Stress Disorder	Yes	72 (80.0%)	34 (81.0%)
	No	18 (20.0%)	8 (19.0%)
Eating Disorder	Yes	52 (57.8%)	29 (69.0%)
	No	38 (42.2%)	13 (31.0%)
Self-Harm/Mutilation	Yes	66 (73.3%)	30 (71.4%)
	No	24 (26.7%)	12 (28.6%)
Suicide Attempt	Yes	64 (71.1%)	34 (81.0%)
	No	26 (28.9%)	8 (19.0%)
Seizures	Yes	17 (18.9%)	11 (26.2%)
	No	73 (81.1%)	31 (73.8%)
Severe or Recurring Headaches	Yes	66 (73.3%)	33 (78.6%)
	No	24 (26.7%)	9 (21.4%)

<sup>1</sup> N.S. = Not Statistically Significant

<sup>2</sup> Pearson's Chi-Square and Fisher's Exact showed no significant differences unless otherwise noted

Some differences were also found between this study and Ross' research. Ross reported 65.4% had a previous diagnosis of substance abuse, but only 37.9% of the participants in this study reported that. But 61.4% reported a previous eating disorder, while Ross found 38.3%. Of particular interest are the differences found concerning previous diagnoses of schizophrenia (Ross = 68.2%, current = 3.0%) and schizoaffective disorder (Ross = 45%, current = 6.8%).

Table 5: Other Diagnoses - Psychiatric:

Description	Disabled	Mean $\pm$ SD	ANCOVA
Sum of Other Psychiatric Diagnoses	Yes (n=42)	1.7 $\pm$ 1.2	N.S. <sup>1</sup>
	No (n=90)	1.5 $\pm$ 0.9	

  

Description <sup>2</sup>		Non-Disabled (n=90)	Disabled (n=42)
None	Yes	38 (42.2%)	15 (35.7%)
	No	52 (57.8%)	27 (64.3%)
Attention Deficit/Hyperactivity Disorder	Yes	2 (2.2%)	1 (2.4%)
	No	88 (97.8%)	41 (97.6%)
Anxiety Disorders	Yes	15 (16.7%)	8 (19.0%)
	No	75 (83.3%)	34 (81.0%)
Avoidant Personality Disorder	Yes	3 (3.3%)	2 (4.8%)
	No	87 (96.7%)	40 (95.2%)
Bipolar Disorder	Yes	19 (21.1%)	6 (14.3%)
	No	71 (78.9%)	36 (85.7%)
<b>Borderline Personality Disorder (Fisher's Exact (1 &amp; 2 sided) = .01)</b>	<b>Yes</b>	<b>9 (10.0%)</b>	<b>12 (28.6%)</b>
	<b>No</b>	<b>81 (90.0%)</b>	<b>30 (71.4%)</b>
Histrionic Personality Disorder	Yes	1 (1.1%)	1 (2.4%)
	No	89 (98.9%)	41 (97.6%)
Obsessive-Compulsive Disorder	Yes	3 (3.3%)	2 (2.4%)
	No	87 (96.7%)	40 (95.2%)
Panic Attacks	Yes	8 (8.9%)	3 (7.1%)
	No	82 (91.1%)	39 (92.9%)
Schizoaffective Disorder	Yes	1 (1.1%)	3 (7.1%)
	No	89 (98.9%)	39 (92.9%)
Schizophrenia	Yes	5 (5.6%)	4 (9.5%)
	No	85 (94.4%)	38 (90.5%)

<sup>1</sup> N.S. = Not Statistically Significant

<sup>2</sup> Pearson's Chi-Square and Fisher's Exact showed no significant differences unless otherwise noted

### *Abuse History*

Many participants responded to the abuse history questions in such a way that it was not possible to use the data gathered for “age abuse began” and “duration of abuse.” Therefore, the data was altered into a nominal format to measure if abuse was reported, the types of abuse experienced, and the relationship to perpetrators or the types of perpetrators. These results should be taken with caution because many people did not respond to this section, or responded only to parts of it because they said it was too emotionally difficult or they stated that amnesia related to the DID hindered their ability to accurately respond (for example, they may have known they were abused but may not have known who to list as perpetrators, or they may have had a vague notion that there was more abuse that they didn’t have access to the memories concerning yet they believed a different alter personality knew the details).

Three significant differences were in the childhood abuse history data (Table 6). Childhood physical abuse committed by extended family members (such as uncles, aunts, or cousins) was reported more frequently by the non-disabled group (21.4% versus 8.9%), sexual abuse committed by friends of family was reported more frequently by the non-disabled group (26.2% versus 12.2%), and verbal/emotional abuse committed by parents was reported more frequently by the non-disabled group (88.1% versus 71.1%).

Table 6: Childhood Abuse History\*:

	Physical Abuse		Sexual Abuse		Verbal/Emotional Abuse	
	Non-Disabled	Disabled	Non-Disabled	Disabled	Non-Disabled	Disabled
<i>Overall</i>	35 (83.3%)	71 (78.9%)	40 (95.2%)	83 (92.2%)	40 (95.2%)	81 (90.0%)
Parents	30 (71.4%)	57 (63.3%)	30 (71.4%)	53 (58.9%)	<b>37 (88.1%)<sup>3</sup></b>	<b>64 (71.1%)<sup>3</sup></b>
Grandparents	1 (2.4%)	4 (4.4%)	3 (7.1%)	10 (11.1%)	2 (4.8%)	5 (5.6%)
Extended Family	<b>9 (21.4%)<sup>1</sup></b>	<b>8 (8.9%)<sup>1</sup></b>	16 (38.1%)	21 (23.3%)	8 (19.0%)	13 (14.4%)
Siblings	4 (9.5%)	14 (15.6%)	6 (14.3%)	16 (17.8%)	4 (9.5%)	12 (13.3%)
Cult	1 (2.4%)	3 (3.3%)	2 (4.8%)	4 (4.4%)	1 (2.4%)	2 (2.2%)
Friends of Family	3 (7.1%)	3 (3.3%)	<b>11 (26.2%)<sup>2</sup></b>	<b>11 (12.2%)<sup>2</sup></b>	3 (7.1%)	4 (4.4%)
Neighbors/Acquaintances	1 (2.4%)	5 (5.6%)	7 (16.7%)	20 (22.2%)	2 (4.8%)	6 (6.7%)
Strangers	0 (0.0%)	3 (3.3%)	3 (7.1%)	6 (6.7%)	2 (4.8%)	2 (2.2%)
Friends	0 (0.0%)	1 (1.1%)	1 (2.4%)	2 (2.2%)	1 (2.4%)	1 (1.1%)

\* Pearson's Chi-Square and Fisher's Exact showed no significant differences unless otherwise noted

<sup>1</sup> Fisher's Exact = .055 (2 sided); .045 (1 sided)

<sup>2</sup>  $\chi^2$  (1, N=132) = 4.0, p = .05

<sup>3</sup>  $\chi^2$  (1, N=132) = 4.6, p = .03

Description	Disabled	Mean $\pm$ SD	ANCOVA
Sum of Types of Childhood Abuse	Yes (n=42)	2.7 $\pm$ 0.6	N.S. <sup>1</sup>
	No (n=90)	2.6 $\pm$ 0.7	
Sum of Types of Childhood Perpetrators	Yes (n=42)	4.5 $\pm$ 2.3	N.S.
	No (n=90)	3.9 $\pm$ 2.3	

<sup>1</sup> N.S. = Not Statistically Significant

No significant differences were found based on types of child abuse experienced, the number of types of child abuse individuals experienced, nor the number of perpetrators categories that answers were divided into. Significant differences were also not found between the two groups when comparing the remaining perpetrator groups: grandparents, siblings, cult, neighbors/acquaintances, strangers, or friends.

One significant difference was found in the adulthood abuse/revictimization history data (Table 7). Adulthood physical abuse committed by strangers was reported more frequently by the non-disabled group (7.1% versus 0.0%). No significant differences were found based on types of adult abuse/revictimization experienced, the number of types of adult abuse/ revictimization individuals experienced, not the number of perpetrators categories that answers were divided

into. Significant differences were also not found between the two groups when comparing the remaining perpetrator groups: parents, extended family, siblings, friends of family, neighbors/acquaintances, friends, dating significant other, or spouse.

Table 7: Adulthood Abuse/Revictimization History<sup>\*</sup>:

	Physical Abuse		Sexual Abuse		Verbal/Emotional Abuse	
	Non-Disabled	Disabled	Non-Disabled	Disabled	Non-Disabled	Disabled
<i>Overall</i>	21 (50.0%)	32 (35.6%)	23 (54.8%)	49 (54.4%)	21 (50.0%)	45 (50.0%)
Parents	2 (4.8%)	3 (3.3%)	2 (4.8%)	3 (3.3%)	6 (14.3%)	8 (8.9%)
Extended Family	3 (7.1%)	2 (2.2%)	3 (7.1%)	2 (2.2%)	0 (0.0%)	0 (0.0%)
Siblings	1 (2.4%)	0 (0.0%)	1 (2.4%)	0 (0.0%)	1 (2.4%)	4 (4.4%)
Friends of Family	1 (2.4%)	0 (0.0%)	0 (0.0%)	1 (1.1%)	1 (2.4%)	1 (1.1%)
Neighbors/Acquaintances	0 (0.0%)	1 (1.1%)	3 (7.1%)	8 (8.9%)	0 (0.0%)	3 (3.3%)
Strangers	<b>3 (7.1%)<sup>1</sup></b>	<b>0 (0.0%)<sup>1</sup></b>	4 (9.5%)	8 (8.9%)	1 (2.4%)	0 (0.0%)
Friends	0 (0.0%)	1 (1.1%)	0 (0.0%)	6 (6.7%)	1 (2.4%)	0 (0.0%)
Dating Significant Other	7 (16.7%)	9 (10.0%)	7 (16.7%)	18 (20.0%)	7 (16.7%)	13 (14.4%)
Spouse	7 (16.7%)	19 (21.1%)	7 (16.7%)	18 (20.0%)	9 (21.4%)	27 (30.0%)

<sup>\*</sup> *Pearson's Chi-Square and Fisher's Exact showed no significant differences unless otherwise noted*

<sup>1</sup> Fisher's Exact (1 & 2 sided) = .031

Description	Disabled	Mean ± SD	ANCOVA
Sum of Types of Adulthood Abuse/Revictimization	Yes (n=42)	1.5 ± 1.3	N.S. <sup>1</sup>
	No (n=90)	1.4 ± 1.3	
Sum of Types of Adulthood Perpetrators	Yes (n=42)	1.8 ± 2.0	N.S.
	No (n=90)	1.7 ± 1.9	

<sup>1</sup> *N.S. = Not Statistically Significant*

For childhood abuse, law enforcement was notified by 13 (31.0%) of the non-disabled group and by 24 (26.7%) of the disabled group. Adulthood abuse/revictimization was reported to law enforcement by 15 (35.7%) of the non-disabled group and by 19 (21.1%) of the disabled group. While no significant differences were found between the two groups when it came to law enforcement involvement, it should be noted how rarely abuse is reported, even in adulthood.

Hypothesis 3 is rejected because the differences found between the groups showed higher incident patterns related to specific perpetrators of childhood and adulthood abuse for the non-disabled group only. This result should be taken with a cautionary note that many individuals

answered in an incomplete manner due to the emotional difficulty related to describing their abuse and the amnesia and dissociation that surrounds their abuse recall.

### *Social Support*

One statistically significant difference between the two groups was found in Table 8: Social Support. The percentage of relationships that know about the DID diagnosis was significantly higher in the disabled group which averaged 42.2% ( $\pm 34.8$ ) compared to 19.9% ( $\pm 27.6$ ) for the non-disabled group ( $F(2, 130) = 16.0, p = .00$ ).

Table 8: Social Support:

Description	Disabled	Mean $\pm$ SD	ANCOVA
<b>Percentage of relationships which know of DID/MPD diagnosis</b>	<b>Yes (n=42)</b>	<b>42.2 <math>\pm</math> 34.8</b>	<b>F(2, 130) = 16.0 p = .00</b>
	<b>No (n=90)</b>	<b>19.9 <math>\pm</math> 27.6</b>	
Percentage of relationships which are supportive concerning DID/MPD	Yes (n=42)	39.5 $\pm$ 39.5	N.S. <sup>1</sup>
	No (n=90)	27.8 $\pm$ 34.5	
Percentage of relationships which reacted negatively and are not supportive concerning DID/MPD	Yes (n=42)	45.9 $\pm$ 38.7	N.S.
	No (n=90)	34.1 $\pm$ 34.7	

  

Description <sup>2</sup>		Non-Disabled (n=90)	Disabled (n=42)
DID/MPD hinders ability to make and/or keep close relationships	Yes	87 (96.7%)	37 (88.1%)
	No	3 (3.3%)	5 (11.9%)
DID/MPD negatively affects relationships with family and friends	Yes	83 (92.2%)	36 (85.7%)
	No	7 (7.8%)	6 (14.3%)
Experience difficulty reaching out to others for help	Yes	83 (92.2%)	36 (85.7%)
	No	7 (7.8%)	6 (14.3%)
Current involvement with a church/religious support network	Yes	29 (32.2%)	11 (26.2%)
	No	60 (66.7%)	31 (73.8%)
Current involvement with a support/therapy group	Yes	35 (38.9%)	22 (52.4%)
	No	54 (60.0%)	20 (47.6%)

<sup>1</sup> N.S. = Not Statistically Significant

<sup>2</sup> Pearson's Chi-Square and Fisher's Exact showed no significant differences unless otherwise noted

There was no significant difference found based on the percentage of supportive or unsupportive relationships in relation to the DID diagnosis between the two groups. Both groups overwhelmingly indicated that they believed DID hindered their ability to make and keep close relationships, they believed DID negatively affected their relationships with family members and

friends, and that they personally experienced difficulty reaching out to others for help, but there was no significant difference between the two groups on these issues. The percentage of individuals participating in a church or religious support network and the percentage of individuals involved with a support or therapy group also showed no significant difference between the two groups.

### *Evaluations of Therapy/Treatments*

Participants rated several types of therapy for effectiveness in dealing with or coping with DID (Table 11). A significant difference was found on the evaluation of effectiveness of writing or poetry as a part of treatment or a coping mechanism, with the disabled group's effectiveness rating averaging  $3.2 (\pm 3.0)$  compared to  $4.8 (\pm 3.3)$  for the non-disabled group ( $F(2, 130) = 8.1$ ,  $p = .01$ ). No significant differences were found between the groups based on their evaluation of art therapy, play therapy, talk therapy, DID/MPD peer/support groups, or journalizing.

Table 9: Evaluations of Therapy/Treatments (based on scale of any number 1 [least] to 10 [highest] for effectiveness for helping cope/deal with DID/MPD ratings):

Description	Disabled	Mean $\pm$ SD	ANCOVA
Art Therapy	Yes (n=42)	$4.3 \pm 3.2$	N.S. <sup>1</sup>
	No (n=90)	$4.1 \pm 3.2$	
Play Therapy	Yes (n=42)	$3.9 \pm 3.0$	N.S.
	No (n=90)	$3.3 \pm 2.8$	
Talk Therapy	Yes (n=42)	$5.0 \pm 3.2$	N.S.
	No (n=90)	$5.5 \pm 3.1$	
DID/MPD Peer/Support Groups	Yes (n=42)	$3.4 \pm 3.0$	N.S.
	No (n=90)	$3.1 \pm 3.0$	
Journalizing	Yes (n=42)	$4.7 \pm 3.2$	N.S.
	No (n=90)	$5.0 \pm 3.1$	
<b>Poetry/Writing</b>	<b>Yes (n=42)</b>	<b><math>3.2 \pm 3.0</math></b>	<b><math>F(2, 130) = 8.1</math> <math>p = .01</math></b>
	<b>No (n=90)</b>	<b><math>4.8 \pm 3.3</math></b>	
Evaluation Average	Yes (n=42)	$4.3 \pm 1.8$	N.S.
	No (n=90)	$4.7 \pm 1.8$	

<sup>1</sup> N.S. = Not Statistically Significant



### *DES Questions and Overall Score*

The DES has been statistically evaluated by Waller, Putnam, and Carlson (1996), and Waller and Ross (1997) in order to find a taxometric system, or taxon, that would help differentiate normal dissociation from pathological dissociation. Their research created the DES-Taxon (DES-T) which is a subset of 8 questions on the DES which are statistically more likely to be endorsed by people with dissociative disorders. A DES-T score is created by averaging the scores from the 8 questions, with a score over 30 being indicative of pathological dissociation. Table 10 summarizes the statistically significant differences found between the two groups on the DES, and provides the DES overall score and the DES Taxon score (neither of which were significantly different). Appendix B provides the results for each of the 28 questions of the DES.

Table 10: Significant DES Questions (based on scale of whole integers from 0 [never] to 10 [always]):

Item	Description	Disabled	Mean $\pm$ SD	ANCOVA
4	<b>Find themselves dressed in clothes that they don't remember putting on.</b>	Yes (n=42)	49.8 $\pm$ 29.6	F(2, 130) = 14.5 p = .00
		No (n=90)	31.2 $\pm$ 30.1	
5	<b>Find new things among their belongings that they do not remember buying.</b>	Yes (n=42)	49.5 $\pm$ 31.4	F(2, 130) = 5.6 p = .02
		No (n=90)	37.7 $\pm$ 32.9	
8	<b>Are told that they sometimes do not recognize friends or family members.</b>	Yes (n=42)	36.0 $\pm$ 32.7	F(2, 130) = 7.7 p = .01
		No (n=90)	21.8 $\pm$ 25.5	
9	<b>Have no memory for some important events in their lives (for example, a wedding or graduation).</b>	Yes (n=42)	69.5 $\pm$ 28.2	F(2, 130) = 6.1 p = .02
		No (n=90)	55.8 $\pm$ 28.5	
25	<b>Have done things that they do not remember doing.</b>	Yes (n=42)	71.2 $\pm$ 28.0	F(2, 130) = 7.2, p = .01
		No (n=90)	58.4 $\pm$ 27.9	
26	<b>Find writings, drawings, or notes among their belongings that they must have done but cannot remember doing.</b>	Yes (n=42)	65.2 $\pm$ 34.1	F(2, 130) = 8.1 p = .001
		No (n=90)	51.1 $\pm$ 31.0	
Total Score	Sum of all items divided by 28.	Yes (n=42)	60.8 $\pm$ 20.3	N.S. <sup>1</sup>
		No (n=90)	56.8 $\pm$ 16.3	
Taxon Score	Sum of questions 3, 5, 7, 8, 12, 13, 22, 27 divided by 8.	Yes (n=42)	58.4 $\pm$ 21.0	N.S.
		No (n=90)	54.5 $\pm$ 18.9	

<sup>1</sup> N.S. = Not Statistically Significant

There were significant findings concerning the DES and DES-T questions in this current study. There were no significant differences between the disabled and non-disabled average scores for the DES or the DES-T. However, two of the questions (5 and 8) that are part of the DES-T showed significant differences, with the disabled group scoring significantly higher than the non-disabled group. On question 5 (find new things among their belongings that they do not remember buying) averaged 49.5 ( $\pm 31.4$ ) for the disabled group and 37.7 ( $\pm 32.9$ ) for the non-disabled group ( $F(2, 130) = 5.6, p = .02$ ). Question 8 (are told that they sometimes do not recognize friends or family members) had an average score of 36.0 ( $\pm 32.7$ ) for the disabled group and 21.8 ( $\pm 25.5$ ) for the non-disabled group ( $F(2, 130) = 7.8, p = .01$ ).

There were differences found on four questions of the DES that are not part of the DES-T. All of these questions (4, 9, 25, and 26) showed higher average scores for the disabled group, reflecting a higher severity or a more frequent occurrence of the subtype of dissociation covered in these questions, specifically amnesia related dissociation. Question 4 (find themselves dressed in clothes that they don't remember putting on) averaged 49.8 ( $\pm 29.6$ ) for the disabled group and 31.2 ( $\pm 30.1$ ) for the non-disabled group ( $F(2, 130) = 14.5, p = .00$ ). Question 9 (have no memory for some important events in their lives, such as wedding or graduation) averaged 69.5 ( $\pm 28.2$ ) for the disabled group and 55.8 ( $\pm 28.5$ ) for the non-disabled group ( $F(2, 130) = 6.1, p = .02$ ). Question 25 (have done things that they do not remember doing) averaged 71.2 ( $\pm 28.0$ ) for the disabled group and 58.4 ( $\pm 27.9$ ) for the non-disabled group ( $F(2, 130) = 7.2, p = .01$ ). Question 27 (find writings, drawings, or notes among their belongings that they must have done but cannot remember doing) averaged 65.2 ( $\pm 34.1$ ) for the disabled group and 51.1 ( $\pm$

31.0) for the non-disabled group ( $F(2, 130) = 8.1, p = .01$ ). Therefore, Hypothesis 4 is accepted because significant differences between the disabled and non-disabled groups were found on the DES, reflecting a higher level or more frequent experience of amnesia-related dissociation in the disabled group.

In summary, Hypothesis 1 is partially accepted because a difference in time spent in therapy prior to DID diagnosis was found. Hypothesis 2 is rejected. Hypothesis 3 is rejected with caution because the emotional distress and amnesia surrounding abuse recall may have affected the reliability of the findings. Hypothesis 4 is accepted because differences between the two groups were found on the DES.

#### *Group Specific Data*

Participants who were either currently or previously enrolled in a governmental disability program completed questions shown in Table 11: Disabled Group Only Information. Only data from current benefit recipients were used because there weren't enough previously enrolled participants to make comparisons between the non-disabled, currently enrolled, and previously enrolled groups.

The average age of enrollment in the governmental disability program was 33.8 ( $\pm 8.2$ ). The three most common comorbid diagnoses for disability purposes were depression (66.7%), PTSD (38.1%), and an anxiety or panic disorder (23.8%). The three most common reasons listed for why DID became disabling were losing time or memory difficulties (52.4%), rapid switching between alter personalities (35.7%), and depression (26.2%). A bachelor's or master's level

college degree had been attained by 38.1%, 19.0% has attained an associate's level degree, and 26.2% had completed some college courses.

Table 11: Disabled Group Only Information:

Description	Sum (n=42)
Age enrolled in governmental disability program:	Mean = 33.8 ± 8.2
<i>Other disability related diagnoses:</i>	
Depression	28 (66.7%)
Post Traumatic Stress Disorder	16 (38.1%)
Anxiety/Panic Disorder	10 (23.8%)
Bipolar Disorder	3 (7.1%)
Borderline Personality Disorder	3 (7.1%)
Obsessive-Compulsive Disorder	2 (4.8%)
<i>Reasons DID became disabling:</i>	
Lost Time/Memory	22 (52.4%)
Depression	11 (26.2%)
Rapid Switching	15 (35.7%)
Self-Injury	3 (7.1%)
Lost/Shifting Abilities	3 (7.1%)
Headaches/Migraines	3 (7.1%)
Anxiety/Panic Attacks	8 (19.0%)
Flashbacks/Body Memories/Intrusion	9 (21.4%)
Repeat Hospitalizations	2 (4.8%)
Suicidality	5 (11.9%)
Insomnia	5 (11.9%)
<i>Highest level of education completed prior to disability:</i>	
High School	7 (16.7%)
Some College	11 (26.2%)
Two Year Degree	8 (19.0%)
Four Year Degree	11 (26.2%)
Master's Degree	5 (11.9%)

Table 12 contains data concerning employment or school performance and peers. Only the non-disability group responses were calculated, even though some of the individuals in the disability group provided answers to some of these questions. The three most common ways in which DID negatively affected work or school tasks were concentration difficulties (34.4%), forgetting or not completing tasks (31.3%), and experiencing anxiety or panic attacks (11.1%). A majority reported that none of the work or school peers were aware of their DID diagnosis

(54.4%), while 21.1% stated that one or two peers had been told, and 7.8% reported that most of their peers knew that they were diagnosed with DID. Of those who had disclosed to peers at work or school 34.6% stated that their peers reacted badly and that they won't disclose again, 34.6% stated that their peers reacted ok and that they may disclose again, and 26.9% reported that they had no problem disclosing to work or school peers. Days absent in the past year from school or work was  $13.3 (\pm 20.7)$ , with  $12.4 (\pm 21.3)$  of those absences being related to DID.

Table 12: Non-Disabled Group Only Information:

Description	Sum (n=90)
<i>How DID/MPD affects performance of work/school tasks:</i>	
Concentration Difficulties	31 (34.4%)
Forget/Incomplete Tasks	28 (31.1%)
Anxiety/Panic Attacks	10 (11.1%)
Absenteeism	3 (3.3%)
Feel Extreme Stress Levels	6 (6.7%)
<i>How many work/school peers know about DID/MPD diagnosis:</i>	
None	49 (54.4%)
One or Two	19 (21.1%)
Most	7 (7.8%)
<i>Reaction of work/school peers and affect on future disclosure:</i>	
Reacted badly – won't disclose again	9 (10.0%; 34.6%*)
Reacted ok – may tell again	9 (10.0%; 34.6%*)
Have no problem telling others	7 (7.8% 26.9%*)
Number of days absent in past year:	Mean = $13.3 \pm 20.7$
Number of those absences related to DID/MPD:	Mean = $12.4 \pm 21.3$

\*Percentage when based upon the 26 respondents who reported disclosure had taken place.

The responses concerning disclosure should be evaluated with the understanding that many respondents stated that they are very careful about whom they decided to tell, and they try to only tell people from whom they expected a positive result. Overall, most elected not to disclose, and many who did disclose to one or two coworkers said they had no choice because employers often had to be told when hospitalizations or frequent absences were necessary.

## Discussion

Turkus (1991) described DID as a chronic disorder with symptoms of dissociation and PTSD. She listed several expected comorbid difficulties including self-harm, substance abuse, eating disorders, impaired social functioning, diminished ability to create and follow through on goals, and an insufficient support system. This potentially discouraging and complicated clinical presentation is nonetheless an accurate description.

In this study the average age therapy began was 23.4, the average age of the first psychiatric hospitalization was 25.1 (67.4% of participants had a history of psychiatric hospitalization), and the average number of psychiatric hospitalizations was 4.7. The overall the average number of years spent in therapy was 11.2, with an average of 13.4 for the disabled group and 8.7 for the non-disabled group. This data confirms the chronic and long-term nature of DID. The DES and DES-T are used to measure dissociative experiences, with a score of 30 or above indicating high levels of dissociation, the probability of pathological dissociation, and the possibility of a diagnosable dissociative disorder being present. The average DES score was 58.8, and the average DES-T score was 56.5. The fact that these scores were found in a group that has on average over 10 years of therapy indicates that either dissociation is a long-term trait rather than a passing symptom in DID, or that traditional therapy is not adequately addressing the current dissociation experienced by individuals with DID.

Several comorbid conditions were found in this study that coincide with Turkus' description and with previous research done on people with DID by Ross (1997). Depression was reported as a previous diagnosis by 97% of the participants in this study, PTSD by 80.3%,

eating disorders by 61.4%, and substance abuse by 37.9% of all participants. A previous suicide attempt was reported by 74.2% of participants, and self-harm or self-injury was reported by 72.8%.

Participants of this study also reported social support deficits. Overall, 93.9% reported that DID hinders their ability to make and/or keep close relationships, 90.2% reported that DID negatively affects their relationship with family and friends, 90.2% reported experiencing difficulty in reaching out to others for help. Participants reported that only 31.1% of their personal relationships were aware of the DID diagnosis. Of these relationships, only 33.7% were supportive in regards to the DID, and 40% were not supportive or reacting negatively to the disclosure concerning the DID diagnosis.

Several significant differences were found between the individuals in the disability group and the individuals in the non-disability group. Differences were found in treatment duration, evaluations of therapy, social support, and DES scores.

Concerning treatment history (Table 3), the disabled group had been in therapy for an average of 4.7 years longer than the non-disabled group, and had spent an average of 2.9 years longer in therapy prior to the DID diagnosis than the non-disabled group. This difference may be due to a more complicated clinical situation for the disabled group, or it could be due in part to failure of the mental health field to properly and promptly making the DID diagnosis.

Three important findings surfaced when comparing the effectiveness ratings for types of therapy or treatment interventions (Table 9). First, a significant difference was found on the evaluation of effectiveness of writing or poetry as a part of treatment or a coping mechanism.

The disabled group gave this part of treatment or style of intervention a much lower effectiveness rating, averaging 1.6 points lower than the non-disabled group. Secondly, all participants in this study were involved in Internet-based DID peer groups that offer discussion, support, and sometimes crisis intervention. Yet this modality was given the lowest overall effectiveness rating, an average of 3.25 based on both groups as one. Talk therapy received the highest, earning 5.25 overall average. Thirdly, it should be noted that no treatment type averaged over 5.5 for either group. This may be an indication that traditional therapy modalities are incomplete when it comes to helping and healing someone who has DID.

Social support data (Table 8) showed one significant difference between the two groups. The disabled group reported a 22.3% higher percentage of relationships that knew about their DID diagnosis. There are several possible reasons for this difference. First of all, the process of attaining disability benefits is often a difficult and lengthy process, which would be difficult to hide from friends and family. Additionally, people who receive disability benefits may feel they have to disclose the reason for their disability benefits when people inquire about what they do for a living or why they are on disability. Many participants who were not on disability stated that they did not tell others about their diagnosis because they feared losing their jobs, losing custody of their children, being labeled crazy, being hospitalized against their will, or facing other negative backlash. This difference may not be clinically useful except as a reminder to therapists that people with DID may hide their diagnosis even from therapists and other important people in their life.



The results from the DES showed no significant differences between the two groups when the overall DES and DES-T scores were compared. However, significant differences were found on specific questions of the DES (Table 10). The disabled group averaged 18.6 points higher on a question concerning findings themselves dressed in clothes that they did not remember putting on, 14.2 points higher on a question concerning being told that they sometimes did not recognize friends or family members, and 14.1 points higher on a question concerning finding writings, drawings, or notes among their belongings that they must have done but cannot remember doing. The disabled group also scored an average of 13.7 points higher on a question concerning memory losses for important events in their lives, 12.8 points higher on a question concerning having done things they did not remember doing, and 11.8 points higher on a question concerning finding new things among their belongings that they did not remember buying. This indicates that the disabled group experiences much higher levels of amnesic dissociation than the non-disabled group. It is also worth pointing out that the disabled group scored higher on a question dealing with findings writing they do not remember doing and that this group also gave writing as a treatment intervention a lower effectiveness rate. Amnesia for doing tasks, art, or writing may make certain treatment interventions more distressing and less effective for this group.

Ross (1997), who is arguably the most prolific researcher in the DID field, offered an interesting caution about his research findings:

The large clinical series I have been describing present a highly biased sample of DID patients. As described... there may be a large number of people in the general population with DID who are high-functioning, relatively free of overt psychopathology, and no

more in need of treatment than most of their peers... If these people exist, virtually nothing is known about them (124).

Differences were found between the participants of this study as a whole compared to past research performed by Ross concerning the rates of comorbid substance abuse, eating disorders, and previous diagnoses of schizophrenia and schizoaffective disorder. These differences most likely have to do with the fact that Ross utilized inpatient populations and inpatient treatment documentation and this study utilized an outpatient population to gather data. Future research using outpatient populations may discover more differences between inpatient and outpatient DID populations. Future research may also find that some of these differences reflect changes in treatment history and clinical presentation that are due to changes in the psychology field's knowledge and treatment of individuals with DID, changes related to insurance coverage of psychiatric services, and changes in standardized or research-based treatment protocols for DID.

This current study has begun to fill this void of information concerning the non-inpatient population of people with DID. The Internet was used in order to reach volunteers willing to participate in this study. This also allowed a large number of people across a diverse geographical area to participate. While this is an innovative use of the Internet, this method presented a major weakness that will need to be addressed by future studies, namely the participant's diagnoses and treatment history were not verified or reassessed using structured interview protocols. Therefore, the findings of this study are preliminary, and will need to be replicated in order to verify these results and to assess the clinical significance and usefulness of

the differences found between inpatient and outpatient populations, and the differences between disabled and non-disabled populations dealing with DID.

### *Clinical Implications*

The participants of this study gave low effectiveness ratings of typical therapy modalities and interventions used in the treatment of DID. This may indicate that clients and therapists need to address expectations of what therapy can accomplish, how much time may be needed, and whether the goal of therapy is to cure or remove the disorder versus restore and maintain highest possible functioning. Rehabilitation counseling offers a good balance between seeking to cure as much as possible while also acknowledging that some disorders and symptoms may never be curable. Rehabilitation counseling can be used to help restore and maintain the highest possible functioning levels, initiate and nurture social support systems, find solutions to current difficulties without waiting for past emotional wounds to be resolved, and create hope that life can improve during therapy instead of only once therapy is completed.

Rehabilitation counseling could attempt to restore or improve functioning levels by focusing on the specific symptoms and experiences listed as reasons why the DID became disabling in Table 11. The three most common reasons listed for why DID became disabling were losing time or memory difficulties (52.4%), rapid switching between alter personalities (35.7%), and depression (26.2%). Table 12 offers areas that could be a focus of treatment for individuals with DID who are not currently receiving disability benefits in an attempt to prevent disability benefits becoming a necessity. The three most commonly reported ways in which DID negatively affected work or school tasks were concentration difficulties (34.4%), forgetting or

not completing tasks (31.3%), and experiencing anxiety or panic attacks (11.1%). These common difficulties may also be useful treatment areas for helping those who are receiving disability benefits successfully return to a vocation.

### *Future Research*

Future research should continue to find ways to access outpatient populations in order to gain a better understanding of how DID affects individuals and their lives. The Internet may prove to be an extremely useful tool for this goal. Care should be taken to ensure that the same level of ethics is maintained when dealing with people through the Internet as is taken when they participate in face-to-face research in hospitals and laboratories. The Internet has many arenas in which people with DID can be found, such as online email discussion groups, multi-user dimensions (MUDs), real-time chat groups, and bulletin boards. Some of these areas are more closed and private requiring screening processes, applications, referrals, and other safety precautions to keep members feeling safe. These more protected groups may yield the most accurate results because there is a reduced likelihood of having imposters (sometimes called “trolls” in the Internet world) corrupt the collected data. These groups may also be harder to find and may require approval from the owners/moderators before a request for volunteer participants can be broadcast.

The open-ended style of questions used in this study generated lists of potential answers that could be used to create a more close-ended and multiple choice based questionnaire. This might increase the usefulness of specific sections, such as the abuse history sections, by making it easier for participants to answer the questions and easier for the researchers to perform

statistical analyses of the data. Future research based on this questionnaire may also find it useful to reduce the number of questions. For example, many participants indicated that the abuse section was emotionally overwhelming, so they discontinued the questionnaire or skipped that section. If that section had been removed from the questionnaire, more data would have been generated because more people would have completed the questionnaire. If that section had been a separate questionnaire, more accurate and useful data may have been generated because people would have been less likely to skip over it and continue with the less emotionally difficult questions.

Another future study with this questionnaire could be finding an outpatient population that is not gathered from the Internet. This would either establish that the population gathered from the Internet is representative of the overall outpatient DID population, or that the online population is a subset of the outpatient DID population.

## Appendix A: The Questionnaire and DES

### *Information*

I am currently gathering data for my thesis concerning DID/MPD as it relates to the field of Rehabilitation Counseling Psychology. I am interested in gathering information from people with DID/MPD and those with DID/MPD who are on Disability because of their DID/MPD. All information will be kept confidential and will be stripped of identifying information/names. Results of this survey will be published on this Web page when they are available. If you would like to be notified when the results are published, please provide your e-mail address.

### *Instructions*

Answer to the best of your knowledge, and please answer every question. Please be safe, some of these questions are hard. Feel free to STOP the test at any time by closing or redirecting your browser window.

### *General Information:*

1. (Nick) Name:
2. Gender of body:
3. Location (State, Country):
4. Ethnic Background:
5. Year of birth:
6. At what age was DID/MPD diagnosed or became common knowledge among a majority of the dominant personalities?

Therapy/Treatment History:

7. At what age did you first enter therapy?
8. How long have you been in therapy (combined years and months, whether for DID/MPD or other issues)?
9. How many years were you in therapy before you were diagnosed as DID/MPD?
10. How long have you been in therapy for DID/MPD?
11. Have you ever been hospitalized for psychiatric problems? If so, please list at what ages, duration of each hospitalization, and reason for hospitalizations.
12. Have you taken medicine prescribed to help you with psychiatric conditions and symptoms? If so, please list current medications and length taken.

Other Diagnoses:

13. Have you ever been diagnosed or treated for the following:
  - a. Asthma
  - b. Irritable Bowel Syndrome
  - c. Depression
  - d. Substance Abuse
  - e. Post Traumatic Stress Disorder
  - f. Eating Disorder
  - g. Self-Harm/Mutilation
  - h. Suicide Attempt
  - i. Seizures

j. Severe or recurring headaches

k. Other psychiatric diagnoses (please list diagnoses)

Disability Information:

This section is for those currently or previously enrolled in a Disability Program such as SSI and SSDI. Disability and disabled in this section refer to the legal term/status of being in such a program. If you have never been in such a program, please skip to the next section.

14. Are you currently on Disability? If yes, what year did you first become legally disabled/enrolled in a Disability program?

15. Please list the diagnoses/disabilities in order of highest impairing problem to lowest impairing problem.

16. What was your highest level of education and employment prior to becoming disabled?

17. What major reasons would you list as causing your diagnoses to become disabling or overwhelming (especially DID/MPD)?

Childhood Abuse Information:

(Example for the relation of the abuser(s) question: If your father abused you, the answer is "father" not daughter or son.)

Age abuse began / Duration of abuse / Relation of the abuser(s) to you

18. Physical Abuse:

19. Sexual Abuse:

20. Verbal/Emotional Abuse:



21. Was law enforcement ever contacted concerning any of the above abuse? If so, what response did law enforcement have? Was legal action ever pursued against any of the above abusers? What was the outcome of such action?

Adult Revictimization History (i.e., adult rape, domestic violence, victim of a crime):

(Example for the relation of the abuser(s) question: If your father abused you, the answer is "father" not daughter or son.)

Age abuse began / Duration of abuse / Relation of the abuser(s) to you

22. Physical Abuse/Assault:

23. Sexual Abuse/Assault:

24. Verbal/Emotional Abuse/Assault:

25. Was law enforcement ever contacted concerning any of the above abuse? If so, what response did law enforcement have? Was legal action ever pursued against any of the above abusers? What was the outcome of such action?

For those employed or in school:

26. How does DID/MPD affect your performance of job/school tasks?

27. How does DID/MPD affect your relationship with coworkers/fellow students?

28. How does DID/MPD affect your attendance?

29. How many days of work/school have you missed in the past year?

30. How many of those days were missed in part because of DID/MPD related problems/illnesses? (Such as stress headaches, lack of internal cooperation, depression, being triggered/having flashbacks, or too tired to go in due to lack of sleep.)

31. Do your coworkers/fellow students know of your DID/MPD? Has their reaction made you more likely or less likely to disclose in the future?

*Social Support:*

32. How does DID/MPD affect your relationship with family members?

33. How does DID/MPD affect your relationship with friends and acquaintances?

34. Are you involved in a support group? (Such as AA, groups for Survivors of Abuse, DID/MPD, etc.)

35. How close are your relationships with family members? Are they generally supportive or non-supportive of you?

36. Are you able to make close relationships? Do you have difficulty in making relationships last?

37. Are you involved with any form of church or religious support network?

38. Do you have problems reaching out to others for help?

39. Do you feel that your DID/MPD hinders your ability to make and keep relationships?

40. What percentage of your relationships (family, friends, acquaintances, work/school, etc.) know that you are DID/MPD?

41. What percentage of your relationships (family, friends, acquaintances, work/school, etc.) are supportive and understanding concerning your DID/MPD?

42. What percentage of your relationships (family, friend, acquaintance, work/school, etc.) that you disclosed your DID/MPD to reacted negatively to the disclosure?

43. What are/were your motivations for disclosing?

44. What are/were your motivations for not disclosing?

Evaluations of Therapy/Treatments:

45. On a scale of 1 (least) to 10 (highest), how would you rate the effectiveness of the following for helping you cope/deal with your DID/MPD:

- a. Art Therapy
- b. Play Therapy
- c. Talk Therapy
- d. DID/MPD Peer/Support Groups
- e. Journalizing
- f. Poetry/Writing

46. What other therapies/treatments have you tried? How would you rate their effectiveness for helping you cope/deal with your DID/MPD?

This rest of the questionnaire is the Dissociative Experiences Scale (DES), copied from The Ross Institute's Web Page with permission: (Please read and continue.)

The Dissociative Experiences Scale (DES) was developed by Eve Bernstein Carlson, Ph.D. and Frank W. Putnam, M.D. The overall DES score is obtained by adding up the 28 item scores and dividing by 28: this yields an overall score ranging from 0 to 100. The DES is posted on this Web page with permission of Dr. Putnam. It is in the public domain and can be copied and used without further permission.

*Directions*

This questionnaire consists of twenty-eight questions about experiences that you may have in your daily life. We are interested in how often you have these experiences. It is important, however, that your answers show how often these experiences happen to you when you are not under the influence of alcohol or drugs.

To answer the questions, please determine to what degree, the experience described in the question applies to you and circle the number to show what percentage of the time you have the experience: (NEVER) 0 10 20 30 40 50 60 70 80 90 100 (ALWAYS)

1. Some people have the experience of driving or riding in a car or bus or subway and suddenly realizing that they don't remember what has happened during all or part of the trip.
2. Some people find that sometimes they are listening to someone talk and they suddenly realize that they did not hear part or all of what was said.
3. Some people have the experience of finding themselves in a place and having no idea how they got there.
4. Some people have the experience of finding themselves dressed in clothes that they don't remember putting on.
5. Some people have the experience of finding new things among their belongings that they do not remember buying.
6. Some people sometimes find that they are approached by people that they do not know who call them by another name or insist that they have met them before.

7. Some people sometimes have the experience of feeling as though they are standing next to themselves or watching themselves do something and they actually see themselves as if they were looking at another person.
8. Some people are told that they sometimes do not recognize friends or family members.
9. Some people find that they have no memory for some important events in their lives (for example, a wedding or graduation).
10. Some people have the experience of being accused of lying when they do not think that they have lied.
11. Some people have the experience of looking in a mirror and not recognizing themselves.
12. Some people have the experience of feeling that other people, objects, and the world around them are not real.
13. Some people have the experience of feeling that their body does not seem to belong to them.
14. Some people have the experience of sometimes remembering a past event so vividly that they feel as if they were reliving that event.
15. Some people have the experience of not being sure whether things that they remember happening really did happen or whether they just dreamed them.
16. Some people have the experience of being in a familiar place but finding it strange and unfamiliar.
17. Some people find that when they are watching television or a movie they become so absorbed in the story that they are unaware of other events happening around them.

18. Some people find that they become so involved in a fantasy or daydream that it feels as though it were really happening to them.
19. Some people find that they sometimes are able to ignore pain.
20. Some people find that that they sometimes sit staring off into space, thinking of nothing, and are not aware of the passage of time.
21. Some people sometimes find that when they are alone they talk out loud to themselves.
22. Some people find that in one situation they may act so differently compared with another situation that they feel almost as if they were two different people.
23. Some people sometimes find that in certain situations they are able to do things with amazing ease and spontaneity that would usually be difficult for them (for example, sports, work, social situations, etc.).
24. Some people sometimes find that they cannot remember whether they have done something or have just thought about doing that this (for example, not knowing whether they have just mailed a letter or have just thought about mailing it).
25. Some people find evidence that they have done things that they do not remember doing.
26. Some people sometimes find writings, drawings, or notes among their belongings that they must have done but cannot remember doing.
27. Some people sometimes find that they hear voices inside their head that tell them to do things or comment on things that they are doing.
28. Some people sometimes feel as if they are looking at the world through a fog so that people and objects appear far away or unclear.

## Appendix B: Statistical Analysis of the DES &amp; DES-T

Table 13: DES Questions (based on scale of whole integers from 0 [never] to 10 [always]):

Item	Description	Disabled	Mean $\pm$ SD	ANCOVA
1	Driving or riding in a car or bus or subway and suddenly realizing that they don't remember what has happened during all or part of the trip.	Yes (n=42)	62.1 $\pm$ 26.8	N.S. <sup>2</sup>
		No (n=90)	58.1 $\pm$ 27.0	
2	Listening to someone talk and they suddenly realize that they did not hear part or all of what was said.	Yes (n=42)	70.7 $\pm$ 21.3	N.S.
		No (n=90)	68.2 $\pm$ 20.1	
3	Find themselves in a place and having no idea how they got there.	Yes (n=42)	47.1 $\pm$ 29.2	N.S.
		No (n=90)	38.2 $\pm$ 29.0	
4	<b>Find themselves dressed in clothes that they don't remember putting on.</b>	<b>Yes (n=42)</b>	<b>49.8 <math>\pm</math> 29.6</b>	<b>F(2, 130) = 14.539</b> <b>p = .000</b>
		<b>No (n=90)</b>	<b>31.2 <math>\pm</math> 30.1</b>	
5	<b>Find new things among their belongings that they do not remember buying.</b>	<b>Yes (n=42)</b>	<b>49.5 <math>\pm</math> 31.4</b>	<b>F(2, 130) = 5.603</b> <b>p = .019</b>
		<b>No (n=90)</b>	<b>37.7 <math>\pm</math> 32.9</b>	
6	Approached by people that they do not know who call them by another name or insist that they have met them before.	Yes (n=42)	39.3 $\pm$ 30.3	N.S.
		No (n=90)	33.6 $\pm$ 29.7	
7	Feel as though they are standing next to themselves or watching themselves do something and they actually see themselves as if they were looking at another person.	Yes (n=42)	56.9 $\pm$ 31.4	N.S.
		No (n=90)	59.1 $\pm$ 31.9	
8	<b>Are told that they sometimes do not recognize friends or family members.</b>	<b>Yes (n=42)</b>	<b>36.0 <math>\pm</math> 32.7</b>	<b>F(2, 130) = 7.729</b> <b>p = .006</b>
		<b>No (n=90)</b>	<b>21.8 <math>\pm</math> 25.5</b>	
9	<b>Have no memory for some important events in their lives (for example, a wedding or graduation).</b>	<b>Yes (n=42)</b>	<b>69.5 <math>\pm</math> 28.2</b>	<b>F(2, 130) = 6.084</b> <b>p = .015</b>
		<b>No (n=90)</b>	<b>55.8 <math>\pm</math> 28.5</b>	
10	Accused of lying when they do not think that they have lied.	Yes (n=42)	58.6 $\pm$ 32.7	N.S.
		No (n=90)	52.0 $\pm$ 28.8	
11	Look in a mirror and not recognizing themselves.	Yes (n=42)	46.9 $\pm$ 35.0	N.S.
		No (n=90)	46.1 $\pm$ 32.0	
12	Feel that other people, objects, and the world around them are not real.	Yes (n=42)	53.1 $\pm$ 31.5	N.S.
		No (n=90)	59.0 $\pm$ 30.9	
13	Feel that their body does not seem to belong to them.	Yes (n=42)	62.1 $\pm$ 30.2	N.S.
		No (n=90)	64.9 $\pm$ 27.9	
14	Remember a past event so vividly that they feel as if they were reliving that event.	Yes (n=42)	66.7 $\pm$ 29.9	N.S.
		No (n=90)	65.8 $\pm$ 28.6	
15	Not being sure whether things that they remember happening really did happen or whether they just dreamed them.	Yes (n=42)	64.5 $\pm$ 30.1	N.S.
		No (n=90)	62.7 $\pm$ 26.0	
16	Being in a familiar place but finding it strange and unfamiliar.	Yes (n=42)	52.9 $\pm$ 27.2	N.S.
		No (n=90)	51.1 $\pm$ 27.6	
17	When they are watching television or a movie they become so absorbed in the story that they are unaware of other events happening around them.	Yes (n=42)	56.2 $\pm$ 38.2	N.S.
		No (n=90)	62.8 $\pm$ 29.9	

Table 13: DES Questions (continued):

18	Become so involved in a fantasy or daydream that it feels as though it were really happening to them.	Yes (n=42)	44.3 ± 37.8	N.S.
		No (n=90)	56.3 ± 30.1	
19	Are able to ignore pain.	Yes (n=42)	74.1 ± 25.7	N.S.
		No (n=90)	72.3 ± 25.1	
20	Sit staring off into space, thinking of nothing, and are not aware of the passage of time.	Yes (n=42)	71.9 ± 27.2	N.S.
		No (n=90)	68.7 ± 27.3	
21	Find that when they are alone they talk out loud to themselves.	Yes (n=42)	72.9 ± 30.5	N.S.
		No (n=90)	64.9 ± 33.1	
22	Find that in one situation they may act so differently compared with another situation that they feel almost as if they were two different people.	Yes (n=42)	76.9 ± 25.8	N.S.
		No (n=90)	74.6 ± 22.6	
23	Find that in certain situations they are able to do things with amazing ease and spontaneity that would usually be difficult for them (for example, sports, work, social situations, etc.).	Yes (n=42)	71.0 ± 22.1	N.S.
		No (n=90)	68.0 ± 23.9	
24	Cannot remember whether they have done something or have just thought about doing that this (for example, not knowing whether they have just mailed a letter or have just thought about mailing it).	Yes (n=42)	67.1 ± 30.2	N.S.
		No (n=90)	67.2 ± 27.6	
25	<b>Have done things that they do not remember doing.</b>	<b>Yes (n=42)</b>	<b>71.2 ± 28.0</b>	<b>F(2, 130) = 7.180</b> <b>p = .008</b>
		<b>No (n=90)</b>	<b>58.4 ± 27.9</b>	
26	<b>Find writings, drawings, or notes among their belongings that they must have done but cannot remember doing.</b>	<b>Yes (n=42)</b>	<b>65.2 ± 34.1</b>	<b>F(2, 130) = 8.057</b> <b>p = .005</b>
		<b>No (n=90)</b>	<b>51.1 ± 31.0</b>	
27	Hear voices inside their head that tell them to do things or comment on things that they are doing.	Yes (n=42)	85.2 ± 25.1	N.S.
		No (n=90)	80.4 ± 25.5	
28	Feel as if they are looking at the world through a fog so that people and objects appear far away or unclear.	Yes (n=42)	61.9 ± 29.2	N.S.
		No (n=90)	59.2 ± 30.1	
Total Score	Sum of all items divided by 28.	Yes (n=42)	60.8 ± 20.3	N.S.
		No (n=90)	56.8 ± 16.3	
Taxon Score	Sum of questions 3, 5, 7, 8, 12, 13, 22, 27, divided by 8.	Yes (n=42)	58.4 ± 21.0	N.S.
		No (n=90)	54.5 ± 18.9	

<sup>2</sup> N.S. = Not Statistically Significant



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## VITAE

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