

## ABSTRACT

Title of dissertation: ELEMENTS OF EMPLOYMENT RELATED  
DISCLOSURE OF DISABILITY AFTER BRAIN  
INJURY

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Few studies have examined the elements of disclosing a disability in the workplace. Those few studies had a primary focus on reasonable accommodations (RA) where the disclosure process was either secondary or tertiary to the study. Further, there have been no studies to date which have examined elements of disclosure for individuals with brain injury (BI). Disclosure of disability is a crucial first step in the request process for a reasonable accommodation in the workplace and is required by the ADA for individuals requesting job related accommodations. This study examined the (a) experiences of work-related disability disclosure for individuals with BI, (b) the injury, demographic and other factors associated with the decision to disclose a disability at work, and (c) employment-related outcomes associated with disclosure. The primary goal of the current study is to describe the population of people with brain injury who disclose their disability in the workplace and to make inferences about the contributing factors

involved in the disclosure process. The study used a cross-sectional survey methods research design.

The study consisted of 200 individuals recruited from an online survey hosted on the Brain Injury Association of America's website. Of these participants, 144 (74.6%) disclosed their disability on at least one job and 91 (45%) were currently working. Level of education ( $\chi^2 = 11.945, 3, p = .008$ ), self-efficacy score ( $F = 7.52; p = .007$ ) and time between injury and current age ( $F = 4.56; p = .034$ ) were significantly related to disclosure. Logistic regression analyses were used to examine the combined effects of several predictor variables with disclosure. In this analysis, only time since injury and self-efficacy (SE) scores were significant, where higher SE scores increased the odds of disclosure, and time since injury decreases the odds of disclosure (the more recent the injury, the more likely the individual was to disclose).

ELEMENTS OF EMPLOYMENT RELATED DISCLOSURE  
OF DISABILITY AFTER BRAIN INJURY

By

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## CHAPTER 1

### Introduction

Although there is a great deal of knowledge regarding brain injury, its functional impairments, and resulting consequences, there is little available information regarding the issue of disability disclosure in the request for job accommodations. Employment-related disability disclosure is required in order to invoke the protections of Title I of the Americans with Disabilities Act (ADA), particularly the requirement that employers provide reasonable accommodations (RA) to qualified individuals with disabilities as defined under the ADA. Studies have supported the importance of RA in improving entry into employment, sustaining employment, and increasing job satisfaction of people with disabilities (Ellison, Russinova, MacDonald-Wilson, & Lyass, 2003; Unger, Rumrill, & Hennessey, 2005). Studies have also shown that people with disabilities are reluctant to disclose their disabilities to employers, for various reasons that will be discussed in the literature review (e.g., Conyers & Boomer, 2005; Ellison et al., 2003).

The proportion of unemployed individuals with brain injury (BI) is significantly higher than the proportion of persons without a disability, with estimated unemployment rates as high as 70% for persons with severe BI (Yasuda et al., 2001). Others have estimated the employment rate ranges from 20% to 50% depending on the severity of the injury, prior work experience and demographic characteristics (Wehman et al., 2003). The return-to-work rate for this population varies throughout the literature, with reports ranging from 12.5% to 70% (Watanabe et al., 2003). Persons with BI who received services from the state/federal vocational rehabilitation program in 2007, had a success rate (competitively employed for 90 days) of only 54% (Rehabilitation Services

Administration, 2009), which was lower than all of the other disabled groups reported for that year.

It is clear that securing and maintaining employment represent major challenges for people with BI, and numerous studies have examined some of the factors contributing to it (Dixon, Thornton & Young, 2007; Lefebvre & Levert, 2006). The majority of these studies, however, have focused on disability and demographic contributors to employment outcomes, with relatively few (Allen & Carlson, 2003; Corrigan & Matthews, 2003; Dalgin & Bellini, 2008) examining features of the work environment, such as the provision of workplace accommodations. What little literature exists in this area supports the benefits of accommodations in improving job performance and sustaining employment (Conyers & Boomer, 2005; Granger, Baron, & Robinson, 1997). Despite the obvious benefits of workplace accommodations, most studies have paradoxically reported that individuals with disabilities, particularly those with non-apparent disabilities, are reluctant to reveal or disclose their disabilities in order to request them (Valle, Santiago, Volpitta, & Conner, 2004; Fesko, 2001b). Under the Americans with Disabilities Act, qualified employees are required to document and disclose their disabilities in order to invoke their rights under Title I to reasonable accommodations in the workplace.

The purpose of this study is to explore the employment-related disability disclosure process for individuals with BI in order to better understand elements of the disclosure process, and personal and environmental factors associated with it. A review of the literature (Chapter 2) establishes that there are few if any empirical studies on workplace disclosure of individuals with BI. Extrapolating findings from other non-

visible disabilities, such as cancer, psychiatric illnesses, and HIV (Conyers & Boomer, 2005; Dalgin & Gilbride, 2003; Ellison et al., 2003; Fesko, 2001b), and LD (Madaus, Foley, McGuire, & Ruben, 2002; Madaus, Ruban, Foley & McGuire, 2003; Madaus, 2008) it is expected about half of individuals with this condition will choose to disclose at work. To date, no studies have focused on the issue of disclosure of disability in the brain injury population, their experiences with disclosure, and how this affects the return to work, job retention, and job tenure.

## Brain Injury

### *Prevalence of BI*

Brain Injury (BI) is one of the leading causes of death and disability worldwide (Shames et al., 2007). In the United States it is the leading cause of both death and disability for individuals under age 45 (Ashman, Gordon, Cantor, & Hibbard, 2006). It is estimated that as many as 5.3 million persons living in the United States have a disability related to BI, which represents approximately 2% of the overall population.

In 2004 the Centers for Disease Control and Prevention (CDC) reported that between 1995 and 2001, an average of 1.4 million people in the U.S. sustained a BI each year, with about 50,000 of these resulting in death, and some 80,000 to 90,000 persons experiencing some degree of long-term functional loss (Gamboa, Holland, Tierney, & Gibson, 2006). Further, BI has been called the "signature injury" of the wars in Iraq and Afganistan, with almost 20% of soldiers sustaining one (Tanielian & Jaycox, 2008; Tanielian et al., 2008).

### *BI Impairments*

BI severity is most frequently defined by three criteria: 1) duration of loss of consciousness (LOC), 2) the Glasgow Coma Scale (GCS) score, and 3) the presence and duration of post-traumatic amnesia (PTA). In general, individuals are classified as having moderate to severe BI if they have a LOC of over 30 minutes, an altered mental status with PTA greater than 24 hrs and a GCS below 12. Mild BI is defined by a LOC of less than 30 minutes, an altered mental status with PTA of less than 24 hrs or a GCS greater than 12. It is important to note that the severity of functional impairment is not always directly related to the severity of the injury (Ashman et al., 2006), and no two injuries are the same. While the location of and extent of neuron damage tends to be strongly correlated to functional impairment, individual differences in brain morphology and in organism functioning make it impossible to predict outcomes in terms of long-term functional impairments.

A Traumatic Brain Injury (TBI) is the result of an external force applied to the skull (which includes inertial forces) which can lead to temporary or permanent pathology in brain tissue. An external force can cause either an open or closed-head injury. In an open-head injury the skull is penetrated such as occurs from gunshot or missile wounds. In a closed-head injury, such as can occur in car accidents or falls, the brain is damaged as a result of a variety of mechanical forces. Open-head injuries often differ dramatically from closed head injuries both in terms of damage and functional impairment (Kolb & Wishaw, 2008). Acquired Brain Injuries (ABI) such as strokes, aneurisms and brain tumors can also lead to brain tissue pathology and cause significant damage depending on the location and extent of damage (Kolb & Wishaw, 2008).

The diffuse nature of BI contributes to an extremely broad range of symptoms which can effect almost every aspect of functioning and can include impairments in arousal, attention, mood, behavior, cognition, meta-cognition (Ashman et al., 2006; Kolb & Wishaw, 2008) and motor control (Kolb & Wishaw, 2008; Walker & Pickett, 2007).

### *Cognitive, Social and Emotional Impact of BI*

Initial and persistent cognitive deficits are the most common impairments of brain injuries. Changes can occur in frontal lobe executive functioning (e.g., problem-solving, set-shifting, impulse control, and self-monitoring), attention, short-term memory, learning, speed of information processing, speech, and language functioning. Collectively, these cognitive impairments are potentially significant barriers to normalization post-injury in terms of independent living, social re-adaptation, family life, and vocational endeavors (McAllister, 2008). The psychosocial and emotional sequelae of individuals with BI include: decreased social contact, depression, and loneliness, and can also cause major challenges to community re-entry post-injury (Morton & Wehman, 1995). Ben-Yishay, Silver, Piasetsky, and Rattok (1987) identified poor self-awareness and unrealistic goals as the main reasons individuals failed to return to work after completing rehabilitation.

Of particular interest in the current study are the differences between neurocognitive and neuromotor impairments in terms of the visibility of the disorder and how visibility/invisibility relates to the disclosure and request for workplace accommodations. As stated earlier, different types of brain injuries lead to different impairments in functioning, some of which are readily apparent (such as neuromotor impairments) to a potential employer, and others which can go undetected

(neurocognitive) without further psychological assessment even when the resulting impairment is quite severe. The extent to which the visibility and severity of the injury affect workplace disclosure decisions will be explored in the current study.

### The ADA and Reasonable Accommodations

Many individuals with BI, particularly those eligible for services from the state/federal vocational rehabilitation system or for Veteran's Administration benefits will merit the protections of Title I of the ADA, which protects eligible individuals from employment discrimination. Title I protections include the requirement that employers provide reasonable accommodations to qualified individuals with disabilities during all phases of employment including the application process. A reasonable accommodation is any change made to the workplace environment, workplace policies or workplace procedures that will enable individuals with disabilities to enjoy equal employment opportunities (Equal Employment Opportunities Commission [EEOC], 2002). Reasonable accommodations are required except in those cases when the provision of such an accommodation is an undue hardship for the employer, which is defined as any modification of the job site or job that is unduly expensive, substantial, and/or disruptive, or which would change the essential aspects of the job itself (EEOC, 2002).

Central to requesting and/or receiving an RA is knowledge of the protections available under the ADA (Gioia & Brekke, 2003), and making the decision to disclose a disability to an employer. Disclosure has been called a “dual-edged sword” in that disclosing a disability can evoke negative stereotypes about disability, while non-disclosure can lead to a lack of reasonable accommodations, which can result in job loss lead (Gates, 2000). Empirical research has demonstrated the benefits that accrue to

individuals with disabilities who request and receive reasonable accommodations to sustain and improve work productivity and performance (Fabian, Waterworth & Ripke, 2003; MacDonald-Wilson, Rogers & Massaro, 2003). Studies have also identified benefits that accrue to businesses that provide accommodations, such as a reduction in turnover, improved productivity, improved employee morale, and a demonstrated commitment to organizational equality and diversity (Johnson, Baldwin, & Butler, 1998; Rutkowski, Daston, Van Kuiken, & Riehle, 2006).

### *Statement of the Problem*

Individuals with BI encounter significant challenges in employment. Some of these challenges are a direct cause of the impairment itself, its subsequent functional limitations, and the psychological barriers related to a reduction in self-awareness of cognitive, emotional, and behavioral changes (Ownsworth, Desbois, Grant, Flemming, & Strong, 2006; Ownsworth & McKenna, 2004; Shames, Treger, Ring, & Giaquinto, 2007; Sherer, Bergloff, Levin, High, Oden, & Nick, 1998). Studies which have examined employment for individuals with disabilities other than BI report that one of the pertinent factors influencing the successful return to work is asking for and receiving RAs. In the process of asking for and receiving a RA, an individual with a disability must first disclose to their employer that they have a disability and then request an accommodation to perform essential job functions.

From the limited empirical database on disclosure involving persons with disabilities other than BI, it is known that the process of disclosing a disability is complex, and few individuals with disabilities that are not readily visible choose to do so (Dalgin, & Bellini, 2008). Also known from these studies are some of the

factors/elements influencing the disclosure decision process such as stigma (Allen & Carlson, 2003), higher level of work position (Conyers & Boomer, 2005), and disability identity (Dalgin & Gilbride, 2003) among others. At present however, it is not yet known what the disclosure process involves for persons with BI or what factors/elements are associated with the disclosure process for these individuals.

While many studies have examined individual and disability factors associated with employment for individuals with BI, and some have examined workplace factors such as workplace supports (Wehman et al., 1990, 1993, 2000, 2003; Wehman, Targett, West, & Kregel, 2005), none have explored the issues of disability disclosure in the request for job accommodations by individuals with BI. As the relationship between disclosure of disability and the subsequent requesting and receiving of workplace accommodations has been associated with more successful employment outcomes and increased work satisfaction for groups of individuals with other types of disabilities (Banks et al., 2001; Madaus, 2008), it is clear that the need to study these issues for individuals with BI is a potentially important avenue in improving employment outcomes. Furthermore, by examining these factors, the current study will provide baseline information for future correlational and experimental research regarding the disclosure decision making process for persons with BI.

#### Research Questions

This study will examine (a) the experiences of work-related disability disclosure for individuals with BI, (b) employment related outcomes associated with disclosure and (c) the disability, demographic and other factors associated with the decision to disclose a disability. The primary goal of the current study is to describe the population of people



who disclose their disability in the workplace and to make inferences about the contributing factors involved in the disclosure process based on this information.

Research Question #1: What are the experiences of work-related disability disclosure for individuals with BI?

Research Question #2: What employment-related outcomes are associated with the decision to disclose?

Dependent Variable: Disclose (yes/no)

Independent variables:

- Positive outcomes associated with disclosure
- Negative outcomes associated with disclosure
- Accommodation request
- Accommodation provision
- Job tenure

Research Question #3: What disability, demographic, and other factors are associated with the decision to disclose a disability?

Dependent variable: Disclose (yes/no)

Independent variables:

- Current salary
- Currently working
- Receipt of health benefits
- Gender

- Educational level
- Race/ethnicity
- Severity of BI
- Visibility of BI
- How frequent does BI affect work
- Knowledge and importance of ADA
- Employment self-efficacy
- Average Age
- Time between injury and current age

#### Definitions

##### *Brain Injury*

Includes any type of brain injury (BI) and does not discriminate between a traumatic brain injury and an acquired brain injury.

##### *Traumatic Brain Injury*

A traumatic brain injury (TBI) is defined as a blow or jolt to the head or a penetrating head injury that disrupts the function of the brain. Concussions, also called “closed head injuries”, are a type of TBI. Not all blows or jolts to the head result in a TBI. The severity of such an injury may range from “mild”, i.e., a brief change in mental status or consciousness to “severe”, i.e., an extended period of unconsciousness, or amnesia after the injury. TBI can cause a wide range of functional changes affecting thinking, sensation, movement, language, and/or emotions. Some symptoms may appear immediately after the injury and other symptoms may not appear for days or weeks.

Because of the nature of the injury and the symptoms, sometimes people may not recognize or admit that they have a problem (Deployment Health Clinical Center, 2010).

### *Acquired Brain Injury*

An acquired brain injury (ABI) includes all persons with BI, but also refers to brain dysfunctions caused by anoxia, infectious processes (meningitis, etc), vascular abnormalities (arterial venal malformations, etc) and invasive growths (tumors, cancers, etc).

### *Reasonable Accommodations*

According to Title I of the ADA of 1990, an accommodation is any change in the work environment, or in the way things are customarily done that enables an individual with a disability to enjoy equal employment opportunities (ADA, 1990).

The ADA also states that the term reasonable accommodation (RA) can include the following:

(A) making existing facilities used by employees readily accessible to and usable by individuals with disabilities; and

(B) job restructuring: part-time or modified work schedules, reassignment to a vacant position, acquisition or modification of equipment or devices, appropriate adjustment or modifications of examinations, training materials or policies, the provision of qualified readers or interpreters, and other similar accommodations for individuals with disabilities.

### *Disclosure*

In this study, disclosure refers to revealing information about one's medical diagnosis, mental health condition, or psychiatric status to someone in the workplace (MacDonald-Wilson, Russinova, Rogers, Lin, Ferguson, Dong, & MacDonald, 2011).

## CHAPTER 2: LITERATURE REVIEW: EMPLOYMENT, DISABILITY FACTORS AND DISCLOSURE AFTER BRAIN INJURY

This literature review utilized the University of Maryland libraries research port to access two primary databases: PsychINFO and Medline (EBSCO). Within these two databases, numerous word searches were performed to locate research pertaining to the study. Some of these searches used combinations of the words: return to work, employment, vocational rehabilitation, rehabilitation, brain injury, acquired brain injury, traumatic brain injury, disclosure, disability disclosure, reasonable accommodations. As well, when key articles were located, their references along with authors citing those articles were searched. A total of 32 articles were found related to the disclosure topic, 17 of which were deemed relevant for the current study. This was due to the fact that many articles were not empirical.

### Employment-Related Disclosure of Disability

In order to invoke the reasonable accommodation protections for eligible individuals with disabilities under the Americans with Disabilities Act, jobseekers and employees are required to disclose their disability to potential or current employers (EEOC, 2002). In a recently reported analysis of the legal charges filed with EEOC under the ADA, reasonable accommodation complaints between 1992 and 2005 accounted for 32% of 213,583 total charges (West et al., 2008); or the second highest complaint category after involuntary termination. These data on actual EEOC charges together with several studies of employers and employees (e.g., Dalgin & Bellini, 2008; Pearson, Ho, Hui, Ip, Lo, Yip, & Nelson, 2003) suggest persistent employer reluctance to provide job accommodations. Moreover, and more importantly, studies have also

documented that employees are reluctant to disclose their disability in order to request accommodations (Baldrige, 2005; Frank & Bellini, 2005; Gates, 2000) due to stigma (Conyers & Boomer, 2005), retaliation threats (Frank & Bellini, 2005), and fear of negative employer evaluations (Goldberg et al., 2005; Granger, 2000), among others. As indicated earlier, a literature search of 32 articles revealed only 17 empirical studies related to disability disclosure in the workplace. The articles reviewed will be organized according to the populations which were studied. While one article included two subjects with TBI (Allen and Carlson, 2003) in their mixed population, none of the other studies examined individuals with BI.

Table 1 lists the articles reviewed that were found to be relevant, along with a brief summary of their: samples, designs, variables, disclosure outcomes and factors related to disclosure. The table has been organized by disability type as discussed in the following review.

Table 1.

*Summary of articles reviewed*

Study	Sample	Design	Variables	Disclosure Outcome	Factors in Disclosure
<i>Psychiatric</i>					
Banks et al., 2007	SE Providers (n=162)	Descriptive Survey	Demographics; level of functioning (GAF); Work setting; Psychiatric Severity at work; DX	82% of SE clients disclosed	Women, no psychiatric symptoms, self-placement correlated with disclosure
Dalgin & Gilbride, 2003	Psychiatric (n=11)	Qualitative (focus group)	Demographic; Dx	Unknown	Disability identity, coping related to

					disclosure
Ellison et al., 2003	Psychiatric (n=350)	Descriptive survey	Demographics, dx, income, benefits, job level, work setting	86.6% disclosed	Familiar with ADA; secure employment; coping; work setting; lower income level, more likely to disclose when applying or offered a job.
Gioia & Brekke, 2003	Schizophrenia (n=20)	Qualitative interviews	Demographics; Negative symptoms (SANS); psychiatric status (BPRS); Social/Voc functioning (SOCS); Self-esteem; benefits; Employment history	20% disclosed	Higher scores on SANS, males, poorer employment history; provider involvement correlated with disclosure
Goldberg et al., 2005	Psychiatric (n=32)	Qualitative interviews	Demographics; DX; income; employment status	60% disclosed	Finding job through VR; higher phase of recovery; knowing how to selectively & strategically disclose correlated with disclosure
Granger et al., 1997	Psychiatric SE job coaches (n=194)	Descriptive survey	Demographic; issues involved in disclosure decisions	80% of SE clients disclosed	Non-disclosure related to stigma; differential treatment; negative employer evaluations

Granger, B.,2000	Psychiatric (n=137)	Focus Groups	Education and skills training	NA	Disclosure related to receiving VR services. Fears of disclosure related to receiving differential treatment from employers
<i>Learning Disorders</i>					
Madaus, 2008	LD (n=500)	Quantitative Descriptive Survey	Demographics; LD severity; functional impairments	55% disclosed	Severe functional impairments correlated with disclosure; Reasons for non-disclosure: stigma; disability management
Valle, Solis, Volpitta & Conner, 2001	Teachers with LD (n=4)	Interview	Demographic variables	NA	Demographic variables, "lived experiences," risks and benefits
<i>HIV/AIDS</i>					
Conyers & Boomer, 2005	HIV/AIDS (n=84)	Quantitative Survey	Demographic; progression of illness; occupational level; work history; work motivation; perceived health status	27% disclosed	Higher position level; # of years post DX; functional impairments related to disclosure
Fesko, 2001(b)	HIV/AIDS (n=18)	Qualitative interviews	Demographics; disease progression; perceived health status; work history	33% disclosed	Non-disclosure reasons: safety; privacy; stigma. Acceptance of disability and coping related to disclosure



<i>Hearing Impairments</i>					
Baldrige, 2005	Hearing impaired (n=555 )	Descriptive survey	Need of accommodations frequency, Demographics, disability severity, age of onset	Study focused on accommodation request frequency	Fear of losing power and status, age of onset, severity of disability, workgroup supportiveness
<i>Cancer</i>					
Stewart et al., 2001	Breast cancer Mail survey, n=378	Mail survey	Frequency, to whom, demographics	70% disclosed to friends and 50% disclosed to work colleagues and supervisors	Embarrassment upset others, source of gossip, stigma, too personal to tell, negative effect on relationships. 73.8% thought disclosure had a positive effect
<i>Mixed Populations</i>					
Allen & Carlson, 2003	Mixed disabilities (n=13)	Qualitative focus group	Demographics; Type of disability; VR assistance; Living situation	30% disclosed	Non-disclosure reasons: stigma; preserve self-esteem; work ethic; impediments to promotion
Fesko, 2001(a)	HIV/Cancer (n=32)	Qualitative comparison interviews	Demographics; job history; progression of illness; perceived health status	33% HIV disclosed; all people with Cancer disclosed	Non-disclosure reasons: stigma; rejection by coworkers; HIV stereotypes
<i>Analogue Studies</i>					
Pearson, et al. (2003)	N=1636 (letters sent out to employers)	Quantitative Analogue	Type of Disability (hearing impaired, depression, mobility impaired, no disability)	331 positive responses, 45% (149) responded to the “no disability” category	Letters which did not mention a disability received the most positive responses (146) followed by the letters which mentioned a hearing

					impairment (68), the mobility limitation (63) and depression (54)
Roberts, Hoff, & Macan, (2006)	N=112 video's of, n=56 applicants with non-visible disability (myelitis) and n=56 applicants with no disability	Quantitative Analogue	Timing of disclosure and presence of disability	NA	Applicants with non-visible disabilities who chose to disclose were rated as more qualified and likeable when disclosure was early in interview

*Psychiatric Disorders and Disclosure*

Gioia and Brekke (2003) utilized a mixed methods approach to study differences in 20 individuals who had schizophrenia, regarding their knowledge of ADA and the use of workplace accommodations. In this study, only 20% of participants who had ADA knowledge chose to disclose their disability. For those who had some knowledge of ADA provisions but chose not to disclose, several negative reasons emerged which included: fear of discrimination (stigma), fear of loss of job and that they had nothing to gain. It is interesting to note that for this group of individuals, the majority was female, all had job earnings above minimum wage and all described their jobs as career based.

Goldberg, Killeen, and O'Day (2005) conducted a longitudinal qualitative study to explore the barriers to employment of 32 participants who were recovering from significant symptoms of psychiatric disabilities. The study focused on factors contributing to the decision to disclose or conceal their disabilities at work, and if so, to

whom, when and the extent of disclosure. Overall, 60% of the study participants chose to disclose their disability.

As part of a national study on job accommodations for people with psychiatric disabilities, Granger (2000) conducted 20 focus groups with 137 participants in 10 different states. Two groups were established. The first group (n= 78) consisted of people who were using state vocational rehabilitation (VR) services to help find employment. The second group (n= 59) consisted of people who were currently working, who found their job without any agency-based assistance. While the exact figure was not given, almost all of the participants in the group who had received VR services had disclosed their disabilities, while the group who had found their jobs independently tended not to disclose. Some of the themes that evolved from the study were that participants from both groups expressed fears of differential treatment which might result from disclosure. Both groups voiced concerns over disclosing to co-workers and stated that it was not a good idea.

Banks et al. (2007) conducted a multi-site study (part of a larger study by Banks et al., 2001) to assess disclosure among participants in a supported employment program. They found that 82% of the participants had their disability revealed by the employment agency, rather than the employee. The study found that employees who disclosed differed from those who did not disclose on a number of demographic and disability characteristics. Participants were less likely to disclose if they were female, had a mood disorder, or exhibited no psychiatric symptoms at work. The top three reasons cited for disclosure were: (a) to enlist or facilitate the support of workplace personnel, (b) negotiate accommodations, or (c) address symptoms of crisis issues.

In another survey research design study, Ellison et al. (2003) examined the patterns and correlates of workplace disclosure for professionals and managers who had psychiatric conditions. The authors found that a large proportion of persons disclosed (82%). Among those who did not disclose, reasons included (a) general concern that disclosure would create problems for them, (b) felt that they could keep their job without disclosing, (c) wanted to be perceived like everybody else and disclosure would make that improbable, (d) concerns that disclosure would bias work evaluations and (e) disclosure would negatively impact future promotions. Factors associated with those who disclosed their disabilities included: a) never receiving federal disability income support (b) being more familiar with the ADA and to a lesser extent, (c) having learned to manage their psychiatric condition. In addition, managers who expressed fewer concerns about losing their job due to their psychiatric condition were more likely to disclose.

Dalgin and Gilbride (2003) studied the employment-related disclosure experiences of people with psychiatric disabilities in 11 focus groups. Participants described five major disclosure related themes, including disability identity, the importance of job matching, and concerns about negative responses. The authors did not report the percentage of those participants who disclosed their disability.

#### *Learning Disorders and Disclosure*

Valle, Solis, Volpitta, and Conner (2001) interviewed four teachers with LD. The study focused in part on the invisibility of LD and compared the issues of disclosure for this group to those of gay and lesbian people. Data analysis revealed that the intersections between demographic variables and individual “lived experiences” contributed significantly to each of the participant’s willingness (or lack thereof) to

disclose their disability in specific contexts. All four of the participants had different experiences with disclosure; however, one of the apparent themes that they all shared was that disclosure is contingent upon the risks and benefits involved within a particular situation. Another conclusion was that individuals who have less internalized stigma surrounding their LD may have less apprehension about disclosing their disability.

In a study which examined disclosure rates for university graduates with learning disabilities (LD), Madaus (2008) surveyed 500 graduates with LD from three universities. The results revealed that 55% of the participants had disclosed their LD to an employer at some point in time. Of those who did disclose, 20% stated that they did so after being hired and 11% reported having disclosed during the hiring process. The author did not state at what point in time the other 69% had disclosed. The most commonly cited reason for disclosure was to make the supervisor aware, or to make co-workers aware. Other respondents stated that they disclosed to explain their job performance to co-workers. Several respondents stated that they disclosed as a result of pride in their accomplishments.

Of the 45% of the respondents who chose not to disclose, the most frequently cited reason was that there was no need for an accommodation and therefore no reason to disclose (61%). The next most frequent response was a concern that disclosure would negatively influence the relationship with their supervisors (30%), or co-workers (29%). Twenty percent stated that they were concerned for their job security and 17% stated that they were concerned about negatively affecting relationships with clients.

#### *HIV/AIDS and Disclosure*

Conyers and Boomer (2005) examined factors associated with the disclosure of HIV/AIDS status to employers among individuals who either used job accommodations or did not. Among the 84 participants in this study, 52 % had used some type of job accommodation; however, only 27% of those individuals had disclosed their health status in order to receive it. Among those who did not use accommodations, only 21% disclosed their health status. Analysis of the data revealed that the factors associated with disclosure of HIV/AIDS status were different among participants who used accommodations and those who did not. Factors which affected disclosure among those who used job accommodations included position level, with those individuals who were in professional or managerial positions being more than eight times more likely to disclose than those in less skilled positions. Among those individuals who had not requested job accommodations, two factors were determined to be significant in predicting disclosure: (a) the number of years being HIV/AIDS positive (the more years with virus, the more likely the person was to disclose) and (b) the extent to which the virus interfered with work tasks (the more the interference, the higher the probability of disclosure).

Fesko (2001b) also used the data to examine disclosure/concealment issues for the HIV+ group only. Of those who choose not to disclose (77%), one of the main concerns/factors in their decision was their own safety and protection. Several stated that the nature of their work environment and coworkers prevented them from disclosing.

#### *Hearing Impairments and Disclosure*

In a study of 555 individuals with hearing impairment, Baldrige (2005) found that when there are concerns regarding the potential loss of power and status in the

workplace, individuals are less likely to request an accommodation. While this study did not specifically address the topic of disclosure, the author concluded that severity of disability was a significant moderator in the frequency of requests for accommodation. For example the frequency that accommodation requests were withheld was greater when requesters were more severely disabled, when they became disabled at an earlier age and when the requester was the only person with a disability at the place of employment. It might be that severe hearing impairments are more visible than milder ones; thus suggesting an association between visibility of disability and disclosure.

#### *Cancer and Disclosure*

Stewart, Cheung, Duff, Wong, McQuestion, Chen, Purdy, and Bunston (2001) utilized a mailed survey to examine breast cancer survivors and the impact that their cancer had on confidentiality, disclosure, work and insurance. They found that over 70% of participants disclosed their diagnosis to friends, children, siblings and partners, whereas only 50% disclosed to work colleagues and supervisors. Some of the reasons given for non-disclosure (the study did not differentiate whether this was at the workplace or not) were: it might be embarrassing or upsetting to others, they did not want to be the subject of gossip, too personal to tell, worried about stigma, awkward, uncomfortable, and upsetting, might negatively affect relationships, and might affect job or career prospects. This is in contrast to the majority of women, who felt that disclosure had a positive effect (73.8%), including: more support, feeling closer to people, and receiving more information and advice from others. Some women, however, believed that disclosure had no effect (17.8%).

#### *Mixed Populations and Disclosure*

Allen and Carlson (2003) utilized interviews, focus groups and interviewer notes to collect data regarding the disclosure process for 13 individuals who displayed a variety of disabilities including: rheumatoid arthritis, osteoarthritis, cancer, depression HIV/AIDS, fracture of the wrist, TBI and intervertebral disc prolapse. The authors point out the psychosocial theme that was most frequently and spontaneously mentioned by participants was concealment of disability. Nine of the participants raised the issue of concealment of their disability in either their personal or vocational relationships with prospective employers. Within the category of concealment, four subthemes were identified: preservation of self-esteem, avoidance of emotionally hurtful responses to disfiguring physical changes, the circumvention of negative employer attitudes regarding productivity, and the cultural normative not to complain. In this study, 70% of participants concealed their disability from their employer.

Fesko (2001a) examined the work-related disclosure experiences of 14 individuals who were HIV+ and 18 individuals who had cancer. In this study, all individuals in the cancer group disclosed, while only 33% of those individuals in the HIV+ group choose to do so. The reasons for either disclosure or non-disclosure were different for these two groups. One reason cited for disclosing/concealing their disability status was concern about being rejected by co-workers or supervisors. Other reasons were concern about the stigma associated with their disease, and fear that co-workers would make moral judgments about them, or that the information would be used against them at work, or that they would be stereotyped. The final reason cited was that their health status was a private matter, and if it was not relevant to their work performance, it was not information that needed to be shared.



### *Analogue Studies and Employer Perspectives*

While the previous studies were from the view of the individual with a disability, the following studies explored the issue of disclosure from the employer's perspective. These two studies are included as they shed some light on and validate the extent to which employee's fears of evoking negative reactions when they disclose their disability are evident in studies of employer attitudes.

Pearson, Ho, Hui, Ip, Yip, and Nelson (2003) mailed multiple cover letters in response to 409 position openings in Honk Kong. Four letters were sent for each of the position openings. The letters only varied on disability status: the type of disability. One letter did not mention disability, one letter stated that the applicant had a hearing impairment; one letter stated that the applicant used crutches and one letter stated that the applicant was recovering from a reactive depression. In response to the mailings: 161 out of 409 employers responded, some to more than one applicant for a total of 331 responses. No statistically significant differences were found when comparing the disability groups with each other. However, the letters which did not mention a disability received the most positive responses (146) followed by the letters which mentioned a hearing impairment (68), the mobility limitation (63) and depression (54).

Examining the effects of the timing of disclosure of an invisible disability during interviews, Roberts, Hoff, and Macan (2006) showed two different videotaped employment interviews to 56 college students. In the first videotape, the interviewee disclosed their invisible disability (transverse myelitis) early in the interview and in the second videotape the interviewee disclosed their invisible disability late in the interview. Students then rated the applicant on their qualifications, their comfort with the disclosure

process, and the extent to which they liked the person. The results of this study demonstrated that when the subject in the videotape chose to disclose their disability early in the interview, they were rated as more qualified and likeable ( $M = 5.15$ ,  $SD = 1.41$ ) than those who disclosed their disability later in the interview ( $M = 4.31$ ,  $SD = 1.51$ ).

In another analogue study which examined invisible disability disclosure during employment interviews, Dalgin and Bellini (2008) presented videotaped interview vignettes to 60 employers of potential candidates for a hypothetical employment position. The subject then completed questionnaires which assessed his/her hiring preferences and perceptions of the applicant's (from the video) employability. In this study, two independent variables were manipulated: the type of invisible disability disclosed (no disability, insulin dependent diabetes, and bipolar disorder), and the extent of the disability disclosure (brief disclosure and detailed disclosure). Similar to the Pearson, Ho, Hui, Ip, Yip, and Nelson (2003) study which found a significant effect for the type of disability in the hiring process, the Dalgin and Bellini study indicated a significant effect for disability type. The employers rated the employability of the candidates with a physical disability significantly higher than the candidate with a psychiatric disability. No significance was found for the extent of disclosure or its interaction with disability type. It is also important to note, that when the researchers examined the interactions between the variables for hiring decisions, no significant levels were found across the experimental conditions, even though the employability of the candidates were ranked differentially.

Table 2 represents a comprehensive list of factors related to disability concealment in employment. These factors were derived from the literature review mainly through in-depth qualitative approach. While the current study is a quantitative design, it is expected that some of the same factors relating to the disclosure/concealment of a disability in the workplace will be similar for individuals with BI. Table 3 represents a comprehensive list of factors related to the disclosure of a disability from the literature reviewed in this chapter.

Table 2.

*Factors related to concealment of disability*

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Factors
Disability identity
Can do it alone (i.e., without accommodations)
Protection from a self-concept as disabled
Condition is socially less acceptable
Avoid reactions of others (e.g., pity, patronizing)
Stereotyped condition is associated with reduced productivity/increased costs
To control timing of disclosure
Stigma/fear of discrimination
Health status is private information
Rejection by coworkers
Fear of disability information being used against them
Safety and protection
Nature of the work environment
Fear of being fired/loss of job (job security)
Nothing to gain by disclosing
Phase in recovery
Females less likely to disclose
Mood disorders
No psychiatric symptoms at work
Disclosure would create problems for them
Can keep job without disclosing
Want to be perceived like everybody else
Bias work evaluations
Negatively impact future promotions
No need of accommodations
Belief of negative influence on relationship with supervisors
Belief of negative influence on relationship with co-workers
Belief of negative influence on relationship with clients
Subject of gossip

Table 3.

*Factors related to disclosure of disability*

---

Factors
Disability identity
To obtain assistance from a social network (e.g., employment, social support)
To access work entitlements/options
If injury is perceived as manageable at workplace
To explain a gap in employment history
If person has strong personal preference for being honest
If public records exist (e.g., workers compensation claim)
Because of legal/ethical needs (e.g., may cause harm to others)
If legislation gives protection from discrimination
Belief that employer has the right to know
To explain choices during job interview
For emotional support
Personal acceptance of HIV+ status
Ability to accept negative consequences
Communication skills of worker
Level of supports available
Receiving supported employment
Job matching
Concern about negative consequences
Phase of recovery
Enlisting/facilitating support of workplace personnel
Negotiating accommodations
Address symptoms of crisis issues
Need for physical accommodations
Higher numbers of years post HIV/AIDS+ Diagnosis
The extent of interference with work tasks (HIV/AIDS+)
Having a managerial or professional employment position
Don't receive federal disability funding
Familiar with ADA
Learned to manage psychiatric condition (leading to a satisfying life)
Feeling of job security
Lived experiences
Lower internalized stigma

Summary

Several studies have examined the issue of disclosure, primarily from the perspective of the employee or individual with the disability, but a few also explored

disclosure preferences of employers. The themes that emerged from these studies (summarized in Tables 2 and 3) form a brief roadmap to help guide the proposed study, which examined the disclosure experiences of a national sample of people with BI, the processes of disclosure, and factors contributing to the decision to disclose/conceal. The proposed study expands the existing literature by sampling from a population that has been largely, if not completely, ignored in the disclosure literature, by examining the disclosure process for this population, and in so doing provide a starting point for more in-depth quantitative and qualitative research.

This study explored the visibility aspects of the injury and how this affects the process of disclosure. Only two of the studies (Dalgin & Bellini, 2008; Roberts & Macan, 2006) acknowledged visibility as a central factor; not from the individual's perspective, but from the employer's perspective. The results of both the Dalgin and Bellini (2008), and the Pearson et al. (2003) study demonstrate that potential employers favor disabilities differently, where disabilities that are more visible (i.e., use of crutches), or physical in nature (i.e., diabetes) are more positively regarded than disabilities that are less visible (i.e., psychiatric). Visible disabilities therefore might be more acceptable to employers than those disabilities that are not readily visible such as those due to mental health conditions, substance abuse disorders or cognitive disabilities (Diksa & Rogers, 1996; Hernandez et al., 2000; Popovich, Scherbaum, Scherbaum, & Polinko, 2003; Scheid, 1999).

In the BI population, the nature of the resultant functional limitations are so heterogeneous that they can manifest in either an invisible (i.e., damage to frontal cortex resulting in a cognitive functional impairment) or visible disability (i.e., damage to motor

cortex resulting in a motor functional impairment). This heterogeneity in the BI population, affords an excellent opportunity to study the effects of visibility on disclosure. It therefore seems paramount to this study to include visibility of disability as a factor as this might prove to offer a better type of organizational structure and way of understanding disability disclosure than previous efforts which had a focus on the examination of different types of disability.

## CHAPTER 3: METHODS

This study examined the extent to which individuals with BI have disclosed their disability in employment, the types of employment settings, extent of injury and the demographic attributes of this population. The primary goal of the current study was to describe the population of people with BI who disclose their disability in the workplace. The three research questions guiding this study were:

Research Question #1: What are the experiences of work related disability disclosure for individuals with BI?

Research Question #2: What employment-related outcomes are associated with the decision to disclose?

Research Question #3: What disability, demographic, and other factors are associated with the decision to disclose a disability?

### *Participants*

Participants were recruited from the Brain Injury Association of America (BIAA) and their affiliates. The BIAA is the leading national organization serving and representing individuals, families and professionals who have had a TBI or other types of BI. Currently BIAA has approximately 30,000 individuals on the mailing list across 44 states in the country. The BIAA helpline called the, “National Brain Injury Information Center” receives about 3,000 requests per year for information, approximately 25% of those callers have asked about research in BI. Inclusion criteria were as follows: participants must be of working age (over 18); at least one year post injury and must have



a pre and post-injury previous employment history. Inclusion criteria were listed in the consent form of the survey.

Initially the response rate to the survey posting was extremely slow. After examining the BIAA website, it was found that the link to the survey was deeply embedded, where one would have to navigate through several links to get to the advertisement and survey link. Efforts were then made by the researcher to contact BIAA affiliates around the United States to seek help in sponsoring the link. Many Brain Injury Association (BIA) affiliates did not have their own websites and could not be of assistance. However, the BIA of Connecticut sent out an advertisement and web address to the survey in their quarterly newsletter. The Brain Injury Alliance of Colorado was contacted and their executive director, Gavin Attwood responded immediately by placing the advertisement and hyperlink to the website directly on their website homepage. This resulted in the immediate influx of completed surveys, which ended up accounting for almost 45% of total surveys collected. The BIA of Arizona, Georgia and California were also contacted which resulted in 5.5% of surveys collected. The National Association of State Head Injury Administrators (NASHIA) was also contacted and their executive director, Lorraine Wargo sent out information pertaining to the survey to their members; however, it is not known if this had an effect on the number of surveys collected. The Brainline Organization a subsidiary of WETA was contacted, but they did not provide assistance.

Of the 200 participants, the average age was 47, and 59.5% were female. Eighty two percent of respondents were white and more than half 106 (53%) lived in a suburban setting, the second highest group coming from an urban location 50 (25%). Of the 201

respondents 88 (44%) were married/cohabitating and 63 (31.5%) were single and 49 were either divorced or widowed (24.5%). In this study, 90 participants responded that they were currently employed with 56 (28%) working full-time, and 34 (17%) working part-time, with the majority, 109 (55%) not currently working. Table 4 summarizes the demographic information on the sample.

Table 4.

*Participant Demographics*

Factor/Variable	Data
Age (In Years)	Mean: 47.4 Median: 49 Standard Dev.: 11.2 Range: 74
Age at time of Injury (In Years)	Mean: 34.7 Median: 34.5 Standard Dev.: 14.1 Range: 86
Gender	Male: 81 (40.5%) Female: 119 (59.5%)
Race/Ethnicity	White: 161 (82.1%) Multicultural/Other: 16(8.2%) Hispanic/Latino: 11 (5.6%) Black: 8 (4.1%)
Living Setting	Suburban: 106 (53%) Urban: 50 (25%) Rural: 44 (22%)
Marital Status	Married/Cohabitating: 88 (44%) Single: 63 (31.5%) Divorced/Widowed: 49 (24.5%)
Employment Status	Not Employed: 109 (55%) Yes, Full-time: 56 (28%) Yes, Part-time: 35 (17%)

Table 5 contains responses regarding participant educational experiences. Most respondents had over a high school education level 198 (96%) and 148 (74.4%) achieved their educational status prior to their BI.

Table 5.

*Educational Experiences*

Factor/Variable	Frequency	Percentage
<i>Education Level</i>		
Less than High School	6	3.0%
High School	59	29.6%
AA or BA	86	41.7%
Masters and Higher	53	25.6%
<i>Education Achieved Before/After BI</i>		
Before BI	148	74.4%
After BI	51	25.6%

*Procedures*

After receiving protocol approval by the University of Maryland’s IRB, a recruitment/invitation statement (see appendix A), and the link to the online survey online using Survey Monkey were provided to Greg Ayotte at BIAA to be posted on their main website. Mr. Ayotte also sent out emails with the link to the survey along with the recruitment/invitation for the research project to all of the BIAA affiliate offices in the country. Individual BIAA offices then decided whether or not they would participate and post the survey link on their affiliate websites. Other organizations and affiliates were contacted as described above.

Once the potential participant entered the survey from the link, they were informed about the study (See Appendix B). Informed consent was obtained by participants’ reading the consent form and then freely and voluntarily choosing to participate in the research project, and completing the online survey. The inclusion criteria for the study were also listed in the consent form.

As an added incentive to participate in the study, participants were given the opportunity to enter a raffle with the chance to win one of five \$25 VISA gift cards. After the raffle was completed, the winners were mailed a gift card according to the contact information provided in the raffle entry. After the raffle, all participant identification was destroyed.

Survey results were downloaded on a weekly basis from Survey Monkey and loaded into a database for analysis utilizing SPSS version 19. The survey was posted for 13 months. A total of 200 completed studies were collected.

### *Instrumentation*

#### National Brain Injury (BI) Study of Disability Disclosure in the Workplace

The survey used in this study was a modified version of the survey used by Madaus (2008) for people with LD. Madaus stated that the 2008 survey was updated from its initial use (Madaus et al., 2003) based on the results of that study, other additions to the professional literature, a review by a panel of content experts, and a pilot study. The Madaus (2008) survey consists of four sections. The first section included demographic and background information, including, education, employment and, and nature and extent of the LD. The second section contained five items related to the ADA. The third section consisted of items related to work satisfaction and the fourth section was related to employment self-efficacy. Sections 2, 3 and 4 used a 5-point Likert scale (1= strongly disagree, 5= strongly agree). The survey demonstrated adequate reliability (.90 for job satisfaction, .94 for employment self-efficacy and .73 for the ADA scale) (Madaus, 2008). For the current study, the work satisfaction scale was not used.

The primary reason for using the instrument in the current study is that it taps into many of the factors appearing in the disclosure literature (i.e., demographics, disability variables, employment information, workplace experiences, reasonable accommodations, and employment self-efficacy) reviewed earlier. However, and more importantly, the Madaus Survey (2008) directly addresses the three research questions of the current project. Several items were deleted from the original survey as they were either not relevant to BI or not relevant to the study's research questions. Tables 5 and 6 give examples of item modifications.

The final instrument used in this study has six sections contained in two parts (see appendix A), totaling 54 items. In all items of the survey, the language was simplified for understanding and clarification. Changes were made to address BI (e.g., LD was changed to BI).

#### *Survey Section Part I*

The first part of the survey contains five sections and has 38 items. Section (A) is respondent information and contains demographic and injury information. Section (B) is educational experiences; Section (C) is employment information. Section (D) focuses on brain injury and work experiences and contains information related to how the individuals' injury impacts their work. Finally section (E) is disclosure experiences and contains questions focused on the disclosure process and experience (to whom, and why), job accommodations, and two items related to knowledge of the ADA. All of the sections in part I of the survey were modified. The survey takes approximately 10-12 minutes to complete (for an individual without a BI).

Several items were deleted from the original survey as they were either not relevant to BI or not relevant to the study’s research questions. Table 6 gives examples of modifications made to the survey questions and Table 7 gives examples of items added to the survey.

Table 6.

*Modification Example of the Madaus (2008) survey to create the current survey*

---

Survey	Description
Madaus (2008)	Does your LD impact your work in some way?
Burnhill (2010)	How often does your BI affect your work?

---

Table 7.

*Example of Items added to the Madaus (2008) survey to create the current survey*

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Survey	Description
Burnhill (2010)	Was your BI mild, moderate, severe, don’t know?
Burnhill (2010)	In addition to your BI, do you have another documented disability, or serious health condition that prevents you from working, travelling, training, school, or activities of daily living?

---

The five sections of part I of the study contain 38 items (see Table 8).

Table 8.

*Survey Section Part I*

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<u>Survey Section</u>	<u>Survey Item</u>
Respondent Information	7 Items
Educational Experiences	2 Items
Employment Information	8 Items
Brain Injury and Work Experiences	6 Items
Disclosure Experiences	15 Items

---

*Survey Section Part II*

Part two of the survey contains an employment self-efficacy scale created by Madaus et al. (2002) and validated in several studies (Madaus et al., 2003; Madaus 2006; Madaus, 2008) on individuals with LD. The Employment Self-Efficacy scale contains 16 items, and is based on a 5-point Likert scale (1= strongly disagree, 5= strongly agree). The instrument had no subscales. In the current study, the inter-rater reliability (coefficient alpha) for the 16-item Self-Efficacy Scale is 0.95 for the 158 of the 200 participants who responded to all items. For more detail on the instrument, refer to the last section of the survey in Appendix C.

*Data Analysis Procedures*

All variables were coded into SPSS. Data was downloaded from Survey Monkey into Excel and imported into SPSS for data analysis.

For research question one: what are the experiences of work related disability disclosure for individuals with BI, descriptive statistics were used to describe the frequencies and percentages of responses.

For research question two: what employment-related outcomes are associated with the decision to disclose, chi-square analysis was used for the nominal variables and ANOVA's for continuous dependent variables.

For research question three: what disability, demographic and other factors are associated with the decision to disclose a disability, logistic regression was used as disclosure is being coded as a dichotomous variable. The odds ratio for each of the independent variables was calculated.

Independent variables for questions two were derived mainly from the literature review and disclosure items derived from the Madaus (2008) survey; however, the independent variables which were included in the final regression model for question three were derived from the literature review and from the results of the data analyses in question two.



## CHAPTER 4: RESULTS

This chapter begins with general survey data pertaining to the experiences of work related disability disclosure for the survey participants. This information is followed with the analysis of research question one: what are the experiences of work related disability disclosure for individuals with BI? Descriptive statistics were used to describe the response frequencies and percentages. Research question two examines employment-related outcomes associated with the decision to disclose. The dependent variable was disclosure and the independent variables were: positive/negative outcomes, accommodation request/provision, and job tenure. Data was analyzed using descriptive statistics, ANOVA's and Chi-Square analysis. Research Question three utilized ANOVA's, Chi-Square analysis and Logistic Regression to examine the dependant variable disclosure with several independent variables: disability factors, demographics, and other factors that were either shown to be statistically significantly related to the dependant variable or believed to be closely associated with the decision to disclose a disability (i.e., severity of injury, time since injury, educational level, salary, job tenure, self-efficacy, visibility of disability, how frequently BI affects work, health benefits, gender, knowledge of ADA, current work status, age and time between injury and current age).

### General Survey Data of the Participants

#### *Disclosure Experiences*

For the entire sample (n=200), 136 (70.5%) self-disclosed their disability for at least one job; 8 or 4.1% had someone else disclose, and 49 or 25.4% did not disclose their disability on any job (See Table 9). For those currently working, 98 (72%) had disclosed

and 38 (28%) had not disclosed. This will be examined for statistical significance later in the chapter.

Table 9.

*Disclosure Experiences on the job*

Factor/Variable	Frequency	Percentage
Self disclosed	136	70.5%
Other disclosed	8	4.1%
Did not disclose	49	25.4%
Total	194	

*Primary Reasons for Disclosure*

Most survey respondents who disclosed, 39 (28.7%) indicated the primary reason was, “to be honest about who I am.” The second highest reason (25.7%) was “other” and the third highest reason (14.7%) was, “to make supervisors aware of my BI.” Table 10, illustrates the primary reasons for disclosure for the sample.

Table 10.

*Primary Reason for Disclosure*

Factor/Variable	Frequency	Percent
To be honest about whom I am	39	28.7%
Other reasons	35	25.7%
To make supervisors aware of my BI	20	14.7%
To get changes made to job so I could work better	15	11%
To protect myself under the ADA	8	5.9%
Need for additional time to complete task	8	5.9%
I didn't disclose, someone else did	5	3.7%
To make co-workers aware of my BI	3	2.2%
To increase self-esteem	2	1.5%
Use of technology as an accommodation	1	0.7%
Total	137	

Examples for the answer choice, “other” were: “for health benefits” or “to get workers compensation,” to explain “not being on the ball,” to “explain absences” or “missed time.” For some individuals, the injury occurred on the job and some

participants stated that, “everyone knew about it.” Other examples involved individuals who actually incorporated BI into their persona, or used their experience to help others.

For more detailed information see appendix D.

*To whom did they disclose?*

For this survey item, participants were given the opportunity to check all responses that applied, many participants chose multiple responses. The responses in Table 11 came from 136 participants.

Table 11.

*To Whom did you Disclose*

Factor/Variable	Frequency	Percent
To supervisor	108	79%
To co-workers	84	62%
To human resources personnel	55	40%
To others	29	21%
Total	276	

Of the sample, 29 (14.5%) listed “other.” Some examples of “other” responses are to: directors, board of trustees, business owners, everyone I know, clients, or that “everyone knows that I suffered some kind of injury by my walking with a cane and slow speech.”

Most study participants disclosed at only one or two jobs; however, many study participants disclosed at more than one job. One participant stated that they disclosed at 17 jobs and another at 15 different jobs. Eight individuals skipped the question. The average number of jobs disclosed at was 1.7. See Table 12 .

Table 12.

*Number of Jobs Disclosed*

Factor/Variable	Frequency	Percent
1-2	84	61.8%
4-5	9	6.6%
5 or more	15	11.0%
Total	136	

*Employment Related Information*

In terms of those employed at the time of survey, 56 (28%) of the sample of 200 reported working full-time, 34 (17%) were working part-time, with the majority, 109 (55%) not currently working (one individual skipped this question). For those currently working, the average job tenure was 97.7 months or a little over 8 years (SD = 103.8 months), and the range was up to 372 months (31 years). The median employment duration was 4.5 years and the mode was only one year. Seventy two participants worked for companies, while 16 individuals were self-employed. Table 13 lists the type of industries participants worked in. For details on the 19.3% who chose to answer “other” to this survey question, see appendix E, and appendix F contains job titles for those participants.

Table 13.

*Employment Information*

Factor/Variable	Frequency	Percent
Education	16	18.2%
Healthcare	15	17.0%
Non-Profit	9	10.2%

Social Services	4	4.5%
State/Local Government	8	9.1%
Federal Government	5	5.7%
Business	3	3.4%
Factory/Industry	2	2.3%
Technology	2	2.3%
Recreation	1	0.5%
Other	17	19.3%
Total	82	

---

Most participants who were currently working at the time of the study 55 (62.5%) received full healthcare benefits and 8 (9.1%) individuals received partial benefits. The largest percentage of employed participants 42 (47.7%) earned over \$50,000, with the second largest group earning less than \$10,000, 19 (21.6%). This represents a wide range of salaries, however 34 (17%) of participants were only working part-time which could explain this variance.

*If Not Currently Employed Why?*

For those were not currently employed at the time of the survey the primary reasons are listed in Table 14.

Table 14.

*Why Not Employed*

---

Factor/Variable	Frequency	Percent
Health Condition	63	57.8%
Other	33	30.3%
No Jobs Available	8	7.3%
In School	5	4.6%
Total	109	

---

For those who chose to answer “other” many reasons were given. Most pertained to either their symptoms, “can’t find work,” “can only get volunteer work” and other

reasons such as “I have experienced a great deal of prejudice at work.” For more information see Appendix G.

*Causes of BI*

The following information in Table 15 lists causes of BI’s as reported by participants.

Table 15.

*Cause of BI*

---

Factor/Variable	Frequency	Percent
MVA	96	48%
Other	53	26.5%
Fall	40	20%
Struck by/Against	23	11.5%
Assault	7	3.5%
Stroke	5	2.5%
Multiple	3	2.0%
Tumor	1	0.5%
Total	228	

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It is apparent by the total number of causes listed, 28 more than were in the study, that several participants had more than one BI. The rates of types of injury are similar to those reported by the Center for Disease Control where falls and motor vehicle accidents are the most frequent causes of BI. Of those who chose the response, “other” 10 BI’s were a result of a sports related injury, 6 were from aneurysms, 3 had encephalitis and 2 had MS. Many of those who responded to the answer choice “other” actually fit into the categories “struck by/against” and “falls” and were coded as such. However, their description was left in place as it adds to the richness of the data and for possible future data examination. See appendix H for further information on “other” responses.

## Experiences of Disability Disclosure

Research question one: What are the experiences of work related disability disclosure for individuals with BI?

Table 16, illustrates what respondents said when they disclosed. The majority of participants simply stated that they had a BI. With the second highest frequency, 43 (31.6%) choosing the category “other.” Participants were given the chance to answer all responses that applied.

Table 16.

### *Disclosure Content*

Factor/Variable	Frequency	Percent
I have a BI	72	36%
Other	43	21.5%
I have a health condition	28	14%
I have a disability	23	11.5%
I was not specific	8	4%
Total	174	

Most of the survey participants who chose the answer choice “other” did so to explain their particular symptoms, such as memory loss or other functional limitations (See appendix I). Some gave answers about the way their injury occurred, such as having been in an automobile accident. Some participants informed their employer that they needed specific accommodations, which implies that the employer already knew about their BI.

### *Type of Accommodation used at Work*

Survey participants were asked what, if any, types of strategies and accommodations they use at their current job and were given the opportunity to check all that apply. Table 17 summarizes this data.

Table 17.

### *Types of Accommodations Used at Work*

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<u>Factor/Variable</u>	<u>Frequency</u>	<u>Percent (out of 200)</u>
Quiet Work Environment	60	30%
Time Management	54	27%
Other	51	25.5%
Setting Goals/Priorities	48	24%
Self-Advocating	42	21%
Support from Family/Others	41	20.5%
Support from Co-Workers	40	20%
Extra Task Time	39	19.5%
Arrive Early	36	18%
Stay Late	32	16%
Assistive Technology	29	14.5%
Problem Solving/Brain Storming	24	12%
Delegation of Difficult Tasks	21	10.5%
Graphic Organizers	19	9.5%
Use of Proof Readers	12	6%
Total	538	

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For those who answered, “other” which was the third most frequent choice, many discussed adjustments to their schedule, slower pace, arranging rides, better lighting, and quite work spaces.

### *Reasons for Non-Disclosure*

Of the 49 individuals who did not disclose at any jobs, 48 answered this question and of those, 28 gave multiple reasons for not disclosing. See Table 18.



Table 18.

*Why not disclose?*

Factors/Variables	Frequency	Percent
Concern for negatively influencing relationships with clients/customers	21	43.8%
Concern for negatively influencing Relationships with co-workers	21	43.8%
Concern of being stigmatized at work	20	41.7%
Concern for negatively influencing Relationships with supervisors	19	39.6%
Concern for job security	16	33.3 %
No reason to disclose, no need for Accommodation(s)	9	18.8%
Disclosure in a previous job created Problems	4	8.3%
Other	22	45.8%
Total	132	

Examples of “other” responses had a common thread with participants making comments such as: “they never had the chance,” “they didn’t thought to do so,” “don’t like to think that TBI is a problem.” A few participants believed that revealing their BI would prevent them from being hired, “disclosure in a previous job interview possibly caused them not to hire me due to head injury no one wants to hire behavior problems.” Several individuals stated that they were either not currently working or retired. Also several participants thought that to disclose would either prevent them from being hired or cause them to lose their job.

Another important aspect of BI, employment and disclosure is how frequently one’s symptoms impact their productivity at work. Most individuals, 115 (59.6%)

indicated that their BI always affected their work and 49 (25.4%) stated that their BI frequently (1-2 times/week) affected their work. Whereas, only 25 (13%) stated that their BI affects their work occasionally or rarely. Four individuals (2%) stated that their BI never affected their work.

### Outcomes Associated with Disclosure

Research Question Two: What employment-related outcomes are associated with the decision to disclose (i.e., positive/negative outcomes, accommodation request/provision, job tenure)?

As noted in the previous section in table 18, many participants chose not to disclose their disability in the workplace due to their belief that negative consequences might occur as an outcome of disclosure (concern for negatively influencing co-workers and supervisors, concern of being stigmatized, etc.). Also previously discussed were reasons why participants chose to disclose their disability which were based on the belief that there could/would be positive benefits from doing so (e.g., to be honest about myself, to increase self-esteem, to obtain job accommodations, etc.). In this section the specific employment outcomes associated with the decision either to disclose or not to will be examined. Specifically, participants were asked two questions regarding workplace accommodations, whether they had ever asked for one, and if so had they ever been denied one. Job tenure will also be examined.

#### *Effects of disclosure*

Of great importance is the impact of having disclosed to an employer. Participants who disclosed were asked if they experienced either positive or negative effects of having done so. Oddly enough, the results were similar with 79 (58%) saying they experienced

positive effects and 84 (62%) saying they experienced negative effects after disclosing, meaning that for some participants they experienced both positive and negative effects having disclosed. It is clear that the decision to disclose is complex and the outcomes unpredictable.

#### *Accommodations & Disclosure*

Of the 136 people who disclosed, 93 (68.4%) asked for an accommodation; while only 9 (18.8%) of those who did not disclose requested an accommodation ( $X^2=35.376, 1, p < .000$ ). In terms of receiving an accommodation, of those who disclosed and requested, almost 50% or 45 respondents were granted an accommodation; whereas of those who did not disclose, only 33% or 3 people were granted one ( $X^2=.852, 1, p < .000$ ).

#### *Tenure and Disclosure*

In terms of job tenure, of those currently working who responded (n=87), there was a significant relationship between length of time on the job and disclosure ( $X^2 = 8.564, 3, p=.036$ ). Interestingly, about 75% of those employed less than one year disclosed; while only 56% of those employed greater than 10 years disclosed.

#### Factors Related to Disclosure

Research Question three examined the disability, demographic, and other factors associated with the decision to disclose a disability (i.e., severity, time since injury, educational level, self-efficacy, salary, race, gender, age, time between injury and age, employment related self-efficacy, visibility of BI, frequency that work is affected and knowledge of and importance of ADA). See Table 19 for a summary of these data.

Table 19.

#### *Factors Related to Disclosure*

Factor/Variable	Never Disclosed		Have disclosed	
	Frequency	Percent	Frequency	Percent
<i>Current salary:</i>				
Less than \$10k	2	14.3%	17	23.3%
\$10,001 to \$20k	0		7	9.6%
\$20,001 to \$30k	1	7.1%	5	6.8%
\$30,001 to \$40k	2	14.3%	6	8.2%
\$40,001 to \$50k	1	7.1%	5	6.8%
\$50,001 to \$60k	1	7.1%	10	13.7%
\$60k and higher	<u>7</u>	50%	<u>23</u>	31.5%
Totals	14		75	
<i>Receiving health benefits:</i>				
Full Benefits	9	64.3%	45	61.6%
Partial Benefits	0		8	11%
No Benefits	<u>5</u>	35.7%	<u>20</u>	27.4%
Totals	14		73	
<i>**Educational level:</i>				
Less than High School	5	10%	1	1%
High School/Post secondary	16	33%	41	28%
AA/BA	17	35%	65	45%
MA and Higher	<u>11</u>	22%	<u>37</u>	26%
Totals	49		144	
<i>Race:</i>				
White	36	77%	118	83%
Black	4	9%	6	3%
Hispanic	5	4%	4	4%
Multicultural/Other	<u>2</u>	10%	<u>14</u>	10%
Totals	47		142	
<i>Severity of BI:</i>				
Mild	9	18.5%	25	17%
Moderate	9	18.5%	49	34%
Severe	27	55%	50	35%
Don't Know	<u>4</u>	8%	<u>20</u>	14%
Totals	49		144	
<i>Visibility of BI:</i>				
Visible	13	26%	42	29%
Not Visible	19	39%	74	52%
Uncertain	<u>17</u>	35%	<u>28</u>	19%
Totals	49		144	

<i>How frequently does BI affect work:</i>				
Always	27	55%	88	61%
Frequently	14	29%	35	24%
Occasionally	4	8%	11	8%
Rarely	3	6%	7	5%
Never	<u>1</u>	2%	<u>3</u>	2%
Totals	49		141	
<i>Know rights under ADA:</i>				
Strongly Agree	2	4.2%	18	13.4%
Agree	12	25%	38	28.4%
Unsure	25	52.1%	47	35.1%
Disagree	6	12.5%	13	9.7%
Strongly Disagree	<u>3</u>	6.3%	<u>18</u>	13.4%
Totals	48		134	
<i>ADA is important to me on a daily basis:</i>				
Strongly Agree	6	12.5%	36	26.9%
Agree	11	22.9%	30	22.4%
Unsure	25	52.1%	25	33.6%
Disagree	2	4.2%	12	9%
Strongly Disagree	<u>4</u>	8.3%	<u>11</u>	8.2%
Totals	42		139	
<i>*Employment Self-Efficacy (score out of 80)</i>	Mean SE Score: 55.1 SD: 14.03;		Mean SE Score: 61.3 SD: 11.82;	
Totals	40		118	
<i>Average age</i>	Mean age: 46.5;		Mean Age: 47.6	
Totals	49		144	
<i>*Time between injury and current age</i>	Mean Years: 15.25;		Mean Years: 11.5;	
Totals	49		144	

\*= $p < .05$ ; \*\*  $p < .01$

For the factors in Table 19, level of education ( $X^2 = 11.945, 3, p = .008$ ), self-efficacy score ( $F = 7.52; p = .007$ ) and time between injury and current age ( $F = 4.56; p = .034$ ) were significantly related to disclosure.

Finally, binary logistic regression analysis was conducted to examine the combined effects of significance of some of the predictors with disclosure as the dependent variable. Based on results of the descriptive analyses, as well as findings from the literature reviewed in Chapter 2, five factors were entered into the analyses (See Table 20).

Table 20.

*Logistic Regression Model*

Factor/Variable	B	S.E.	Wald	df	Sig.	Exp(B)
EdLevel			6.827		.078	
EdLevel (1)	-3.557	1.459	5.941		.015	
EdLevel (2)	-.042	.614	.005		.946	
EdLevel (3)	.168	.551	.093		.760	
Time since injury	-.051	.018	7.997		.005	
BISeverity			7.063		.070	
BISeverity (1)	1.106	.610	3.282		.070	
BISeverity (2)	.342	.582	.346		.556	
BISeverity (3)	1.839	.859	4.584		.032	
SEScore	.043	.016	6.924		.009	
Currentjob (1)	-.220	.503	.192		.661	
Constant	-1.220	1.142	1.141		.285	

Because of missing data, only 158 cases were entered into the analysis. Overall, the model is a reasonably good fit for the data ( $X^2 = 28.25, 9, p < .001$ ) with 82% of the

cases correctly classified. The Hosmer-Lemshow statistic was not significant, and the -2LL was 150.333. In logistic regression, the odds ratios indicate the strength and direction of the relationship between the predictor and the binary dependent variable, with odds ratios greater than 1 indicating that the odds of disclosing the disability increases when the predictor increases, and where the odds ratio is less than 1 indicating that the odds of disclosing decrease when the predictor variable increases. In this analysis, only "time since injury" and "self-efficacy score" are significant (using the Wald Statistic) when considered together with the other predictors in the model. As is evident in Table 20 higher SE belief scores slightly increase the odds of disclosure, and time since injury decreases the odds of disclosure, or the more recent the injury, the more likely the individual is to disclose (by about 5%). While other factors in this model were not significant at the .05 level, given the small sample size and the exploratory nature of this study, we might cautiously conclude that "severity of injury" is significantly related to disclosure in this model, with the odds ratios indicating that compared to the "mild" disabilities, those with moderate and severe were more likely to disclose. A similar pattern in the model is evident for level of education. These findings are consistent with those in Table 19.

This chapter presented summary statistics for the three research questions that guided the study. Although there were few significant statistical differences (given the power of the study), there were several interesting exploratory findings that emerged. These will be discussed in the next chapter.

## CHAPTER 5: DISCUSSION

This study examined the experiences of work-related disability disclosure for individuals with BI, the injury, demographic and other factors associated with the decision to disclose a disability at work, and employment-related outcomes associated with disclosure. The primary goal of the current study was to describe the population of people with brain injury who disclose their disability in the workplace and to make inferences about the contributing factors involved in the disclosure process. The first section of this chapter summarizes and discusses the key findings. Findings are also placed in the context of the rehabilitation literature previously reviewed, discussing its consistency with past research and looking at possible reasons for any divergence from these studies. The following sections of the chapter will discuss implications for practice, limitations of the study, and suggestions for future research.

### Summary and Interpretation of Results

Perhaps the most important finding of this study is that the vast majority of the participants either self-disclosed or allowed someone else to disclose their disability in at least one job, giving a total disclosure rate of 74.6%. This is sufficiently different from the majority of studies based on other disability populations reviewed in chapter two, where most of the disclosure rates were below 50%. Although the Ellison et al's. (2003) study had a 86% disclosure rate, their sample included primarily professionals and managers (with psychiatric conditions) and thus did not represent a more general working population. Banks et al. (2007) also had a very high disclosure rate (82%), however, their population sample were all receiving supported employment services, where the disclosure was typically made by the employment agency. One study study found



disclosure rates as low as 20% (Gioia & Brekke, 2003) but there were only 20 participants in that study, and therefore it is nearly impossible to make any predictions regarding the general population. However, in all the studies reviewed only one study included two individuals with a BI, making this study the first of its kind.

Some of the primary reasons for disclosure in this study included self-identity, “being honest about who I am” (28.7%), requesting a job accommodation, or “to make supervisors aware of my BI” (14.7%), and “to get changes made to the job so I could work better” (11%). A few of the respondents, who checked "other" in terms of reasons to reveal their disability, had positive responses, such as "Disclose? It's just part of who I am", or another participant who wrote disclosure was part of the effort to "educate others." These reasons are similar to those in other studies. For example, Schrader, Malzer, Erickson and Bruyere (2011) found that about two-thirds of the respondents who participated in their on-line survey rated the “need for accommodations” and “supportive supervisor relationships” as being some of the main reasons for disability disclosure. Although most of the studies reviewed in chapter two tended to describe more reasons for non-disclosure of disability, other positive reasons for disclosure in this literature included coping and better management of disability (Dalgin & Gilbride, 2003; Fesko, 2001b), as well as disclosing their disability in order to request an accommodation (Fesko, 2001b; Gioia & Brekke, 2003; Madaus, 2008)

A finding that was not surprising was the association between level of education and disclosure. In this study, in general, the lower the level of education, the more likely the individual was to disclose, although this finding requires very cautious interpretation as the sample only included six respondents who had *not* received a high school diploma.

However, the majority of participants in this study had a high level of education. For example for those who disclosed, 71% had an AA/BA or higher. For those who did not disclose 57% had achieved an education level of AA/BA or higher. In the Ellison et al. (2003) study which found a high rate of disclosure amongst professionals and managers, a tentative conclusion could be that it is not only job level, but higher levels of education that contribute to higher disclosure rates.

Deeper exploration of level of education for this sample indicated that a substantial minority (26%) achieved their educational level after their brain injury (with 45% of this sub-group acquiring an associate's or bachelor's degree). It may be that acquiring credentials after experiencing a significant disability contributes to improving disability acceptance, which, in turn, confers some advantage in having the confidence to reveal the disability in the workplace. Not surprisingly, there was a significant association between severity of disability and educational level ( $X^2=22.359, 9, p=.008$ ) where, for example, 82% of respondents who described their brain injuries as "mild" achieved a post-secondary degree (AA or higher), compared to 57% of those with severe disabilities.

While current salary was not significantly correlated with disclosure, it appears that those who did not disclose earned higher wages in general. Of those who did not disclose, 57% earned over \$50,000, whereas for those who did disclose, 45% earned over \$50,000. Once again this finding must be interpreted with caution as the differences in group size were quite large (144 participants disclosed versus 49 who did not disclose).

Related to the disability issue is the timing: interestingly, the more recent the injury, the more likely the individual was to disclose. While not significant, tenure was also closely related to disclosure where individuals with more than five years on the job

being less likely to have disclosed. Most likely the longer the individual has been at the same job, the closer their relationships are with co-workers supervisors and HR personnel to a point where dual relationships exists (i.e., friendships) within the work setting, and disclosure would not have been as much of a factor. Another plausible explanation for higher rates of disclosure for individuals with more recent injuries, or put another way, the lower rates of disclosure for individuals further away from their initial injury could be that over time individuals with BI learn how to manage or compensate for their resultant functional limitations and therefore are less likely to need or seek out accommodations in the workplace.

Although there was no significant association between the item regarding knowledge of the ADA and time since injury, we might tentatively attribute this difference to increasing employer acceptance of the ADA in the workplace, making it easier for those whose injuries were more recent to decide to disclose. This area requires further research to understand the interplay between employer knowledge of the ADA and employee likelihood to disclose.

In contrast to high levels of education being correlated to disclosure, salary was inversely related to disclosure, where those who were earning higher salaries were less likely to have disclosed. However, this finding should be interpreted cautiously as there were few respondents currently working who reported on this variable. Previous literature (Ellison et al., 2003) has demonstrated that those in professional and managerial positions (the assumption being that they also earn higher salaries) were more likely to have disclosed. It is also possible that higher level jobs are more flexible regarding the provision of accommodations.

Also of interest is that of those who did disclose, the positive and negative consequences of disclosure were about equal, where 58% of those who disclosed reported positive benefits from their disclosure and 62% reported negative ones. Therefore a delicate balance exists between disclosure and the outcome which adds a level of complexity to an already complex process. However, it was not determined in the current study what the benefits or negative consequences are.

The relationship between self-efficacy beliefs and disclosure outcome was positive and significant, an important finding in terms of practical implications, and one that is consistent with other studies reviewed earlier. For example, Allen and Carlson (2003) and Dalgrin and Gilbride (2003) found SE beliefs, or coping skills to be associated with disclosure for other populations. Others have found SE beliefs to be correlated with life satisfaction (and community integration) for persons with BI (Cicerone & Azulay, 2007) and a positive contributor to the neurological rehabilitation process ( Dixon, Thornton, & Young, 2007). The knowledge that SE is correlated to disclosure in this BI sample is a significant addition to the scant research currently available relating to BI and SE beliefs.

Even though severity of BI was not significantly associated with disclosure in the Chi-square analyses, it appeared to be more important in the logistic regression analyses where other significant factors were considered simultaneously. Not surprisingly, individuals who reported their disabilities as being more severe were more likely to disclose on the job. Although this makes intuitive sense, caution regarding those with mild BIs and their reluctance to disclose should be considered.

With the advent of a new imaging technique called Diffusion Tensor Imaging, there have been major new findings regarding the study of mild TBI (mTBI). Mild TBIs are very common to athletes, military personnel and the elderly (Bennett, Mac Donald, & Brody, 2012). Health professionals are beginning to realize that there are many invisible cognitive and psychological factors including long-term persistent attention and memory difficulties following an mTBI that often go undetected on standard neuropsychological tests (Ozen & Fenrlandes, 2012). While those individuals with mild BIs in the current study reported that their disability less frequently affected their work performance, and were also less likely to disclose, it might be that the more subtle effects of the impairment on performance potentially create work performance problems such as task completion (Ozen & Fenrlandes, 2012). As discussed later in the chapter, helping individuals with mTBI to recognize potential performance problems, and understand when disclosure might be necessary in order to request accommodations, is important.

Surprisingly, neither of the two items related to knowledge of the Americans with Disabilities Act and the importance of it for everyday work, was significant for this sample. In fact, it is somewhat alarming that among this highly educated sample of individuals with disabilities (most of them reporting severe disabilities), 62% reported uncertainty or less regarding their knowledge of their rights under the Americans with Disabilities Act, even though more than 75% of the sample disclosed their disabilities on the job. As surprising, perhaps, is that 47% of the sample was either uncertain or disagreed with the statement regarding the importance of the Americans with Disabilities Act in their lives.

An issue that is not clear in this study is the incongruence between knowledge of ADA rights and their importance in everyday work experiences. For example, of the 49 individuals who did not disclose their disability, 9 had asked for accommodations at their place of employment. This addresses the issue of how people understand job accommodations form either a legal/formal, or as an informal process. Further, the majority of both those who disclosed and those who did not were “unsure” of both their knowledge of ADA rights and its importance on a daily work basis as previously discussed further brings to light the issue of formal or informal knowledge of ADA rights and protections. This is quite disconcerting considering the high level of education of the sample.

This finding has several implications. First, it may suggest the difference between the brain injury population and other groups of individuals with disabilities. For example, Ellison et al. (2003), in her study of people with psychiatric disabilities, found that knowledge of the ADA significantly discriminated between those who chose to disclose and those who did not, as did Goia and Breke (2003) in their qualitative study of individuals with psychiatric disabilities. Given the high unemployment rate of individuals with brain injuries cited in chapter one, it may be that their perspective on their disabilities, or their capacity to evaluate its effect on their job performance, and subsequently their need to invoke the ADA for accommodations, is somehow compromised. Lack of knowledge about the ADA, and its importance in their lives, might also suggest that self-advocacy interventions for this population need to be specifically tailored to the functional needs of individuals with brain injury.

Even though several studies have examined the implications of visibility of disability in the workplace (Allen & Carlson, 2003; Dalgin & Bellini, 2008; Dalgin & Gilbride, 2003; Pearson, et al., 2003) this study failed to find any correlations either with the dependent variable or with other factors/variables in the study, even though it was initially speculated on the potential importance of this issue for the BI population. It might be that 23% of the participants who reported being "unsure" as to whether their BI was visible or not to others would compromise the analysis of this issue and its effect on disclosure. In fact, this uncertainty raises concerns regarding the nature of the BI population, and their capacity to accurately assess the perceptions of others, one of the limitations of this study. Future studies which examine visibility factors with this population should bear this in mind when collecting data.

#### *Implications for Practice*

There are several practical implications emerging from this study. One finding, for example, demonstrated a significant link between time since injury and disclosure, where the more recently the injury had occurred, the more likely an individual was to disclose. However, the more recently the individual was injured, the less likely they reported being employed at the time of the study. These results, together with the ones cited earlier regarding knowledge of the ADA suggest several implications for practice.

One implication is the need to intervene early in the BI recovery process in terms of discussing jobs and preparing individuals for employment. Early intervention with specific job-ready goals (preparing a resume, participating in a job club), not only prepare the individual for the workplace ("work hardening"), but also increase the probability of improving their work-related self-efficacy beliefs.

Another implication for practice is the need to assist individuals with brain injury to be able to understand and positively project their disability to employers when they disclose and request reasonable accommodations. Positively projecting their disabilities to employers requires less focus on functional impairments (memory deficits; attenuated concentration), and more focus on anticipated benefits of the provision of accommodations (increased productivity; improved efficiency, etc) (Fabian, et al., 1993; MacDonald-Wilson et al., 2011).

The findings that the outcomes of disclosure are almost matched between having negative or positive outcomes in the workplace also suggests the need for individuals to work with a vocational rehabilitation counselor to discuss the ramifications that disclosure might have on their jobs prior to making the decision or taking the action of disclosing. It is apparent from this sample, as well as others (Madaus, 2008; Schrader, et al., 2011), that there are very real negative consequences to disability disclosure, and that the decision to reveal a "hidden" health condition represents a risk in terms of evoking stigma and other negative workplace reactions. In the Schrader, et al. (2011) study of a national sample of 599 individuals with diverse disabilities which examined the disclosure process, several respondents indicated the importance of considering how "disability friendly" the workplace was, and the need to look for "supportive supervisors and co-workers" in the decision to reveal a disability. While this might not always be possible, counselors and disability advocates can assist employees or job seekers with disabilities to present their condition and request job accommodations in as positive a manner as possible, as suggested earlier, as well as seeking assistance from supportive supervisors in revealing their disability and requesting accommodations. Understanding



the nature of the work environment (size of company, structure, culture) are all important considerations for employees, but also for ADA advocates and technical assistance staff that provide consultation and assistance to individuals with disabilities concerning ADA and accommodation issues.

What the above findings demonstrate is the need for more knowledgeable and timely intervention on the part of rehabilitation counselors for individuals with BI who have lower levels of education, have been recently injured and are in the lower salary range with mild to moderate severity. Most importantly this study points out that counselors need to discuss ADA issues and how these regulations can impact consumer's rights regarding the provision of reasonable accommodations in the workplace. As an example of the lack of ADA awareness, when asked to list the main reason for disclosure, one individual stated that, "the folks at VR instructed me to do so."

Caution must be exercised on the part of both the counselor and the advocate as the outcomes of disclosure can depend on a number of factors/variables which can lead to either a positive (receipt of job accommodations, increased rapport with supervisors and co-workers) or negative (not being hired, loss of job, being stigmatized or labeled by supervisors and co workers). As this was the first study of its kind, perhaps future research might shed light on methods and approaches to disclosure for individuals with BI. Others have examined the issue of disclosure in other disability populations from a perspective of when, to whom, what is said and why (MacDonald-Wilson, et al., 2011). Perhaps these same principles can be applied to the BI population as it appears that many of the same factors/variables are involved in the decision to disclose a disability in the workplace.

### *Limitations*

One of the most obvious limitations in this study is the small sample size (n=200) and the disproportionate number between the group that disclosed (n=144) and the group that did not disclose (n=49), thus yielding a lower power for statistical analysis and a less likelihood of detecting significant differences, increasing the Type I error rate. However, even with this limitation and low power, several items were significantly related which lends credit to the strength of their relationships.

Another limitation in the study was that the majority of respondents were White and highly educated, although other on-line surveys have noted this phenomena (Schrader, et al., 2011). Also, almost half the study participants were from Western states (49.5%) thus they were over-represented in the sample. Only 10% of the participants came from the East Coast with only eight from Maryland. The rest of the respondents were spread throughout the United States.

Though the use of the survey method to collect data has demonstrated a low cost highly effective means of gathering data, it is important to understand that this type of data collection is not based on probability sampling, but rather on a volunteer or convenience sampling (Mertler, 2002). For example most survey participants were highly educated and in professional jobs. This trend creates difficulty in making generalizations from the sample to the general population of individuals with BI. It has also been noted that web-based surveys can exclude important segments of the population who reside in small towns and rural communities and for individuals without access to the internet, or who are not computer illiterate (Smyth, Dillman, Christian, & O'Neil, 2010). This might

have been a limitation in the current study as well, as only 44 (22%) of participants lived in a rural area.

Further, in many instances it is difficult to know if selection bias can lead to inaccurate results using on-line survey methods as little or nothing is known about the non-respondents (Heiervang & Goodman, 2011). As an example, in this study a greater proportion of females responded, whereas in the general population BI's are a more frequent occurrence among males (Rutland-Brown, Langlois, Thomas & Xi, (2006).

Although more research has improved vocational rehabilitation efforts to increase employment outcomes for individuals with brain injury, it is clear that this group demonstrates persistently poor employment outcomes (Yasuda et al., 2001; Wehman et al., 2003; Watanabe et al., 2003). Although a number of complex factors contribute to this picture, one important issue remains the experiences and beliefs of work related disability disclosure for this population. This study is one of the first that examined elements of disability disclosure for individuals with brain injury, suggesting several avenues for improving practice and research. It is clear that we need additional studies that can further explore the nature of the problem, and interventions that can address it.

#### *Implications for Future Research*

The current research represents the first study of its kind to examine disability disclosure factors/variables for the BI population and as such had limited research to build on. Future research is needed to confirm the findings and to further validate the differences and similarities that exist between the BI population and other disability populations that were noted in the previous chapter. During the course of the literature review it was revealed that most previous research focused on accommodations in the

workplace and ignored, almost entirely, the important first step of having to disclose a documented disability to the employer. Further, those studies that did examine workplace accommodations did not include the BI population, which as mentioned in chapter one, represents a large proportion of individuals with disabilities who encounter challenges in employment.

Other important factors that need to be addressed in future research studies are the limitation in sample size and sampling methods. In regards to sample size, while this was a nationally advertised study, it was mainly through BIAA that the electronic link to the survey was publicized. Future survey method studies should involve a consortium of BI providers across the nation to recruit participants in the hopes of obtaining a much larger sample. This would help to address the stratification of the population in the sample and thus the findings might be more generalized to the overall population of individuals with BI. In the current study a significantly higher proportion of individuals chose to disclose, the sample was highly educated and was predominantly female. These demographics are most likely not representative of the overall BI population and a larger sample size might demonstrate more accurate results and more statistical power.

Other methods of data collection, such as structured and semi-structured interviews, could provide a more accurate means of data collection than self-reported survey methods. As many of the individuals in the current study were “unsure” of the severity of their injury and the visibility of their injury, this suggests that a lack of self-awareness (SA) of functional limitations exists, a phenomenon which has been recognized in the BI population (Hart, Seignourel & Sherer, 2009; Vanderploeg, Belanger, Duchnick, & Curtiss, 2007). It is strongly suggested that in future research the

focus should be on a specific group of individuals with BI (for example mTBI) and that data other than that which is self-reported be collected. Also, if the interview format is utilized, it is strongly suggested that some form of triangulation be employed to assess SA.

Further, as this instrument was adapted from the Madaus (2008) survey on the LD population, it is the first of its kind to be used for individuals with BI. It is recommended that if the survey method is used, it would be beneficial to leave out the answer choice of “unsure” or “don’t know” as it might force individuals to triangulate their own responses with significant others, counselors or other health professionals (in fact that suggestion could be made with the answer choice). As this was the first time this type of survey was used to explore disability disclosure for individuals with BI, perhaps new instruments can be created based upon the limitations of the current survey, or others.

Also, as this exploratory study and the few other studies on disclosure have demonstrated, the decision to disclose a disability in the workplace involves complex issues. Perhaps a longitudinal study could help gather data pertaining to disclosure as individuals with BI’s progress through their recovery, their careers or struggle with job attempts and provide a more accurate representation of these complex issues as they evolve.

While this was a quantitative study (although it did obtain some richness of data), future studies utilizing qualitative methods would greatly help obtain a more clear picture of the factors/variables surrounding this difficult life decision. It is hoped that the dissemination of these results will contribute to the beginnings of a knowledge base and serve as a starting point for future research studies.

## Appendix A

### National Brain Injury (BI) Study of Disability Disclosure in the Workplace

According to Title I of the 1990 Americans with Disabilities Act (ADA) in order to receive a reasonable accommodation in the workplace, which can sometimes be a critical step towards becoming employed or maintaining one's current job, one must first disclose to the employer that they have a disability. Several studies have examined the various elements that surround employment related disability disclosure in other populations, yet to date, no one has examined this critical step for individuals who have had a BI. The current study will be the first to examine these elements and in so doing seeks to create a solid foundation from which future research can learn more about this process.

The survey can be completed in approximately 20 to 30 minutes online via the link below or you may contact David Burnhill, the research coordinator, at (301) 675-3713 to have a questionnaire mailed to your home. Both survey methods allow the researchers to keep the individuals personal identity separate from survey responses.

The survey will run from: November 2011 to March 2012

<http://www.surveymonkey/nationalBIstudy.com>

Thank you for your participation and feel free to call (301) 675-3713 if you have questions or comments you would like to make!

## Appendix B

### Consent Form

Project Title: National Brain Injury (BI) Study of Disability Disclosure in the Workplace

1. Why is this research being done?

This is a research project being conducted by Dr. Ellen Fabian and David Burnhill at the University of Maryland, College Park. We are inviting you to participate in this research project because you have had a BI. The research project is designed to explore the elements involved in disclosing a disability to an employer for persons with BI.

2. What will I be asked to do?

You will be asked to complete a survey which consists of 54 items. The survey will take approximately 20-30 minutes to complete. You must be at least 18yrs of age, have a pre and post injury work history and have at least one year since the time of your injury. After completing the survey, you may choose to participate in a raffle for a chance to win one of five \$25 VISA gift certificates by providing your contact information.

3. What about confidentiality?

We will do our best to keep your personal information confidential; however, please note that potential threats to securing confidentiality are possible on all web-based servers. Given this information, please understand that your name, contact information, e-mail address, and your survey responses will not be linked together; therefore, your responses will be anonymous. You will be providing your name and contact information after completing the survey if you choose to participate in the raffle. Once the raffle results are complete, your name and contact information will be destroyed. All collected data with identifiable information will be kept in password protected computer files, locked file cabinets, and storage areas. Once the data is analyzed and the research results are documented, the data will be deleted from the computers and all paper materials will be shredded. If we write a report or article about this research project, all results will be presented by grouping the responses; no identifying information will be released.

4. What are the risks of this research?

There are no known risks associated with participating in this research project.

5. What are the benefits of this research?

This research is not designed to help you personally, but the results may help the researchers learn more about the elements involved in disclosing a disability in the workplace for individuals who have had a BI.

6. Do I have to participate in this research? Can I stop participating at any time?

Your participation in this research is completely voluntary. You may choose not to take part at all. If you decide to participate in this research, you may stop participating at any time. If you decide not to participate in this study or you stop participating at any time, you will not be penalized or lose any benefits to which you otherwise qualify.

7. What if I have questions?

If you have any questions about the research study itself or need alternative formats of the survey, you can contact us by e-mail at [efabian@umd.edu](mailto:efabian@umd.edu), [dburnhill@umd.edu](mailto:dburnhill@umd.edu) or phone at 301-405-2872 or 301-675-3713. If you have any questions about your rights as a research subject or wish to report a research-related injury, please contact the Institutional Review Board by e-mail at [irb@deans.umd.edu](mailto:irb@deans.umd.edu), by phone at 301-405-0678, or by mail at the Institutional Review Board Office, University of Maryland, College Park 20742.

8. Statement of Age of Subject and Consent

By agreeing to participate in the research project, you are indicating that (a) you are at least 18 years of age; (b) the research has been explained to you; (c) your questions have been fully answered; and (d) you freely and voluntarily choose to participant in this research project.

By going to the next page, you are agreeing that you have read the information above and agreed to participate in the study! Thank you in advance for taking the time to fill out this survey!





B. EDUCATIONAL EXPERIENCES

1. What is your highest level of education achieved:

- No Formal Schooling
- Elementary Education
- Special Education/Certificate
- Secondary Education/no HS Diploma
- High School Graduate/Equivalency
- Post Secondary Education, No Degree
- AA Degree
- Bachelors Degree
- Masters Degree
- Higher than Masters/Professional Degree; Please Specify:  
\_\_\_\_\_

2. Was your highest education level achieved before or after your BI (check one)? Before \_\_\_\_\_  
After \_\_\_\_\_

C. EMPLOYMENT INFORMATION:

1. Are you currently employed in a paid job?

- Yes,  Full time (35 or more hours per week)  
 Part-time (34 hours per week or less)
- No (proceed to item 8)

2. What type of industry are you employed in? (Check all that apply)

- |   |   |
|---|---|
| <input type="checkbox"/> Agriculture            | <input type="checkbox"/> Business         |
| <input type="checkbox"/> Education              | <input type="checkbox"/> Factory/Industry |
| <input type="checkbox"/> Federal Government     | <input type="checkbox"/> Health Care      |
| <input type="checkbox"/> Homemaker              | <input type="checkbox"/> Military Service |
| <input type="checkbox"/> Media                  | <input type="checkbox"/> Non-Profit       |
| <input type="checkbox"/> Recreation             | <input type="checkbox"/> Social Services  |
| <input type="checkbox"/> State/Local Government | <input type="checkbox"/> Technology       |
| <input type="checkbox"/> Other (please specify) |   |

3. What is your current job title? \_\_\_\_\_.

4. How long have you held your current job? Years: \_\_\_\_\_ Months: \_\_\_\_\_

5. Are you self-employed? Yes \_\_\_\_\_ No \_\_\_\_\_

6. Does your job provide you with employee benefits (e.g., health insurance, paid vacation, sick days, retirement account)?

Yes, full benefits

Yes, partial benefits, which ones:

\_\_\_\_\_ No

7. What is your current annual salary?

Less than \$10,000

\$50,001 - \$60,000

\$10,001 - \$20,000

\$60,001 - \$70,000

\$20,001 - \$30,000

\$70,001 - \$80,000

\$30,001 - \$40,000

\$80,001 - \$90,000

\$40,001 - \$50,000

More than \$90,000

8. If you are not currently employed, why?

In school

Caring for children

Caring for family member(s) other than children

Health condition

No jobs available

Other (please specify)

#### D. BRAIN INJURY AND WORK EXPERIENCES

1. Cause of BI (please check all that apply):

Fall

Motor Vehicle accident

Assault

Struck by/Against

Stroke

Tumor

Other

2. Was your BI (please circle one):

Mild

Moderate

Severe

Don't Know

3. How often does your BI impact your work (please circle one):

Never

Rarely

Occasionally

Frequently

Always

4. In which areas does your BI impact your work? (please check all that apply)

- |   |  |
|---|--|
| <input type="checkbox"/> Writing Skills         | <input type="checkbox"/> Movement/Mobility           |
| <input type="checkbox"/> Talking                | <input type="checkbox"/> Motor Skills                |
| <input type="checkbox"/> Hearing                | <input type="checkbox"/> Organizing                  |
| <input type="checkbox"/> Reading                | <input type="checkbox"/> Working in Groups           |
| <input type="checkbox"/> Understanding          | <input type="checkbox"/> Time Management             |
| <input type="checkbox"/> Using numbers          | <input type="checkbox"/> Interacting with Others     |
| <input type="checkbox"/> Fatigue                | <input type="checkbox"/> Interacting with Supervisor |
| <input type="checkbox"/> Other, please specify: |  |

5. In your own opinion is your BI visible to others? (please circle one)

Yes                      No                      Uncertain

6. Do you have another disability or serious health condition that prevents you from working, travelling, training, school, activities of daily living?

Yes    No

If "Yes", please specify: \_\_\_\_\_

E. DISCLOSURE EXPERIENCES

1. Have you or someone you know ever disclosed your BI to an employer?

- Yes , I did  
 Yes, someone I know did  
 No

2. Have you or someone you know disclosed your BI at your current job (please check one)?

- Yes, I did \_\_\_\_\_  
Yes, someone I know did \_\_\_\_\_  
No \_\_\_\_\_ (if no skip to question 8.)

3. To Whom was your BI disclosed? (please check all that apply)

- Supervisor
- Co-workers
- Human resources personnel
- Other(s), please specify:

4. Check the reason(s) you chose to disclose your BI in the workplace (please check all that apply):

- Need for additional time to complete job tasks
- Use of technology as an accommodation
- To get some changes made to my job so I could work better
- To make co-workers aware of my BI
- To make supervisors aware of my BI
- To be honest about who I am
- To increase Self-Esteem
- To protect myself under the ADA
- I didn't choose to disclose, someone else did it
- Other, please specify:

5. What was the main reason that you chose to disclose your BI (from above answers) \_\_\_\_\_

6. What did you say when you disclosed?

- I have a BI
- I have a health issue/medical condition
- I have a disability
- I didn't refer to a disability/injury, just my skills and accommodation needs.
- Other(s), please specify:

\_\_\_\_\_

\_\_\_\_\_

7. If you have ever disclosed your BI in a job, have you experienced positive effects of disclosing?

Yes\_\_\_ No\_\_\_

If yes, can you provide examples? (optional)

8. If you have ever disclosed your BI in a job, have you experienced negative effects of disclosing?

Yes\_\_\_ No\_\_\_

If yes, can you provide examples? (optional)

9. In how many jobs have you disclosed your BI? \_\_\_\_\_

10. Check the reason(s) you chose not to disclose your BI at any jobs: (please check all that apply)

- \_\_\_\_\_ Concern for job security
- \_\_\_\_\_ Concern for negatively influencing relationships with clients/customers/patrons
- \_\_\_\_\_ Concern for negatively influencing relationships with coworkers
- \_\_\_\_\_ Concern for negatively influencing relationships with supervisors
- \_\_\_\_\_ Concern of being stigmatized by others at work
- \_\_\_\_\_ Disclosure in a previous job created problems
- \_\_\_\_\_ No reason to disclose, no need for accommodation(s)
- \_\_\_\_\_ Not applicable; I have disclosed in each of my jobs since my injury
- \_\_\_\_\_ Other, please specify:

11. Have you ever asked for accommodations or changes to your job (e.g. hours, the way things get done) because of your BI?

Yes\_\_\_ No\_\_\_ (if no, proceed to item 16)

12. If you have ever asked for an accommodation, have you ever been denied one?

Yes\_\_\_ No\_\_\_

13. Which, if any, of the following strategies and accommodations do you use in your current job? (check all that apply)

- |                                   |  |
|-----------------------------------|--|
| ___ Arrive early to work          | ___ Self-advocating for job related ne |
| ___ Assistive technology          | ___ Setting goals and priorities       |
| ___ Delegation of difficult tasks | ___ Stay late at work                  |
| ___ Graphic organizers            | ___ Support from family/significant    |

- |                          |                               |                          |  |
|--------------------------|-------------------------------|--------------------------|--|
| <input type="checkbox"/> | Problem solving/brainstorming | <input type="checkbox"/> | Time management                        |
| <input type="checkbox"/> | Quiet work environment        | <input type="checkbox"/> | Time outside of work to complete tasks |
| <input type="checkbox"/> | Use of proof-readers          | <input type="checkbox"/> | Other (please specify):                |
- 

For items 14 and 15, please circle [check] the statement that best describes your agreement with each item.

14. I believe that I know about my rights under the Americans with Disabilities Act (ADA):

Strongly Disagree      Disagree      Unsure      Agree      Strongly Agree

15. I believe that on a day-to-day basis, the ADA is important to me as an employee with a disability:

Strongly Disagree      Disagree      Unsure      Agree      Strongly Agree

**Part II**

**Instructions:** This section is designed to gather information about your attitude towards your current job, as well as your perceived confidence in your ability to perform your current job. If you are not currently employed, respond to the items as they relate to your attitude towards the most recent job you have held.

Please circle the appropriate number to indicate your agreement with each item.

<b>Strongly</b>	<b>= 1</b>	<b>Disagree = 2</b>	<b>Unsure = 3</b>	<b>Agree = 4</b>	<b>Strongly = 5</b>
<b>Disagree</b>					<b>Agree</b>
<b>SD</b>		<b>D</b>	<b>U</b>	<b>A</b>	<b>SA</b>

“I am confident in my ability to . . .”

	SD	D	U	A	SA
1. Use creative ways to perform my job	1	2	3	4	5
2. Take the initiative for carrying out an important project	1	2	3	4	5
3. Exercise leadership in my job	1	2	3	4	5
4. Make good use of my strengths, skills, and abilities	1	2	3	4	5
5. Interact with my coworkers	1	2	3	4	5
6. Communicate clearly with my supervisors	1	2	3	4	5
7. Communicate clearly with my colleagues	1	2	3	4	5
8. Plan how to meet the demands of my job	1	2	3	4	5
9. Cope effectively with job related stress	1	2	3	4	5
10. Develop new skills needed for doing my job well	1	2	3	4	5
11. Productively use my time on the job	1	2	3	4	5
12. Adapt to the demands of new responsibilities in my job	1	2	3	4	5
13. Manage my workload and time pressures	1	2	3	4	5



- |   |   |   |   |   |   |
|---|---|---|---|---|---|
| 14. Apply the skills I have learned in job situations | 1 | 2 | 3 | 4 | 5 |
| 15. Work effectively with co-workers                  | 1 | 2 | 3 | 4 | 5 |
| 16. Assume challenges related to my job               | 1 | 2 | 3 | 4 | 5 |

## Appendix D

### Reasons to Disclose, “Other”

	Frequency
affirmative hire	1
All knew about my fall and the information was first given as an update to my condition.	1
because I must bring my service dog with me	1
Because I should be covered by the Health Plan	1
because of my seizures	1
But only after I had difficulty doing my job	1
couldn't learn new computer programs	1
Disclose? Its just part of who I am. My recovery has been judged as awesome.	1
Disclosed at time due to missed work to recover	1
everyone knew of my fall in another facility while passing medications and i was off work on temporary diabilistf for a month	1
happened on weekend- I was employed so was in hospital and couldn't go to work	1
hurt on the job so it was reported immediately	1

I am answering based on when I was employed at the time of my injury.	1
I am working on an advocacy project, and my brain injury is integral to my role as a user.	1
I hoped the scapegoating, blaming, criticizing, and bullying would stop.	1
I needed FMLA to justify reduced hours and productivity at work; I lost my job before I realized I could have been protected under the ADA	1
I needed time off work after accident, I have disclosed to coworkers on a later job I felt like I was hiding	1
I talked about my brain injury informally, in the process of getting to know folks at the job I took two years after my brain injury and a return to full-time work at the job I held when the brain injury occurred.	1
I was having a hard time with the contractual work and was concerned that I would miss something that might affect my clients.	1
I work at an advocacy organization	1
In order to keep my job; I was off work for 9 months.	1

it just comes up because my actions are wierd or uncertain sometimes	1
Just needed help - Didn't understand what was happening	1
medico-legal concerns	1
Memory problems too visble	1
Mood changes/quiet affect at times & HA causing light sensitivity	1
Most everywhere I work, people know about my BI because it was in the papers for many years since I was assaulted by a widely known sports figure.	1
most of my more recent paid work has been in natural health--a field in which there is openness to individuals who are perfect and to those who are not perfect--I would not disclose if I were to work in psychology, my professional field, as they pathologize BI	1

<p>my att Peter Upton &amp; Asst Att General Charles Hulin told me to tell spv JaneJohnson that I had aTBI As I fell in july My std was d/c in Nov 2010 she kept telling me don't say you have a tbi. just go out and live. I sent note to her and the manager of our dept. the i get a letter that I vol quit. why would i quit i carried theinsurance. so now no income no insurance and att is still fighting to get std and Ltd reinstated.</p>	<p>1</p>
<p>My injury occurred while on the job, I attempted to work for almost 2 years without sufficient medical or rehabilitative treatment. Doctors continued to say "I would be OK within a year"; 2-1/2 years passed and I still could not function at work. 3 years passed and I finally began to recieve proper Rehabilitation, however after 6 months of "inpatient" therapy and no outpatient therapy opportunities, I returned to work for only 2 hours per day. My company did not make accommodations and released me "as there was no work available for me". The EEOC and ADA time limits had expired after the 4+ years and I could not file.</p>	<p>1</p>

my job is very high pressure and I frequently forget system policies and procedures.	1
needed time off due to BI	1
poor time management necessitated work hour accomodations	1
reasoning for dr appts and illness	1
relatinoship enhancement	1
The ADA, in my experience, has not protected individuals with cognitive, brain injury issues - I advocate for many who have literally lost their cases or have been thrown out after filing EEOC complaints. Their appears to be no support or way for individuals to document and fight the employers' actions	1
The folks at Vocational Rehabilitation instructed me to do so.	1
to develop a better report with the client/participant base for a day hab facility i was assisting with	1
To educate others about disability	1
to explain my fatigue and why I wear noise canceling headphones	1
to explain my twisted actions and sense of humor	1

To explain why it is that some days I am unable to work because of my head pain and to explain my poor memory.	1
To give an explanation as to why I wasn't "on the ball" as much as I used to be.	1
Use as a tool to help my clients w/ brain injury	1
work related injury	1
worked there when i was hit by the car	1
workers comp protocol	1
Workers' Compensation Claim -medical appts.	1
Total	35

Appendix E

Type of Industry

	Frequency
1/2 time in home care	1
Artist	1
Cleaning	1
cosmetology	1
Engineering consulting	1
Food Industry	1
Grocery Store	1
law	1
Legal	1
library aide	1
lifecoach	1
Minor maintenance	1
Nanny	1
Special Events	1
Sports Official	1
unemployed	1
writing	1
Total	17



Appendix F

Job Titles

	Frequency
1-1 Special Ed Para educator	1
Account Executive (sales)	1
Adjunct Faculty and Registered Nurse	1
Administrative Assistant	1
Analyst	1
Artist	1
Assistant County Attorney IV(retired)	1
attorney	1
Attorney at Law	1
BUSINESS OWNER	1
Business Owner/Physical Therapist	1
C.O.T.A. in geriatrics	1
caregiver	1
Cashier	1
Cashier	1
Certified Medical Assistant	1
Church Custodian	1
Community Resource	1
Consultant	
Consumer Support Advocate	1
Contract writer	1
CONTRACTING OFFICER	1
Customer Service Rep	1
Customer Svc/Logistics Manager, USA	1

data governance analyst	1
Day stocker	1
Dir of Community Ed/Public Information	1
Director of Clinical Services	1
Director of Parenting Education/Youth & Family Counselor	1
Disability Advocate / ILAT Specialists	1
Education Specialist	1
Educational Assistant-special Ed.-public shcool	1
Eligibility Services Worker	1
eligibility Tech	1
Employment Manager	1
environmental scientist	1
Event Staff	1
Executive Director	2
Facilities Distribution Manager	1
floor clerk	1
Food Service Worker	1
Grant coordinator	1
health educator	1
home sitter animal sitter long term stays	1
Human Resources Assistant	1
Hydrologist	1
IT Analyst	1
Librarian	2
Library Director	1
LSN Leader	1
Master Certified Coach	1
Minor Maintenance	1
Nanny	1

Network Coordinator	1
NMR Spectroscopist	1
Nurse	1
Official	1
one on one aide	1
Organizational Consultant	1
Owner of consulting company	1
Park Ranger	1
Permanent Supportive Housing Coordinator	1
Personal care attendant	1
postdoc	1
Primary Clinician (LCSW)	1
Program Director	1
Project Estimator	1
Project Management Consultant	1
project manager	1
PSA	1
Psychologist	1
RN	1
School Psychologist	1
secretary	1
Security Analyst	1
shelver	1
Speech Language Pathologist	1
Sr Telephony Analyst	1
stylist	1
Supervisor, Facility	1
Systems Administrator	1
teacher	2
Teacher / Middle School	1
Science Coordinator	
Teacher/product specialist	1

unemployed	1
unemployed but am a registered nurse and was the Director of Staff Development prior to termination in 6/2010	1
Total	88

## Appendix G

### If not Currently Employed, Why?

	Frequency
Application not accepted	1
applied for jobs no one hired me	1
aquarium	1
BI	1
BIA memory, reading problems, neuro fatigue, etc. I live in HUD housing and I work with the disabled and elderly to help them improve their quality of life. I've come a long way since my TIA when I spoke jebberish, fell asleep after reading a few words, etc.	1
can only get volunteer work	1
Can't find work	1
can't work-on private disability because of head injury	1
Caring for family, no jobs available	1
considered temp disabled federal workers compensation.	1
disability 50 % and a qualified injured worker for vocational rehabilitation ...workers comp case settled last may 2011 only	1
disabled due to PCS	1
Discriminated because of TBI	1
early retirement	1

Given Admin. Separation due to BI and health issues	1
Have worked periodically in a part-time capacity but most recent job was unsatisfactory.	1
I have applied many times over the years for appropriate work. Have yet to find a company that will accomodate for both my physical and mental impairments (neuro fatigue, primarily cognitive). I have attempted to operate my own consulting business but due in part to the economy, difficulties in managing multiple tasks and lack of market my business has failed.	1
I have experienced a great deal of prejudice when trying to work	1
I try and volunteer all that I can with a group of abused and neglected kids.	1
in a program	1
laid off 3 years ago	1
Lost last two jobs	1
lost my security clearance because of BI, security clearance a condition of employment	1
no place will hire me too much risk	1
on workman's comp	1

passed away	1
retired	1
Self employed but limited to 10 hours week.	1
self employed PT	1
Studying for COTA test next month	1
Tbi	1
TBI	1
trauma to brain	1
tryin to advocate by example how i live ever day	1
Unable to focus/concentrate.no employment for this disability @ part-time level. my definition of 'Part-Time', means 4 hrs/day; employer 's underatanding of 'Part-Time', is at least 25 hrs/wk.	1
unable to sustain employment	1
Was laid off in Jan. 2010, but had worked full-time prior to the layoff.	1
worked for aetna sent note on tbi psc and then got a letter stating i quit	1
WORKING AS AN OTR & HAVING A FAMILY PROVED TO BE TOO MUCH	1
Writing a book.	1
Total	33

## Appendix H

### Cause of BI

	Frequency
Valid	
accidently hit on l side of face w/a baseball bat	1
Airplane crash	1
aneurysm	1
Aneurysm	1
anuerism	1
Auto vs bicycle accident	1
Bicycle Crash (helmet on) at 30MPH	1
car vs pedestrian	1
electric shock-utility construction fault with ground potential rise	1
Encephalitis	1
encephalitus	1
Encephalitus	1
Fall in association with another medical condition	1
Farm accidnet	1
Fell asleep on my back after a night of partying threw up and choked on it	1
fell while administering medications to residents..am I registered nurse	1
First diagnosed as stroke then as MS w/brain lesions	1
Foot ball collision	1
Garage fell door on head	1



Gun shot to head	1
gun shot wound, sports concussions, mishaps causing black outs	1
Hemorrhage from AVM	1
hit and run by automobile while bicycling/wearing helmet	1
hit by a drunk driver	1
Hit by a drunk driver while on the back of a motorcycle	1
hit head on beam	1
Hx of physical sports	1
ischemia caused by ventricular fibrillation	1
Jumped head first from the 2 <sup>nd</sup> story	1
Motorcycle accident	1
multiple sclerosis w/ ongoing progressive injury	1
Neurotoxicity / toxic encephalopathy. 4 significant exposures	1
Parachute malfunction while serving in the U.S. Army 82 <sup>nd</sup> Airborne Division.	1
Pedestrian hit by an automobile	1
ruptured brain aneurysm	1
Ruptured brain aneurysm	1
Ruptured Middle Cerebral Artery(MCA) Aneurysm	1
SEIZURE	1
Self Defense Class, Thrown to ground multiple times	1
septis	1
Sports-related injury	1

stuntwoman multiple stunts	1
☐toxic exposure workplace	1
un shit wound	1
was hit by a car as a pedisttrain	1
WLKING AFTER CANCER, other's car out of control	1
Workplace accident	1
Total	49

## Appendix I

### What was said during disclosure?

	Frequency
Again, my employer knew about the injury because I was out of work for four months.	1
Concussion	1
Condition made aware at time of injury to employer from notification by spouse.	1
described the accident and injuries that it caused	1
don't remember /different w/ different jobs - somethinmes	1
I have had accute illness	1
DVR the department of vocational rehabilitation and my job coach talked to my initial boss	1
had an auto accident	1
head injury brain damage	1
I am a brain injury advocate and only disclosed to co-workers after I published my book AM I BRAIN DAMAGED? MEMOIR OF RETURN TO LIFE AFTER MY HEAD INJURY	1
I did not disclose - I have learned through bad experience from 4 previous attempts to return to work not to disclose if I want to keep my job.	1

<p>I did not disclose about my BI since the repercussions from the first professional job where I was always put on the defense as if I was doing everything incorrectly, and they were trying to force me out.</p>	<p>1</p>
<p>i fell in the previous nursing home while giving medications suffered from a concussion and mild traumatic brain injure</p>	<p>1</p>
<p>I have a BI that is causing numerous problems, therefore I'm asking to take leave as needed under FMLA until I am back up to normal work level</p>	<p>1</p>
<p>I have a brain injury and if you would like to know more about it feel free to ask. Since we focus on many disability issues education is common.</p>	<p>1</p>
<p>I have post concussive syndrome as a result of cracking my skull in the fall.</p>	<p>1</p>
<p>I have written a paper on my story and its easier for me to give it to them so they can read it and come back to me with questions. Its to hard for me to verbally share.</p>	<p>1</p>

<p>I informed my supervisor, that I understood, but my brain needed a little more time to register some things, the pathways were rerouting.</p>	<p>1</p>
<p>I know things have been different since my accident and hitting my head.</p>	<p>1</p>
<p>I referred first to my skills and accomodation needs, and then discussed certain aspects of my disability where it made sense to share</p>	<p>1</p>
<p>I still have not found a job</p>	<p>1</p>
<p>I suffer from many symptoms of PCS</p>	<p>1</p>
<p>i told them that i had a serious auto accident and i get headaches etc etc</p>	<p>1</p>
<p>I wanted accommodation. Sought out attorneys - all unsuccessfully, went to my congressman, attempted appeals... all unsuccessfully. I was so "impaired at the time" and financially strapped that there was no one available to advocate for me.</p>	<p>2</p>
<p>I was having problems following the accident and wanted to try and keep working. I then asked for help from him to oversee my work.</p>	<p>1</p>

<p>I was injured on the job I didn't understand bi</p> <p>neurologist said permanent from toxins and to cope and compensate and boss said don't tell and for 10 years I just worked over hard and didn't realize the social behavior things and so got in trouble for not working with others and not being social and looking mean. I had no idea this from bi until the last one in 2008.</p>	1
<p>I was injured, and I am back. (Broken/fused back as well)</p>	1
<p>It just came out in general conversation.</p>	1
<p>it was fall on the job injury; everyone knew about it</p>	1
<p>it was reported on workman's comp</p>	1
<p>just explained the accident I was in, never really called it a BI until I was recently in contact with Natasha at the Iowa office</p>	1
<p>Just said I was in a wreck. Struggled for 4 months, then took off a few months. Returned to lay-off notice.</p>	1
<p>mild BI plus neck and back injuries</p>	1
<p>my supervisor knew i sought this position as a safer job option as my injury occurred at previous job</p>	1

N/A: My employer knows of my BI because it happened at this workplace.	1
Need to move around often and also take frequent breaks.	1
People always question why I use the dog because i "look fine"	1
psc ,short term memory loss and ha with photo sensivity bing a LPN i need to remember things	1
Sometimes I have said seizure disorder (which I no longer take medication for, fortunately). That I was in a serious car accident and I had a head injury and multiple orthopedic and soft tissue injuries & surgeries,	1
The accident I was in has resulted in a brain injury, which is going to be a long-term disability battle for me that I hope you will work with me on.	1
The entirety of the car crash...i was hit while driving my car by a drunk driver and TBI is part of my "story". I don't discribe my inury/BI as a disability.	1
They knew when they hired me.	1
they were updated while I was still in the hospital	1
Total	43

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