PREDICTING DISABILITY SELF-IDENTIFICATION:
A MIXED-METHODS APPROACH

by

Adena T. Rottenstein

A dissertation submitted in partial fulfillment
of the requirements for the degree of
Doctor of Philosophy
(Psychology)
in the University of Michigan
2013

Doctoral Committee:

       Professor Lorraine M. Gutierrez, Chair
       Emerita Professor Patricia Y. Gurin
       Emeritus Professor John W. Hagen
       Professor Tobin A. Siebers
       Assistant Professor Bradley J. Zebrack

TABLE OF CONTENTS

LIST OF TABLES

LIST OF APPENDICES

APPENDIX

CHAPTER 1

Introduction

According to the 2010 U.S. Census, approximately 56.7 million individuals or roughly 20% of the U.S. population are people with disabilities (Brault, 2012). Moreover, given the aging of the baby-boomer generation, and the increased likelihood of disability among older adults, the proportion of people with disabilities in the U.S. is only set to increase (Brault, 2012). However, while approximately 1 in 5 individuals may be classified as a person with a disability, it is essentially unknown how many of these individuals would *self-identify* as disabled.

The concept of self-identification or "self-categorization" (Tajfel, 1978, 1981; Tajfel & Turner, 2004; Turner, Hogg, Oakes, Reicher, & Wetherell, 1987) is one of psychology's most pre-eminent areas of scholarship (Brown, 2000). It relies on the assumption that individuals will easily adopt and give emotional weight to a collective identity when given even the slightest means of self-categorization (e.g. the minimal group paradigm). However, for those individuals who may be members of stigmatized groups (Goffman, 1963), self-identification becomes a more complex process, one in which people will often choose *not* to self-identify.

The question of self-identification among people with disabilities, a highly stigmatized minority group, is a topic of relatively recent exploration and little consensus. While there has been promising work as to the nature of disability identity (e.g. Gill, 1997; Hahn, 1997; Hahn & Belt, 2004; Darling, 2003; Swain & French, 2000; Putnam, 2005; Nario-Redmond, Noel, & Fern, 2012), there is a lack of agreement with regards to both the rates at which people with disabilities

will self-identify as disabled (e.g. Hahn & Belt, 2004; Beart, Hardy, & Buchan, 2005; Watson, 2002; Shakespeare, 2006), and to the factors that will predict said self-identification. The purpose of this study therefore, is to explore two questions:

(1) At what rate do people with disabilities self-identify as disabled?

(2) What factors predict said self-identification?

Our exploration of these questions will take place via preliminary analyses and a three-study research sequence on data acquired through a large-scale survey of people with disabilities from throughout the United States. It is our hope that findings from our work will be useful across many fields of study including but not limited to medicine and rehabilitative sciences, higher education, psychology, sociology, anthropology, disability studies, and community organizing.

CHAPTER 2

Literature Review

Disability self-identification is a topic of interest that spans many scholarly areas. The pieces reviewed for this study came from, among others, the fields of medicine, social work, sociology, history, anthropology, disability studies, psychology, and so on. When conducting the review, our main purpose was to identify factors which would predict disability self-identification, regardless if it was a factor which would increase or decrease the likelihood to self-identify. Through this process we identified the following 14 factors of interest. (Please see Table 1 for a summary of all factors and their related hypotheses).

Disability Characteristics (4 Factors)

The first four factors we will explore are best understood as disability characteristics, that is, they are attributes associated with a person's primary disability condition.

Factor 1: Disability Type. The vast majority of literature reviewed for this study mentioned disability type as a key factor in influencing a person's decision to self-identify as disabled. While the language varied, the general consensus was that those with physical or sensory disabilities are more likely to self-identify, while those with mental health conditions, cognitive/learning disabilities, and developmental/intellectual disabilities are less likely to self-identify (e.g. Barnes, Mercer, & Shakespeare (1999); Chappell, 1998; Sayce, 2000; Olney & Kim, 2001; Beart, 2005, etc.). It is predicted, therefore, that participants with physical or sensory

disabilities will be more likely to self-identify as disabled than participants with any other disability type.

Factor 2: Age of Onset. Many sources mentioned age of onset or age of acquisition as a key predictive factor in self-identification (e.g. Hahn & Belt, 2004; Darling & Heckert, 2010; Putnam, 2005). These sources were consistent in stating that those who acquire their conditions early in life, especially those with congenital (from birth) conditions, will be more likely to self-identify as a person with a disability. We will therefore test the prediction that subjects with congenital or early onset conditions will be more likely to self-identify.

Factor 3: Severity of Condition. Several sources cited the severity of one's condition as a key predictor in disability identification (e.g. Rhodes, Small, Ismail, & Wright, 2008; Litner, Mann-Feder & Guérard, 2005; Putnam, 2005). To be clear, the concept of 'severity' is best understood as the degree to which one's condition lessons one's ability to perform activities of daily living, e.g. communicating with others, seeing, hearing, moving about, etc.

In general, the literature tends to posit that the more severe the condition, the more one is likely to identify as a person with a disability. For example, in a study of people with epilepsy living in the UK, Rhodes, et al. (2008) found that participants who experienced the symptoms of epilepsy (seizures) often and intensely, were more likely to identify as disabled than those who experienced the symptoms of epilepsy less often. We will therefore test the prediction that condition severity will be positively related with self-identification.

Factor 4: Visibility. The visibility of one's condition, best understood as the degree to which a casual observer can easily mark one as a person with a disability, is one of the most commonly discussed factors in self-identification. With rare exception, e.g. Reeve (2002), the vast majority of scholarly work asserts that those with visible conditions will be more likely to

self-identify than those with invisible or hidden conditions. The key factor appears to be the ability to engage in "passing" behavior, i.e. presenting oneself as non-disabled to the world (Livneh, Martz, & Wilson, 2001; Watson, 2002; Olney & Brockelman, 2003). It is therefore predicted that those with visible conditions will be more likely to identify as a person with a disability than those with invisible or hidden conditions.

Disability & Environment (4 Factors)

While the first four factors we identified focused on disability attributes experienced on the individual level, the next four factors will speak to how an individual with a disability relates to both the disability community and broader society. This line of research is compatible with the social model of disability which posits that disability, like race and gender, as a socially constructed phenomenon in which the associated disadvantages stem not from physical or mental differences, but from societal beliefs and practices which limit people with disabilities in a variety of ways (Oliver, 1990).

Factor 5: Disability Community Involvement & Activism. As with the previous three factors, there is a clear consensus in the literature (e.g. Hahn & Belt, 2004; Whitney, 2006; Wilczenski, 1992; Hahn & Beaulaurier, 2001; Swain & French, 2000) that involvement in the disability community, e.g., engagement in disability rights activism, will be associated with high levels of disability self-identification. This line of thought matches well with psychology's scholarship on collective/social identity theory (Tajfel & Turner, 2004). It is especially relevant to the work of Jean S. Phinney, who posits that self-identification with a minority group is oft contingent on knowledge of and interaction with said group (Phinney & Ong, 2007). It is

therefore predicted, that those who actively engage with the broader disability community will be more likely to identify as a person with a disability than those who have little association[1].

Factor 6: Label Confusion. Factor six, label confusion, can best be understood as the difficulty people with disabilities often experience when trying to find an appropriate term to self-identify or self-label with. The difficulty stems from ever-fluctuating labels for people with disabilities, be it for (1) "political correctness," (e.g. disabled vs. differently-abled, physically challenged, handi-capable, etc.), (2) modified medical classifications (e.g. Reflex Sympathetic Dystrophy (RDS) is now known as Complex Regional Pain Syndrome (CRPS)), or (3) successful petitioning by the disability community (e.g. dwarf vs. short stature/little person, hearing impairment vs. hearing loss, etc.), (Linton, 1998; Haller, Dorries, & Rahn, 2006; Zola, 1993).

Regardless of the source of confusion, the literature appears to agree that label confusion may lead a person to be less likely to identify as disabled (Watson, 2002; Beart, 2005). Ergo, it is predicted that those individuals who experience label confusion will be less likely to identify as a person with a disability than those who do not experience such confusion.

Factor 7: Educational System. It is well known that children with disabilities in the United States are routinely segregated to "special education" classrooms (Blackman, 1989). While most of the literature on this phenomenon focuses on a debate between those who wish children with disabilities to be "mainstreamed," and those who wish children with disabilities to continue in segregated settings, there are a few studies which examine how our educational system may influence self-identification among people with disabilities. Within these articles, two competing viewpoints emerge.

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[1] We recognize that this relationship could operate in the opposite direction as well, i.e. those who self-identify are more likely to seek out the community. However, Jean Phinney's work operates under a "stage" model where the seeking out more information about one's minority community stage occurs before the self-identification stage.

From one perspective, special education often leaves students feeling ostracized and rejected (Dole, 2001), leading to the hypothesis that they will be less likely to identify as disabled in an attempt to decrease the stigma they so often experience. From a different perspective, special education provides students with disabilities the opportunity to meet and interact with other students with disabilities, and this early interaction with a miniature disability community may be key in developing a positive self-identity which incorporates disability status (Asch, 1988; Stainback, Stainback, East, & Sapon-Shevin, 1994).

Thus, in exploring the impact of our education system, we will test competing hypotheses, one which predicts that students who experienced some form of special education will be *less likely* to identify and one in which said students will be *more likely* to identify.

Factor 8: Federal Support. The eighth and final disability-related factor we chose to explore was whether or not the participant was a recipient of disability-related federal aid. Interestingly, this factor did not come from the literature review, but was instead proposed during a consultation with an employee of our local Center for Independent Living (A. Gossage, personal communication, March 3rd, 2011). The rationale behind the suggestion was that in his experience, many clients of the CIL first came in for services concerning registration and receipt of Social Security Disability Insurance (SSDI). It is therefore hypothesized that people who receive SSDI or other federal aid will be more likely to identify as a person with a disability as they must legally do so to receive federal aid.

Intersection of Disability & Other Social Identities (6 Factors)

While this research study is primarily focused on the concept of a person's disability identity, it is important to note that no social identity exists in a vacuum, that is, one's experience with a disability status will intersect with one's experiences with gender, race/ethnicity, sexual

orientation, socio-economic status, age, and other social identities (Goodley, 2011; Shakespeare, 1996; Vernon & Swain, 2002; Davis, 2006). As such, it was important to us as researchers to explore the impact of other sociological factors when trying to understand the complex nature of disability self-identification. Six such factors were explored in this particular study.

Factor 9: Gender. The intersection of gender and disability has been and continues to be an area ripe for scholarly work (e.g. Fine & Asch, 1988; Garland-Thomson, 2005, Morris, 1991, 1992, 1993, 1996, etc.). One key finding in this area of inquiry is the notion that women with disabilities, as members of two low-status groups, will experience a double-oppression of ableism and sexism. As evidence:

> "disabled women are more likely to be poor than disabled men; are less likely to have access to rehabilitation and employment; are more likely to experience public space as threatening; are more likely to live in their parental home and experience sexual abuse…" (Goodley, p. 35).

As such, it can be reasoned that women with disabilities are more likely to experience negative encounters related to their disability, and that these encounters may be more intense than an experience with sexism or ableism alone. It is predicted therefore, that women will be more likely than men to identify as a person with a disability.

Factor 10: Marital/Partnership Status. While researching the relationship between gender and disability, we came upon an interesting article by Rhoda Olkin (2003). In said article, Olkin explores why women with physical disabilities who wish to leave their partners, will stay in their unhealthy relationships. This made us question whether partnership status, normally considered a privileged status, would increase or decrease the likelihood of disability self-identification.

From one perspective, people with disabilities may be in relationships because they feel they are too vulnerable to survive on their own. Thus, they would be more likely to self-identify. However, from a different perspective, people with disabilities often find intimate relationships difficult to obtain (DeLoach, 1994). As such, those who do find success in acquiring a partner may see themselves as different from their peers (i.e. less likely to self-identify).

Ergo, when exploring the relationship between marital/partnership status and disability identity, we shall test competing hypotheses: one in which people with disabilities in relationships will be more likely to identify, and one in which they will be less likely to identify.

Factor 11: Race/Ethnicity. The intersection of race and disability is an important area of scholarly work despite the paucity of research in this area (Block, Balcazar, & Keys, 2001). What little work there is however, suggests that people of color with disabilities, similar to women with disabilities, face a form of double oppression (Stuart, 1992, 1993). For example, studies have reported that Black people with disabilities commonly experience discrimination when applying for social services (Baxter, 1995), and Asian people with learning difficulties experience a disproportionately high rate of poverty when compared to both their non-Asian and non-disabled peers (Azmi, Emerson, Caine, & Hatton, 1996).

Important to our question of identity though, is the argument and evidence that people of color with disabilities will experience oppression not only from broader society, but from within both racial and disability communities themselves (Vernon, 1999). For example, in a study of young Black disabled people, Bignall and Butt (2000) reported that participants described experiences of racial segregation in environments already segregated by disability.

Experiences of ableism in one's racial community and racism in one's disability community may lead many people of color with disabilities to feel that they do not fully belong

9

to or identify with either a racial or disability identity (Mpofu & Harley, 2006; McDonald, Keys, & Balcazar, 2007). It is therefore hypothesized that people of color with disabilities will be less likely to identify as disabled than non-people of color with disabilities.

Factor 12: Social Class. The relationship between disability and social class has been a topic of study for hundreds of years (Liberatos, Link, & Kelsey, 1988). Sadly, the fundamental conclusion across a myriad of scientific fields is that disability is intrinsically linked with lower social class (Block, et al., 2001). To quote Dan Goodley (2011), "where there is poverty, we will find disability," (p. 42). While the field of Disability Studies has commented on how social class may exacerbate or mitigate negative experiences associated with disability (Morris, 1991; Block et al., 2001; Vernon, 1999), virtually no work has been done to explore the relationship between social class and disability self-identification. Given the scarcity of literature, we have decided to refrain from making any specific predictions regarding the relationship between self-identification and social class; our analyses will be exploratory in nature.

Factor 13: Sexual Orientation. Fortunately, there is a growing body of literature which explores the intersection of sexual orientation and disability. This work centers on the connection between Queer Studies and Disability Studies, and is largely theoretical in nature (e.g. McRuer, 2006a, 2006b; McRuer and Wilkerson, 2003; Thompson, Bryson, & de Castell, 2001; Sherry, 2004), though there is the occasional empirical piece (e.g. Whitney, 2006). The central thesis of this work is that disability status challenges norms in the LGBT (lesbian, gay, bisexual, and transgender) community, and LGBT status challenges norms in the disability community, while both identities challenge the norms of broader society. The effects on self-identification however, are inconclusive. As such, we shall leave our predictions open for the relationship between sexual orientation and disability self-identification.

Factor 14: Age. The relationship between disability and age is an important area of scholarly inquiry (Priestley, 2001; Putnam, 2002), with much attention paid to the dynamic of families who are raising a child or children with disabilities (e.g. McLaughlin, Goodley, Clavering, & Fisher, 2008). Because our study is limited to adults (18 years of age or older), we targeted our review to exploring the relationship between disability identity and older adulthood. This review uncovered a fairly consistent finding that the majority of older adults do not identify as a person with a disability (Darling & Heckert, 2010; Kelley-Moore, Schumacher, Kahana, & Kahana, 2006; Langlois, Maggi, Harris, Simonsick, Ferrucci, & Pavan, 1996). Ergo, we have a clear-cut prediction that older adults will be less likely to self-identify as a person with a disability.

Table 1

Factors of Interest & Related Hypotheses

Factors Identified in Literature Review		Hypotheses
Disability Characteristics	Disability Type	Participants with physical or sensory conditions will be *more likely* to self-identify than those with other disability types.
	Age of Onset	Participants with congenital conditions will be *more likely* to self-identify than those who acquired their conditions later in life.
	Severity of Condition	Participants with severe conditions will be *more likely* to self-identify than those with conditions which are less severe.
	Visibility	Participants with visible conditions will be *more likely* to identify than those with invisible or hidden conditions.

Disability & Environment	Disability Community Involvement & Activism	Participants who are active in the disability community will be *more likely* to identify than those who are not active.
	Label Confusion	Participants who experience label confusion will be *less likely* to identify than those who do not experience label confusion.
	Educational System	Competing Predictions. Participants who experienced some form of special education may be *less likely or more likely* to identify.
	Federal Support	Participants who receive disability-related federal aid will be *more likely* to identify than those who do not receive aid.
Intersection of Disability & Other Social Identities	Gender	Female participants will be *more likely* to identify as a person with a disability.
	Marital/Partnership Status	Competing Predictions. Participants who are in intimate relationships may be *less likely* or *more likely* to identify.
	Race/Ethnicity	People of color with disabilities will be *less likely* to identify as disabled.
	Social Class	No specific predictions are made. Analyses will be *exploratory* in nature.
	Sexual Orientation	No specific predictions are made. Analyses will be *exploratory* in nature.
	Age	Older adults will be *less likely* to identify as a person with a disability.

CHAPTER 3

General Methods

Procedures

Our study was conducted using online survey methodology and a mix of quantitative and qualitative analyses. Details regarding survey construction, data collection, and data cleaning follow.

Survey construction. When constructing the survey, we had two goals in mind: first, to successfully operationalize all variables of interest, and second, to create an instrument that would be as accessible as possible across all disability types.

Survey construction: Ensuring accessibility. Our first step in creating an accessible survey was to keep its language simple. To be precise, we shied away from advanced vocabulary, complex sentence structure, double negatives, and idioms. To evaluate our success in keeping the language simple, we used Microsoft Word's reading statistics tool to calculate the Flesch–Kincaid reading level for our survey. Our score indicated that our survey was slightly below an eighth-grade reading level.

Once the language of the survey was finalized, we shifted our attention to ensuring that the presentation of the survey was accessible. As our intention was to administer the survey online, a primary concern was to find a hosting site that was compliant with Section 508 of the 1973 Rehabilitation Act. Section 508 is a 1998 amendment to the Rehabilitation Act that mandates accessibility in electronic and information technology (see www.section508.gov). It

essentially requires that information distributed electronically is accessible to both disabled and non-disabled populations. After reviewing a number of survey hosting sites, we decided to go with www.Qualtrics.com, a website which not only complies with Section 508, but also provides users with a "Check Survey Accessibility" tool to be used while building a survey site.

In constructing the survey site, we paid great attention to the Seven Principles of Universal Design for web accessibility (http://projectone.cannect.org). With regards to principle one, *equitable use*, we ensured that the site was accessible to those who navigate via mouse, but also to those who navigate by using the keyboard alone, speech-recognition software, or screen-readers. We also made sure that people with low-vision could use screen magnifiers to enlarge the text as they saw fit. Participant feedback on the survey indicated that these efforts were mostly successful, though there was some difficulty when survey takers utilized screen-readers other than JAWS.

Regarding principle two, *flexibility in use*, we made sure that participants could complete the survey at their own pace, i.e. there was no predetermined work speed to complete the survey. As a result of this effort, we had a wide range of time to completion with some participants completing the survey in 15 minutes, and some taking over 2 hours to complete.

Ensuring principle three, *simple and intuitive*, was accomplished by keeping the survey's design consistent across all three pages, and by providing clear instructions at the beginning of each new section. We also made sure to provide feedback after each page was completed, and after the study itself was completed. Importantly, we made sure that as each question was answered, the next question was highlighted in a different color.

Principle four, *perceptible information*, was addressed through the look of the website. Following WebAim (Web Accessibility In Mind: www.Webaim.org) guidelines, we opted to use a single, larger than average (14-16 pt.), sans-serif font (Veranda) throughout the survey, with no text in graphic form, and plenty of white space between questions. We also limited our use of font variations, e.g. **bold**, *italic*, or ALL CAPITAL letters. Moreover, we made sure that there was a strong contrast between the webpage's background (light: lavender) and text (dark: black).

Compliance with principles five through seven required simple modifications to survey design. Principle five, *tolerance for error*, was easily accomplished by allowing participants to go back and change their answers to survey questions at any time. Principles six and seven, *low physical effort* and *size and space for approach and use* respectively were accomplished primarily by keeping our questions in a logical order (1, 2, 3… etc.), and making the navigation buttons (Next, Submit, etc.) large, distinct, and surrounded by white space.

Once the site was constructed, we asked ten volunteers with varying disability statuses to review the survey. Importantly, one of our volunteers was a blind student who used screen-reading software to complete the survey. The volunteers were generous with their feedback, and as consequence, the following changes were made to the online site: (1) instructions explaining each subsection of the survey were modified to appear at the top of each page in a font significantly larger than the question text which followed, (2) question language was further simplified and re-arranged to be as simple and straight-forward as possible, (3) response options were, as much as possible, kept to the same number and same direction (low to high), and all reverse coded items were reworked or eliminated. Happily, the volunteer who used a screen-reader to review the site had no difficulty in accessing and completing the survey.

Survey construction: Summary of items. The final survey itself was divided into three pages/subsections. The first page contained 5 open-ended qualitative questions, one of which served as the source for our dependent variable. The second page contained 11 closed-ended quantitative questions which tapped into our *disability characteristics* and *disability & environment* predictive factors. The third page contained 11 quantitative and 4 qualitative questions. The 11 quantitative questions tapped into our *intersection of disability and other social identities* factors, and also included a few questions assessing general demographics. The last 4 open ended questions focused on feedback about the survey itself. To recap: our survey was 31 questions in length, divided into three subsections, with a total of 22 quantitative questions, and 9 qualitative questions. Please see Appendix A for a copy of our final survey.

Data collection. The data collection process for our study was simple, yet extensive in nature. The following section provides details on the five month process of participant recruitment.

Organizations used for recruitment. From March to August of 2011, customized "initial contact" e-mails were sent to over 800 disability-related organizations throughout the United States. These organizations varied in size, location, population served, and mission, for example, some organizations were national, e.g. the Amputee Coalition of America, while others were local, e.g. the Southwest Louisiana Independence Center. Moreover, some organizations were cross-disability, e.g. the Alliance of People with Disabilities (based in Washington), while others were condition specific, e.g. The American Federation for the Blind. Importantly, some organizations utilized a more "social model" approach to their work, e.g. The New York Center for Disability Rights, while others followed a more traditional "medical model" approach, e.g.

The Lymphoma Research Foundation. Our decision to cast such a wide net in recruitment was to ensure variability within our data, and the generalizability of our results.

Initial contact e-mail. The first e-mail sent to the organizations (Appendix B), introduced the principal investigator, reviewed the project and its rationale, and asked if the organization would be comfortable forwarding along a recruitment message to its members. Importantly, the IRB approved recruitment message itself was contained within the initial contact e-mail to ensure that participating organizations could easily forward or copy & paste the recruitment message to their list-serves, message boards, or websites.

Two follow-up e-mails, one sent one week after the initial contact e-mail, and one sent two weeks after the initial contact e-mail, were sent to non-responsive organizations. If the organization did not respond after three attempts at contact, they were dropped from our contact list. Interestingly, there were several organizations which did not respond to the first e-mail, but did respond to the second, follow-up e-mail. In most of these instances, the person responding to our second e-mail had already forwarded along our recruitment message, not realizing that we expected a response.

Of the organizations which responded to our initial e-mail, most wrote to let us know that they had forwarded the recruitment message along to their members. Several organizations provided us with the information/tools necessary to forward the recruitment message to their members ourselves, e.g. added us to their discussion board. A few organizations were kind enough to write back and decline our request, but for the most part, if the organization was not interested in forwarding along our message, they simply did not respond. For an approximation of our final contact list, please see Appendix C (Table C1).

When a potential participant received the recruitment message from their related organization, they were given a web-link to our survey site. When participants accessed the survey website, they were first taken to the study's consent page. Once consent was given (via a click of a button), participants were taken to the three-page survey itself. Completion of the survey was followed by a thank you page expressing our gratitude and providing our contact information to any interested parties. It should be noted at this time that no financial compensation was given to our survey participants; they graciously took their time to answer our questions with no promise of fiscal reward. For this we are quite honored.

Data cleaning. A total of 3,059 surveys were submitted via Qualtrics. Surveys were then screened to eliminate (a) 44 instances of duplicate submission (e.g., participant took the survey on more than one occasion, or clicked the "submit" button more than once), (b) 46 instances of ineligible participants (e.g., under the age of 18, non-disabled parents, caretakers, or service-providers, etc.), and (c) 250 instances of surveys missing substantial amounts of data (e.g. more than 50% of the survey left unanswered). Data cleaning resulted in a final sample size of 2,764 participants used for the present analyses.

Participants

General demographics. Participants were 2,764 people with disabilities ranging in age from 18 to 94 years ($M = 48.98$, $SD = 13.77$). With regards to gender, 64% of our sample identified as female, 34% as male, and 1% as transgender or "other" (1% did not answer). About 82% of the sample identified as White, European or European American, 6% as Black, African or African American, 5% as other, 3% as Latino/a, Hispanic or Hispanic American, 1% as Native American or Alaskan Native, and less than 1% as Middle Eastern, Arab or Arab

American (about 1% did not answer). Sexual orientation was measured on an ordinal scale with 79% of our sample identifying as completely heterosexual, 7% as mostly heterosexual, 4% as bisexual, 2% as mostly homosexual, lesbian or gay, and 4% as completely homosexual, lesbian or gay (3% identified as "other" and 2% did not answer). With regards to partnership status, 44% of our sample identified as married or partnered, 28% as single, 17% as divorced, separated, or widowed, and 10% as dating or in a relationship (1% did not answer).

Three variables were used as indicators of social class: level of education, employment status, and household income. In terms of education, our sample was fairly divided between those who had less than a four-year degree: 32%, those who had a four-year degree: 31%, and those who had more than a four-year degree: 36% (less than 1% did not answer). With regards to employment, roughly 50% of our sample were working either part or full time, 16% were unemployed students or workers, and 15% were retired (19% identified as other, and 1% did not answer). In respect to annual household income, about 16% of our sample earned $15,000 or less, 23% of our sample earned between $15,000 and $35,000, 28% earned between $35,000 and $75,000, and 27% earned $75,000 or more (about 6% did not answer).

Disability-specific demographics. Participants in our study were provided with the option of selecting more than one medical condition as their disability. Selections ranged from 1 to 34 conditions with an average of 4 conditions per person ($M = 3.89$, $SD = 3.49$). Participants were then asked to indicate their "primary" condition. The majority of our sample, about 40%, identified as having a neuromusculoskeletal/movement-related disability as their primary condition. An additional 19% identified as having a mental health condition, 17% as having a sensory impairment (e.g. blind, deaf, etc.), and 12% as "other" (12% did not answer). With regards to age of onset, 29% of our sample was born with their primary disability and 70%

acquired their disability later in life (about 1% did not answer). Regarding visibility, roughly

57% of our sample had a condition which was easily visible to an outside observer, while 42%

had a condition which was invisible or easily hidden (about 1% did not answer).

CHAPTER 4

Study 1

Introduction

In this first study we explored our 14 factors of interest utilizing the quantitative questions in our survey. Details on the operationalization of our dependent variable (self-identification), and independent variables (14 factors) will follow.

Methods

While our final survey contained 31 questions, only 19 were used in the present study. We shall first review how our dependent variable was operationalized, and then how our independent/predictor variables were operationalized.

Dependent variable: Disability self-identification. Of the first five questions asked in our survey (all qualitative) only one was used for the present study. It was question two: "Do you identify as a person with a disability? Why or Why not?" As this question would essentially serve as the basis for our dependent variable (disability self-identification), much thought was put into its wording. To be precise, because this was an American sample, we chose to use "person-first" language when referencing disability status; that is; we used the expression "person with a disability" over "disabled person" or "handicapped" as this is the most commonly accepted terminology in the U.S. (Shakespeare, 2006). Moreover, because the central premise of our study was the importance of self-identification, we opted to use the language "do you *identify*

21

as…" rather than "are you a…." or "do you have a…" to highlight both the self-identification process and the underlying assumption that disabilities are not attributes which can be separated from the individual as a whole.

Independent/predictor variables. As previously stated, our study explored 14 different predictor variables in three subgroups: disability characteristics, disability & the environment, and intersection of disability and other social identities. We will now review each of these factors in turn.

Factor 1: Disability Type. Because the literature is inconsistent in classifying disabilities into different types, e.g. "mobility impairments" vs. "physical disabilities", and unclear as to which conditions specifically fall into these different categories, the operationalization of Factor 1 was by far the most difficult component of our survey construction. As it would allow us to collect more precise and detailed data, we decided to construct the "disability type" question as a large list of conditions rather than a small list of disability categories.

Given the debate as to which conditions are or are not classifiable as disabilities (Linton 1998), it was very important to us that the conditions on our list have strong evidence for their "legitimacy". In order to accomplish said task, we had an extensive consultation at our local center for independent living (A. Gossage, personal communication, March 23rd, 2011). Through this consultation, we were given access to a list of 47 different disability conditions used by all centers for independent living in the state of Michigan in their annual Federal 704 Report. (This report is given to the Department of Education's Rehabilitation Services Administration, and is used to determine "core funding" for the centers).

Once our initial list was in place, we sought out two additional consultations with professionals in this area of study. Both consultants were faculty at the University of Michigan,

one in the area of Disability Studies & Social Work, and the other in Physical Medicine and Rehabilitation. As a result of these secondary consultations, the following changes were made to our "disability type" survey question: (1) Eight new conditions were added (mostly mental health related) resulting in a final list of 55 conditions, (2) an open-ended option of "Other" was added to the list, giving participants the ability to write in their own conditions, (3) the question format and related instructions were changed to allow participants to select more than one disability condition. Consequently, a second "disability type" question was added to the survey asking participants to list their "primary" condition if they had selected more than one option from our list of 55. Due to its size, please see Appendix A for an exact replication of how the "disability type" questions were presented.

Factor 2: Age of Onset. Age of onset was operationalized through the following survey question: "At what age did you acquire your condition?" with five response options (1 = *Born with my condition*, 2 = *Between 1-9 years old*, 3 = *Between 10-19 years old*, 4 = *Between 20-29 years old*, 5 = *Older than 30 years old*). We opted to keep the age range relatively young as our primary interest was in the difference between those who were born with their conditions or acquired them at a relatively young age, and those who acquired their conditions during adulthood.

Factor 3: Severity of Condition. Severity of condition was operationalized through two different survey questions. The first was modeled on a Activities of Daily Living instrument, and appeared with the following stem question: "Because of the condition(s) you listed above, do you have difficulty with…" It then contained the following six sub-questions: "Seeing (even if wearing glasses)?, Hearing (even if using hearing aids)?, Walking or climbing stairs?, Remembering or concentrating?, Self-care (such as washing or dressing)?, Communicating

23

(understanding or being understood by others)?" There were four response options for each sub-question (1 = *No difficulty*, 2 = *Some difficulty*, 3 = *A lot of difficulty*, 4 = *Total Difficulty (I am unable to do this activity)*).

The second measure of severity was an estimation of the total number of disabilities a person reported experiencing. It was not a survey question in itself, but rather a variable created by analyzing the "disability type" data (adding all the conditions selected from the list of 55 plus any additional conditions listed in the "Other" section). The rationale behind this second measure was that the experience of multiple disabilities would be, in general, more severe than the experience of a single disability.

Factor 4: Visibility. Visibility was operationalized through the following survey question: "Unless I disclose it, my condition(s) is/are largely hidden to those around me." The question had four response options (1 = *Strongly Disagree*, 2 = *Disagree*, 3 = *Agree*, 4 = *Strongly Agree*), and a follow up question (only revealed to those who indicated a hidden condition) regarding rates of disclosure: "You have indicated that your condition is largely hidden from others. How often do you disclose (tell others about) your condition?" The five "disclosure" response options were as follows: 1 = *Never*, 2 = *Rarely*, 3 = *Sometimes*, 4 = *Often*, 5 = *Always*. These questions were based in part on literature reviewed on LGBT identity, and the choice to disclose (come out of the closet).

Factor 5: Disability Community Involvement & Activism. Disability community involvement and activism was operationalized through two different survey questions. The first tapped into general community involvement, and asked: "How active are you in organizations with other people with disabilities?" with three response options (1 = *Not at all active*, 2 = *Somewhat active*, 3 = *Highly active*). The second question was geared more towards community

24

activism. It asked, "How involved are you in disability advocacy / disability rights?" and had the following three response options (1 = *Not at all involved*, 2 = *Somewhat involved*, 3 = *Highly involved*). It was important for us to have two separate questions for this factor as one could be involved in the disability community in more of a social, somewhat passive way, or one could be involved in the disability community in a very active, perhaps radical way (e.g. (Hahn & Beaulaurier, 2001).

Factor 6: Label Confusion. Label confusion was operationalized through the following survey question: "Which of the following labels is most accurate when describing you?" with five response options (1 = *Disabled person*, 2 = *Person with a disability*, 3 = *Non-disabled person*, 4 = *Able-bodied person*, 5 = *Other (Please Specify)*). Retrospectively, it does not appear that we successfully operationalized our label confusion concept. The question we asked would be better understood as a form of label preference. Regardless, we included this factor in our analyses to see, from an exploratory point of view, what we would find.

Factor 7: Educational System. Educational system was operationalized through the following survey question: "Were you at any point during your elementary, middle, or high school education, on an Individualized Education Plan (IEP)?" with two response options (1 = *Yes*, 2 = *No*). The decision to focus on IEPs was suggested in consultation with one of the dissertation committee members whose area of research focused on students with disabilities in higher education who suggested that this could have an impact on self-identification.

Factor 8: Federal Support. Federal support was operationalized through the following survey question: "Do you receive assistance/support from any of the following sources (You may select more than one)?" with five response options (1 = *Supplemental Security Income (SSI)*, 2 = *Social Security Disability Insurance (SSDI)*, 3 = *Medicare*, 4 = *Medicaid*, 5 = *Other*

(Please Specify)). This list was acquired through the aforementioned consultation with our local Center for Independent Living.

Factor 9: Gender. Gender was operationalized through the following survey question: "What is your gender?" with four response options (1 = *Male*, 2 = *Female*, 3 = *Transgender*, 4 = *Other (Please Specify))*. When writing this question we aimed to be as inclusive as possible by listing both the *Transgender* and *Other* options. Interestingly, several participants did choose the *Other* option, most of whom wrote in "GenderQueer."

Factor 10: Marital/Partnership Status. Marital/partnership status was operationalized through the following survey question: "What is your marital/partnership status?" with four response options (1 = *Single*, 2 = *Dating/in a relationship*, 3 = *Married or partnered*, 4 = *Divorced, separated, or widowed*). As with gender, we attempted to be as inclusive as possible by writing this question with both Heterosexual and LGBT persons in mind.

Factor 11: Race/Ethnicity. Race/ethnicity was operationalized through the following survey question: "What is your race/ethnicity?" with seven response options (1 = *Asian, Asian American, or Pacific Islander*, 2 = *Black, African, or African American*, 3 = *Latino/a, Hispanic, or Hispanic American*, 4 = *Middle Eastern, Arab, or Arab American*, 5 = *Native American or Alaskan Native*, 6 = *White, European, or European American*, 7 = *Other (Please Specify))*. It should be noted that many participants who chose to use the "Other" response option did so to indicate that they were of a mixed racial background. (In the future, it would be wise to allow participants to select more than one option for this question).

Factor 12: Social Class. Operationalizing social class was a tricky task in that there appears to be many contradictions in the literature as to how to best measure it. Ultimately we chose to follow a social classification model described by Rose (1995). In order to do so, we had

three measures: one for employment, one for education, and one for income. Employment was operationalized through the following survey question: "What is your current employment status?" with six response options (1 = *Full-time*, 2 = *Part-time*, 3 = *Unemployed Student*, 4 = *Unemployed Worker*, 5 = *Retired*, 6 = *Other (Please Specify)*).

Level of education was operationalized through the following survey question: "What is the highest level of education you have completed?" with eight response options (1 = *Less than High School*, 2 = *High School / GED*, 3 = *Some College*, 4 = *2-year College Degree*, 5 = *4-year College Degree*, 6 = *Master's Degree*, 7 = *Doctoral Degree* 8 = *Professional Degree (JD, MD)*).

Lastly, income was operationalized through the following survey question: "What is the approximate combined annual income of all members of your household?" with eight response options (1 = *Under $15,000*, 2 = *$15,000-$24,999*, 3 = *$25,000-$34,999*, 4 = *$35,000-$49,999*, 5 = *$50,000-$74,999*, 6 = *$75,000-$99,999*, 7 = *$100,000-$249,000* 8 = *$250,000 or more*).

Factor 13: Sexual Orientation. Sexual orientation was operationalized through the following survey question: "How would you describe your sexual orientation?" with six response options (1 = *Completely heterosexual*, 2 = *Mostly heterosexual*, 3 = *Bisexual*, 4 = *Mostly homosexual, lesbian, or gay*, 5 = *Completely homosexual, lesbian, or gay*, 6 = *Other (Please Specify)*). The wording of this question comes from a previous study conducted by the candidate (Moradi & Rottenstein, 2007), and is phrased to reflect the fluid nature of sexuality.

Factor 14: Age. Age was operationalized through the following simple, open-ended, survey question: "What is your age?"

Preliminary Analyses

Before we could embark on the data analyses relevant to our primary research questions, we had to first conduct fairly extensive preliminary analyses on the questions related to our dependent variable of disability self-identification, and one of our independent variables: Disability Type.

Disability self-identification: Qualitative analyses. As our dependent variable came from a qualitative question, it was necessary for the research team to classify participant answers in order to create quantitative data for our intended analyses. Reviewing a sub-sample (approximately 10%) of participant responses, two members of the research team utilized constant comparative analyses to develop 4 codes related to the question of self-identification. These codes were "Yes", "No", "Sometimes" (indicating that the participant self-identified depending on the situation), and "No Answer". Once the codes were finalized, four researchers were trained (with a 90% inter-rater reliability) to code the complete dataset using NVivo 9 software. (More detail regarding the qualitative analysis of the self-identification question will be presented in Study 2).

Preliminary analyses on "Disability Type". While most of our survey questions were easily transformed into variables for data analysis, the "Disability Type" question required extensive preliminary work in order to create useful variables for analyses. Our first task was to create a new variable indicating participants' primary condition by number. A step-by-step review of these analyses is as follows (please keep in mind that we provided 55 disability conditions for participants to select, that participants could select more than one condition, that participants were given the option to write in "Other" conditions, and that participants were asked to indicate their primary condition in a follow up question).

Creating the "Primary Disability Type" Variable. Because our participants were given

such freedom in responding to our original Disability Type question, many steps were needed to

classify each participant with a "Primary Disability Type." Our first step in this process was to

create a new variable called "Sum Conditions" by adding the number of conditions participants

selected from the list of 55 disability types we provided. We then sorted our data by "Sum

Conditions" from smallest to largest. We then removed 85 participants who did not answer the

"Disability Type" question in any way; that is, none of the 55 conditions were selected, and no

answer appeared in the "Other" or "Primary Condition" sections.

Our next step in creating a "Primary Disability Type" variable was to code those

participants who had a clear primary condition. In order to do so, we looked to our Sum

Conditions list, and isolated participants who only chose 1 of the 55 conditions provided in our

"Disability Type" survey question. We made sure that these were participants who also did not

write anything in the "Other" or "Primary Condition" sections. Codes for the "Primary

Disability Type" variable were simply the number (1-55) associated with the conditions listed in

our survey. (Approximately 650 participants were coded in this step).

Once this was complete, we moved on to those participants who indicated multiple

conditions, and whose primary condition fell into our original 55 categories. To be clear, these

were participants who had (1) selected 1 or more of the 55 conditions, (2) had or had not written

a condition in the "Other" section, and (3) had indicated (written in) a primary condition which

matched our original 55 codes. These participants were assigned to the same codes (1-55) used

with our first group of participants. (Approximately 1,460 participants were coded in this step).

We then went on to tackle participants who had indicated multiple conditions, but whose

primary condition fell out of our original 55 conditions. To be clear, these were participants who

(1) selected 1 or more of the 55 conditions, (2) *had* written in a condition in the "Other" section, and (3) had indicated (written in) a primary condition which did *not* match our original 55 codes. To address this group of participants, we created a master list of every single condition participants had listed in the "Other" section with a tally of how many times these "other conditions" were mentioned. We then took the top 15 most common codes and added them to our list of 55, expanding our response options for the "Primary Disability Type" to 70 conditions. Please see Table 2 for a list of these additional codes.

Table 2

Additional Primary Disability Type Codes

Code #	Condition Type
56	Reflex Sympathetic Dystrophy Syndrome (RSDS) or Complex regional pain syndrome (CRPS)
57	Paralysis
58	Charcot-Marie-Tooth Disease (CMT)
59	Ataxia
60	Lupus / Systemic lupus erythematosus (SLE)
61	Ehlers-Danlos syndrome
62	transverse myelitis
63	Neuropathy
64	Chronic Pain
65	Spinal Stenosis
66	Osteogenisis Imperfecta
67	Fatigue/Chronic Fatigue Syndrome
68	Migraines
69	Schizoaffective Disorder/Schizophrenia
70	Neurological Disorder/Condition
71	Other

The addition of these 15 conditions enabled us to classify an additional 330 participants. Unfortunately, this left approximately 200 participants who had conditions without codes. We opted to create a new code (71: Other), for these remaining participants. At the end of this

process we were able to code 2,438 participants of a total 2,764. The remaining 326 were classified as missing data in our file. These 326 included the original 85 who did not answer the question in any way in addition to those who (a) listed multiple conditions in the primary condition section, (b) stated in the primary condition space that they 'could not decide' or that 'all of their conditions were equally impactful', (c) selected/listed multiple conditions, but did not state anything in the primary condition section. (For a table showing the frequency of all 71 primary disability conditions, please see Appendix D, Table D1).

Creating Disability Type Categories. Once we had a clear list of our primary disability conditions, we then moved on to classifying them into larger categories. This would make analyses for the Disability Type factor far easier to conduct, and much more consistent with the hypotheses presented in the literature review. The process of creating these larger categories was also complex; fortunately however, we were able to enlist the help of a faculty consultant from the area of Physical Medicine and Rehabilitation who pointed us in the direction of diagnostic groups used by the World Health Organization's *International Classification of Disease (ICD-10)* (WHO, 2010).

From the ICD-10, we used the *International Classification of Functioning, Disability and Health* section for a list of eight disability categories, and the *Body Function & Structures – Impairment Components* to classify our 70 conditions into these eight categories. The eight categories were: (1) mental functions/structure of the nervous system, (2) sensory functions/ structure of eye, ear, and pain, (3) voice and speech functions, (4) functions/structure of the cardiovascular, haematological, immunological, and respiratory systems (5) functions of digestive, metabolic, endocrine systems, (6) genitourinary and reproductive functions, (7) neuromusculoskeletal and movement-related functions & structures, including the nervous

31

system and other body structures, and (8) functions of the skin and related structures. We added a

ninth category: "Other" for those conditions which did not seem to fall under any of the eight

primary categories. For a complete breakdown of which conditions fell under which categories,

in addition to formal definitions of each disability type, please see Appendix E (Tables E1-E8).

Results

      Participant self-identification. The first research question posed in our introduction to

this study asked at what rate people with disabilities self-identify as disabled. Based on our

qualitative coding, it appears that the majority of individuals in our sample (69%) self-identified

as a person with a disability. An additional 16% explicitly did not identify as a PWD, while 9%

indicated that they "sometimes" identify, depending on the situation, (6% did not answer).

      Given this breakdown, we decided to treat self-identification as a dichotomous dependent

variable. That is, we placed all participants into one of two categories "Yes" or "No." The No

category was comprised of both the participants who were coded as "No" and the participants

who were coded as "Sometimes." Those who did not answer were removed from further study.

Please note, because we had such an uneven distribution in self-identification, it was necessary to

combine the "sometimes" participants with the "no" participants to give us enough statistical

power for meaningful analyses.

      Identifying codes with predictive strength. Because we chose to work with a

dichotomous dependent variable, we opted to use logistic regression for all of our predictive

analyses. If a predictor variable was categorical with more than two levels, one served as the

reference level with respect to the other comparison levels. Moreover, because of the large nature

of our sample size, and the consequent possibility of our p-values being artificially inflated, we

decided to use Nagelkerke R-Square values as indicators of predictive strength. To be precise, we set the cutoff point for meaningful results at 0.01. Of the 28 logistic regressions run, (please recall that several factors were operationalized into more than one variable), only 10 met our criteria. These ten variables were related to a total of six predictive factors; that is, of our original 14 factors of interest, only 6 were empirically supported as significant: Disability Type, Severity of Condition, Visibility, Social Class, Sexual Orientation, and Age. Please see Table 3 for a review of these findings.

Table 3

Univariate Logistic Regressions for Study 1

Factor	Variable	Nagelkerke R-Square	Reached .01 Cutoff
Disability Type	Disability Type Categories	0.020	X
Age of Onset	Congenital vs. Acquired	0.007	
Severity of Condition	Difficulty Seeing	0.009	
	Difficulty Hearing	0.003	
	Difficulty Walking	0.026	X
	Difficulty Remembering/Concentrating	0.003	
	Difficulty Self-Care	0.030	X
	Difficulty Communication	0.003	
	Total # of Conditions	0.017	X
Visibility	Hidden vs. Visible	0.028	X
	Disclosure	0.047	X
Disability Community	Organizational Involvement	0.007	

Involvement & Activism	Disability Rights Advocacy	0.008	
Label Confusion	Label Preference	0.005	
Educational System	Individualized Education Plan	0.006	
Federal Support	SSI	0.003	
	SSDI	0.006	
	Medicare	0.000	
	Medicaid	0.005	
	Total # of Federal Support	0.007	
Gender	Gender	0.004	
Marital/Partnership Status	Marital/Partnership Status	0.008	
Race/Ethnicity	Race/Ethnicity	0.008	
Social Class	Employment	0.013	X
	Education	0.004	
	Income	0.011	X
Sexual Orientation	Sexual Orientation	0.018	X
Age	Age	0.012	X

Interpreting predictive factors. In addition to determining predictive strength, we also felt it important to understand (a) the direction of the prediction, i.e. increasing vs. decreasing likelihood of self-identification, and (b) variable components, i.e. the exact components that were driving the strength of the prediction. In order to do so, we looked to the beta, standard error, Wald, odds ratio, and p-values for each component of our 10 significant predictive variables. We

will now review the predictive variables in the order subscribed by the original predictive factors they are related to. Also, to be consistent, we have chosen to maintain the original numbers for each predictive factor. (Please see Appendix F, Table F1, for a summary of these findings).

Factor 1: Disability Type. We found that those in the "Functions/Structure of the Cardiovascular, Haematological, Immunological, and Respiratory Systems" category were 0.55 ($p < .05$) times less likely to identify as a PWD than those in our reference category of "Other", while participants in the "Neuromusculoskeletal and Movement-related Functions & Structures" category were 1.49 ($p < .05$) times more likely to identify as a PWD than those in our reference category of "Other". These findings appear to partially support our hypotheses for disability type as those with physical conditions, operationalized as Neuromusculoskeletal and Movement-related Functions & Structures were more likely to self-identify. Moreover, we found that those in other categories were less likely to self-identify. We did not however, find support for the hypothesis that those with sensory conditions would be more likely to self-identify.

Factor 3: Severity of Condition. Three different variables supported the significance of condition severity: difficulty walking, difficulty with self-care, and total number of conditions. Regarding *difficulty walking*, we found that those in the "no difficulty" or "some difficulty" categories were 0.49 ($p < .001$) and 0.64 ($p < .001$) times *less* likely to identify than those in our reference category of "total difficulty: I am unable to do this activity".

Similarly, with regards to *difficulty with self-care*, we found that those in the "no difficulty" or "some difficulty" categories were 0.39 ($p < .001$) and 0.57 ($p < .05$) times *less* likely to identify than those in our reference category of "total difficulty: I am unable to do this activity". In a parallel vein, those with a higher *number of conditions* were 1.08 ($p < .001$) times *more* likely to self-identify than those were a lower number of conditions.

The findings from all three *severity of condition* variables appear to support our hypothesis that those with more severe conditions will be more likely to self-identify than those with less severe conditions.

Factor 4: Visibility. Two different variables supported the significance of disability visibility. With regards to the *hidden vs. visible* variable, predictive power was driven by all three categories. To be precise, those in the categories of "Strongly Disagree", "Disagree", and "Agree" were all *more* likely [2.36 ($p < .001$), 1.65 ($p < .01$), and 1.39 ($p < .05$) respectively] to identify as a PWD than those in our reference category of "Strongly Agree."

Relatedly, for the *disclosure* variable, predictive power was driven by those who chose *not* to disclose an invisible condition. To be precise, participants who Never, Rarely, or Sometimes disclosed were 0.19 ($p < .01$), 0.23 ($p < .001$), and 0.34 ($p < .01$) times *less* likely to identify as PWDs respectively, than those in our reference category of "Always."

The findings from both visibility variables appear to support our hypothesis that those with visible conditions will be more likely to self-identify than those with hidden conditions.

Factor 12: Social Class. Two different variables supported the significance of social class as a predictive factor. The first variable, *employment status*, showed that those who fell under the category of "unemployed student" were 1.92 ($p < .01$) times *more* likely to self-identify than those in our reference category of "other".

The second variable, *income*, showed that those who fell under the "Under $15,000" and "$25,000-$34,999" categories were 1.95 ($p < .05$) and 1.90 ($p < .05$) times more likely to self-identify than those in our reference category of "$250,000 or more".

As our hypotheses for social class were exploratory, our results seem to indicate that those who are unemployed are more likely to identify as a person with a disability, than those

36

who are employed. Similarly, those who are in lower income brackets also appear to be more likely to self-identify as disabled.

Factor 13: Sexual Orientation. While none of the odds ratios were statistically significant ($p < .05$), there does appear to be an interesting pattern in the data in which those who classify themselves as heterosexual are less likely to self-identify as disabled, while those in every other category were more likely to identify (relative to our reference category of "other"). Like social class, the hypothesis for sexual orientation was exploratory in nature. While we did not find statistically significant findings, it does appear that those who are experiencing a double-minority position, are *more* likely to self-identify. This is a fairly strong contradiction to the patterns we saw concerning double minority status in the literature review.

Factor 14: Age. Like sexual orientation, age had no statistically significant odds ratios. Unlike sexual orientation, it appeared that all age categories were more likely to self-identify as disabled relative to our reference category of "90-94 years". Findings regarding the age factor appear to support our hypothesis that older adults will be less likely to self-identify.

Discussion

In this study, the researchers identified 14 factors which they felt would significantly predict disability self-identification. The 14 factors were then operationalized into 28 variables used in logistic regression. In the end, only 6 of the 14 factors appeared to significantly predict disability self-identification. Happily, all six significant factors appeared to partially or fully support the hypotheses presented in the literature review.

While the operationalization and measurement of the factors appeared to go well (with the exception of label confusion), the use of logistic regression for analyses posed some

limitations on the results. In the future, it would be nice to play around more with which category

acts as the reference level, or to find a different means of analyzing our data.

CHAPTER 5

Study 2

Introduction

As with Study 1, Study 2 investigated factors which would predict disability self-identification. However, in our second study, we switched from a deductive,quantitative approach to an inductive,qualitative approach. To be precise, we utilized grounded methodologies to develop predictive themes directly from the participants' themselves rather than rely on pre-determined factors from our literature review. Our decision to take this mixed-method approach stems from our belief that the lived experience of disability gives our participants an expertise just as valuable and valid as that of professional scholars.

Methods

As with Study 1, Study 2 also used the survey question: "Do you identify as a person with a disability? Why or Why not?" as the basis for the dependent variable of disability self-identification. In contrast, the source of the independent/predictive variables in Study 2 came not from predetermined literature review factors, but from the very same qualitative survey question used to operationalize the dependent variable.

To clarify, in addition to using constant comparative analyses to create the four disability self-identification codes (*Yes, No, Sometimes, No Answer)*, the research team also used constant comparative analyses to create 28 *prediction* codes, several of which had sub-codes (please see

Appendix G for a full listing of the codes & sub-codes). As with Study 1, once the codes were finalized, a four-member research team trained (with a 90% inter-rater reliability) coded the complete dataset using NVivo 9 software.

After all the coding was finished, we transferred the data from our NVivofile to our SPSS file (which contained all previously mentioned data from the survey questions). Consequently, each of the prediction codes and sub-codes appeared as new variables in our dataset with two response options (1 = *Present,* 0 = *Not Present*). We then performed logistic regressions, each containing a dichotomous predictor variable (1 = Present, 0 = Not Present) and a dichotomous dependent variable "Self-Identification" (Yes = 1, No/Sometimes = 0) to test the predictive strength of the qualitative themes.

Results

Prediction Codes. As previously stated, 28 prediction codes were identified through our qualitative analyses. We shall now review all 28 codes/themes. They will be organized by frequency; that is, the most referenced theme will go first and the least referenced last. In addition, the themes will be presented with the following information provided: (a) the name of the theme, (b) the number of times it was referenced by our participants, (c) a brief definition of the theme, (d) a quote from the text that exemplifies the theme [with original language unchanged], (e) a discussion of the presence of any sub-codes, and finally (f) a discussion of if and how the theme may (or may not) match our previous discussed 14 predictive factors from our literature review. (Please note, because we go into extensive detail regarding the main themes in text, we refer you to Appendix G for details on the sub-themes/codes).

Theme 1: Disability Type. This theme, referenced 1,290 times in text, is indicative of those who identified as disabled due to the type of disability they have. An example: "*Yes, with severe TBI it's hard not to know my limitations*." The "disability type" code has 10 sub-codes, two of which have further sub-codes themselves; (see Appendix G). Interestingly, our most frequently referenced qualitative theme is a perfect match for our most commonly mentioned predictive factor in our initial literature review: Factor 1: Disability Type.

Theme 2: Difficulty and Limitations. This theme, referenced 516 times in text, is reflective of those who experience a variety of difficulties due to their disability, and/or mention how their disability limits them in a number of ways. An example: "*Yes. Mood Disorder that interferes with daily functioning, which results in periods of disrupted productivity and strained interpersonal relationships*." The "difficulty and limitations" code has 3 sub-codes (see Appendix G). In the context of our original 14 factors, this theme is best seen as a sub-factor of Factor 3: Severity of Condition, as the experience of a great number of difficulties or limitations would make one's disability a more severe experience.

Theme 3: Assistive Technology. This theme, referenced 418 times in text, is illustrative of participants who use assistive technology, e.g. CART services, hearing aids, wheelchairs, service dogs, etc.). An example: "*Yes. Why? Because it took 2 seperate adaptive devices and or software(s) just so I can answer your question. My guide dog also gives it away.*" The "assistive technology" code has 4 sub-codes (see Appendix G), and like the theme above, can be seen as a sub-factor of Severity of Condition.

Theme 4: Visibility. This theme, referenced 374 times in our text, is indicative of those whose disability is visible to a casual observer. An example: "*Yes. Usually its the first thing people notice. I usually don't tell people online that I'm disabled unless I'm telling them a lot*

about myself. The "visibility" code has 2 sub-codes (see Appendix G), and is a perfect match for our fourth factor from the literature review "Visibility".

Theme 5: Feelings. This theme, referenced 293 times in text, is reflective of those who mentioned specific feelings due to or about their disability. For example, "*yes, with pride. it is a piece of who I am, an attribute. A part of me that has made me the person I am.*" The "feelings"code has 2 sub-codes (see Appendix G), and interestingly, does not appear to match any of our original 14 predictive factors.

Theme 6: Stigma and Label. This code, referenced 260 times in text, is illustrative of those who experience stigma and discrimination in society, including feeling pressure from their community or work place, or feeling looked down upon in general. It also includes the feeling of being 'labeled' as disabled, or the desire to avoid such a label. An example: "*no, I try to hide my disability to avoid comments, questions, discrimination.*" The "stigma and label" code has no sub-codes, and like Theme 5, does not appear to match any of our original 14 predictive factors.

Theme 7: Age or Year. This code, referenced 251 times in text, is reflective of those who mention the age of onset and/or duration of their condition. An example, "*Yes, I have been suffering with Bipolar disorder for over 20 years.*" The "age or year" code has no sub-codes, and is a perfect match for our original Factor 2: Age of Onset.

Theme 8: Secondary. This code, referenced 207 times in text, is illustrative of those whose disability identity is not a core part of how they view themselves. An example: "*Yes, it is a part of who I am but it is not all of who I am - it doesn't define me, just affects the choices I make.*" The "secondary" code has no sub-codes, and does not appear to match any of our original 14 predictive factors.

Theme 9: Advocacy. This code, referenced 194 times in text, is indicative of those who are disability rights advocates and educate others about their disability/disabilities. An example: "*Yes, I always inform people of my disabilities. I do this to try to help people understand that those with disabilities, may not often look as though they are disabled and to try to bring our plight to the forefront that we can and are employable.* The "advocacy" code has no sub-codes, but is a perfect match with our original Factor 5: Disability Community Involvement & Activism.

Theme 10: Shaped. This code, referenced 191 times in text, is reflective of those who believe their disability has strongly shaped them as a person. For example, "*Yes. Simply put, it is who I am. It is an integral part of my life experience, plays a significant role in my life and has made me into the person I am today.*" The "shaped" code has no sub-codes, nor does it appear to match any of our original 14 predictive factors.

Theme 11: Symptoms. This code, referenced 182 times in text, is illustrative of those who listed symptoms. To be clear, this does not mean listing disabilities, but listing physical and mental experiences they have. For example, "*Yes because my condition, Charcot Marie Tooth (sensory and motor neuropathy) often prohibits me from walking without pain or extreme dizziness. I often have to stop and regain balance.*" The "symptoms" code has 2 sub-codes (see Appendix G), and can best be classified as relating to our original Factor 3: Severity of Condition.

Theme 12: Employment.This code, referenced 162 times in text, is indicative of those who feel that their identities are influenced by employment-related issues. They could be speaking about their job or lack of a job or how their disability affects their performance at a job. For example, "*I am disabled. I can no longer do the job I used to do. I am not physically able to*

43

do my job anymore." The "employment" code had 1 sub-code (see Appendix G), and can be best understood as relating to our original Factor 12: Social Class.

Theme 13: Situational. This code, referenced 154 times in text, is indicative of those individuals who only identify when they are performing certain tasks, or are around certain people. For example, *"Only when I need to receive services or am assisting others with disabilities; Otherwise, I do not identify myself as a person with a disability because that is not who I am."* The "situational" code has no sub-codes, and does not appear to match any of our original 14 predictive factors.

Theme 14: Primary. This code, referenced 120 times in text, is reflective of those who feel their disability is a primary aspect of their identity. For example, *"Yes, because it defines who I am and why I am the way I am."* The "primary" code has no sub-codes, nor does not appear to match any of our original 14 predictive factors.

Theme 15: Accommodations. This code, referenced 116 times in text, is illustrative of those who have accommodations, such as extended time on tests, installed ramps on stairs at work, etc. For example, *"I identify as a person with a disability as I am mobility impaired and need certain accomodations. However that does not impede me from leading a full life. I just have to plan thing more, be more creative and pace myself affectively."* The "accommodations" code has no sub-codes, but it does appear to relate to Factor 3: Severity of Condition.

Theme 16: Treatment. This code, referenced 115 times in text, is indicative of those who mentioned they are disabled because they take medications, have had surgery, or are currently receiving some other form of medical treatment. An example: *"Yes as I have had 11 surgeries and walk with crutches and braces."* The "treatment" code has no sub-codes, but it does appear to relate to our original Factor 3: Severity of Condition.

Theme 17: Overcome. This code, referenced 106 times in text, is indicative of those who feel they have "overcome" or conquered their disability condition(s). For example, "*Yes. In life, I believe we must identify our obstacles and acknowledge the fact that we have and are overcoming them. I don't see my disabilities as limitations but as accomplishments of challenges I have conquered.*" The "overcome" code has no sub-codes, but it does appear to relate to our original Factor 3: Severity of Condition.

Theme 18: Adapt. This code, referenced 99 times in text, isreflective of those who had to find new ways of doing things, and adapt to a new way of living. Importantly, this theme is different from our "accommodations theme" as accommodations require external help, whereas in 'adapt,' the individual relies on their own self to create new methods of getting old tasks done. An example: "*yes. I do because my life is entirely different since acquiring my disability. I have also created an environment around myself that allows me to be open.*" The "adapt" code has no sub-codes, but it does appear to relate to our original Factor 3: Severity of Condition.

Theme 19: Entire Life.This code, referenced 97 times in text, is illustrative of those who have had a disability their entire life, or have grown up with their disability. For example, "*Yes I am Paraplegic since birth. I use a manual wheelchair for mobility.*" The "entire life" code had no sub-codes, but is a perfect match for our original Factor 2: Age of Onset.

Theme 20: Community. This code, referenced 86 times in text, is indicative of those who belong to a disability community, either locally or at large. An example, "*Yes.in the sense that I advocate for and work with others with the same disability. I am president of a local disability non-profit. We put on a camp and have an art program for people with the disability.*" The "community" code has 2 sub-codes (see Appendix G), and is a perfect match for our original Factor 5: Disability Community Involvement & Activism.

Theme 21: Dependent. This code, referenced 68 times in text, is reflective of those who are not able to act/live independently without others (mostly referencing dependence on family and/or friends). For example, "*Yes. I have a rare form of Muscular Dystrophy and am in a wheelchair. I need helpers at school and at home.*" The "dependent" code has no sub-codes, but can be seen as relating to our original Factor 3: Severity of Condition.

Theme 22: Chronic.This code, referenced 64 times in text, isillustrative of those who have a disability which is chronic (i.e., it will last for the rest of their lives). It can also indicate that their disease is progressive (i.e., it is getting worse). An example: "*No.However, I am a person riddled with physical pain 24/7.*" The "chronic" code has no sub-codes, but can be seen as falling under our original Factor 3: Severity of Condition.

Theme 23: Diagnosis.This code, referenced 59 times in text, is indicative of those whosedisability self-identification is influenced by a formal medical examination and diagnosis. For example, "*Yes. I was diagnosed at age 2 with Nemaline Myopathy.*" The "diagnosis" code has no sub-codes, and would fall best on our original Factor 6: Label Confusion (as the medical jargon associated with a formal diagnosis may be confusing to a person experiencing a condition).

Theme 24: Different. This code, referenced 59 times in text, isreflective of those who have always felt "different" because of their disability. For example, "*Yes. Pretty much have to, as I am far from typical.*" The "different" code has no sub-codes, nor does it appear to match any of our original 14 predictive factors.

Theme 25: Accident. This code, referenced 56 times in text, is illustrative of those who stated that they acquired their disability due to an accident. For example, "*Of course I do. I'm a paraplegic (paralyzed from the waist down) due to a head-on collision on December 4, 1960.*"

I've been a w/c user for over 50 years now." The "accident" code has no sub-codes. It does not appear to match or fall under any of our original 14 predictive factors.

Theme 26: Independent.This code, referenced 42 times in text, is indicative of those who stated that they are independent, regardless of their disability. For example, "*I don't generally identify myself as a disabled person and don't depend on others to do things for me. I am quite independent and want to maintain that as long as I can."* The "independent" code has no sub-codes, but does appear to relate to our earlier Qualitative theme of "Dependent". As such, it is falls under our original literature review Factor 3: Severity of Condition.

Theme 27: Social Benefits.This code, referenced 25 times in text, is reflective of those who receive some form of financial social benefits (e.g. social security or retirement benefits). An example: "*Yes. My condition has forced me to retire on disability."* The "social benefits" code has no sub-codes, but does appear to be a perfect match for our original Factor 8: Federal Support.

Theme 28: Everybody's Disabled.This code, referenced 16 times in text, is indicative of those who feel that everybody has a disabilities and abilities of their own. An example: "*Yes. Because to me disability is not "Disability", rather a different "Ability". Based on this, I am convinced that every single human being has some kind of "disability" meaning different ability."*The "everybody's disabled" code has no sub-codes. It does not appear to match any of our original 14 predictive factors.

Identifying codes with predictive strength. As was done in Study 1, we utilized a Nagelkerke R-Square cut off of .01 to determine meaningful predictive strength among the different regression equations. Of the 56 logistic regressions run (28 themes plus 28 sub-themes),

only 11 themes met our criteria; (please see Appendix H, Table H1, for a review of these findings).

Interpreting predictive factors. While we used the Nagelkerke R-Square to determine relative predictive strength for our top 11 variables, it is also important to understand in which direction these predictions are occurring. In order to do so, we looked to the beta, standard error, Wald, odds ratio, and p-values for each component of our predictive variables. (Please see Table 4 for a summary of these findings.)

Table 4

Top 11 Predictors for Study 2

Theme	Predictor	β	*SE*	Wald	Odds Ratio
1	Disability Type				
	Present	0.45	0.10	20.60	1.58***
	Constant	0.87	0.05	265.91	2.38
1.8	Mute				
	Present	-1.72	0.39	19.55	0.18***
	Constant	1.03	0.05	515.59	2.80
1.9	Physical				
	Present	0.65	0.13	25.61	1.91***
	Constant	0.90	0.05	337.03	2.45
4.1	It is Hidden				
	Present	-0.86	0.16	29.51	0.42***
	Constant	1.08	0.05	517.29	2.93
4.2	It is Visible				
	Present	0.98	0.24	17.08	2.67***
	Constant	0.96	0.05	433.70	2.60
10	Shaped				
	Present	1.24	0.26	22.66	3.45***
	Constant	0.95	0.05	427.09	2.58
13	Situational				
	Present	-3.07	0.28	119.29	0.05***
	Constant	1.16	0.05	590.73	3.19
14	Primary				
	Present	2.36	0.59	15.96	10.54***
	Constant	0.97	0.05	455.33	2.63
15	Accommodations				
	Present	0.83	0.15	32.39	2.29***
	Constant	0.90	0.05	349.97	2.45

	Overcome				
17	Present	-1.10	0.20	31.37	0.33***
	Constant	1.06	0.05	522.57	2.90
18	Adapt				
	Present	-2.10	0.18	138.09	0.12***
	Constant	1.17	0.05	588.33	3.23

*p < .05. **p < .01. ***p < .001.

Themes which increased the likelihood of self-identification. Six of our eleven

significant, predictive, qualitative themes increased the likelihood of disability self-identification.

A review of these findings follow, with the significant themes ordered by Odds Ratio, i.e. those

themes with the higher Odds Ratios will be listed first, and those with lower Odds Ratios will be

listed last.

Participants who were coded with Theme 14: *Primary* were 10.54 ($p < .001$) times more

likely to self-identify than those who did not have the "primary" theme present. Participants who

were coded with Theme 10: *Shaped* were 3.45 ($p < .001$) times more likely to self-identify than

those who did not have the "shaped" theme present. Participants who were coded with Theme 4:

Visibility were 2.67 ($p < .001$) times more likely to self-identify than those who did not have the

"it is visible" theme present. Participants who were coded with Theme 15: *Accommodations*

were 2.29 ($p < .001$) times more likely to self-identify than those who did not have the

"accommodations" theme present. Participants who were coded with Theme 1.9: *Physical (a*

sub-code of Theme 1: Disability Type) were 1.91 ($p < .001$) times more likely to self-identify

than those who did not have the "physical" sub-theme present. Lastly, participants who were

coded with Theme 1: *Disability Type* were 1.58 ($p < .001$) times more likely to self-identify than

those who did not have the "disability type" theme present.

Themes which decreased the likelihood of self-identification. Five of our eleven

significant, predictive, qualitative themes decreased the likelihood of disability self-

identification. A review of these findings follow, with the significant themes ordered by Odds Ratio, i.e. those themes with the higher Odds Ratios will be listed first, and those with lower Odds Ratios will be listed last.

Participants who were coded with Theme 4.1: *It is Hidden (a sub-code of Theme 4: Visibility)* were 0.42 ($p < .001$) times less likely to self-identify than those who did not have the "it is hidden" sub-theme present. Participants who were coded with Theme 17: *Overcome* were 0.33 ($p < .001$) times less likely to self-identify than those who did not have the "overcome" theme present. Participants who were coded with Theme 1.8: *Mute (a sub-code of Theme 1: Disability Type)* were 0.18 ($p < .001$) times less likely to self-identify than those who did not have the "mute" sub-theme present. Participants who were coded with Theme 18: *Adapt* were 0.12 ($p < .001$) times less likely to self-identify than those who did not have the "adapt" theme present. Participants who were coded with Theme 13: *Situational* were 0.05 ($p < .001$) times less likely to self-identify than those who did not have the "situational" theme present.

Discussion

In this study we utilized a grounded approach to find 28 predictive factors for disability self-identification. Of these 28, only 9 appeared to be wholly original, that is, not relate to the 14 factors determined by our previous literature review. For a breakdown of how the qualitative themes intersect with the literature review factors, please see Table 5.

Table 5

Intersection of Qualitative Themes and Literature Review Factors

Factors Identified in Literature Review	Qualitative Themes
Disability Characteristics	

1	Disability Type	• Disability Type
2	Age of Onset	• Age or Year • Entire Life
3	Severity of Condition	• Difficulty and Limitations & Symptoms • Dependent vs. Independent • Chronic & Treatment vs. Overcome & Adapt • Assistive technology & Accommodations
4	Visibility	• Visibility
	Disability & Environment	
5	Disability Community Involvement & Activism	• Advocacy • Community
6	Label Confusion	• Diagnosis
7	Educational System	• Accommodations
8	Federal Support	• Social Benefits
	Intersection of Disability & Other Social Identities	
9	Gender	• None.
10	Marital/Partnership Status	• None.
11	Race/Ethnicity	• None.
12	Social Class	• Employment.
13	Sexual Orientation	• None.
14	Age	• None.

Regarding the themes that did not match our original predictive factors, it appears that many are related to components/dimensions of other minority identity models, specifically the

Black identity work of Robert Sellers (Sellers, Smith, Shelton, Rowley, & Chavous, 1998). To expand, *primary, secondary,* and *shaped* all appear to relate to the identity concept of centrality, i.e., how important a person's [disability] is in defining themselves. Similarly, *situational* appears to relate to the identity concept of salience, or how one's minority identity can become more or less salient depending on the context or situation one is in.

Moreover, *feelings* appears to relate to the identity concept of private regard, i.e. positive/negative judgments made by people about their own identities; while *different* and *stigma* appear to relate to the concept of public regard, that is, positive/negative judgments an individual perceives society to make with regards to their minority group. More information these and other components of social/collective identity can be found in the lovely review by Ashmore, Deaux, and McLaughlin-Volpe (2004).

In contrast, the themes of *accident* and *everybody's disabled* do not seem to fall under identity concepts proposed by other scholars. Instead, they seem uniquely relevant to only a disability identity. To expand, the theme of accident can be seen as a unique factor for those who acquire their condition(s) later in life. In this way it is related to age of onset, but could be better understood as a 'type of onset' variable. Relatedly, the theme of everybody's disabled seems to be reflective of the social (Oliver, 1990) or affirmation (Swain & French, 2000) models of disability.

In addition to identifying predictive themes, this study also tested the significance, strength, and direction of said themes. Regarding significance, only 11 of the 28 themes were determined to be statistically significant. Interestingly, we had an almost even match between those themes which predicted an increase in self-identification, and those themes that predicted a decrease in self-identification.

52

It is also interesting to note that the theme of *Disability Type* had by far the most references, but had the least predictive power (relative to its peers) in the significant themes that increased likelihood to self-identify. Perhaps in the future, we could explore how specific conditions influence disability self-identification. It would also be interesting to develop quantitative measures for our newfound qualitative themes. The idea of disability severity for example, has some obvious room to grow in its operationalization (adding sub-factors).

CHAPTER 6

General Discussion

The purpose of this research project was to investigate the idea of disability self-identification, specifically, how often it occurs among people with disabilities, and what factors can predict it. Our findings indicate that the majority of people with disabilities do identify as disabled.

However, this finding is in contrast with several empirical studies (see Shakespeare, 2006), and may be due to a bias in our recruitment method. To be precise, the majority of our participants were recruited because of their affiliation with an organization that either focuses on disability in general, or on a specific medical condition. In this way, our findings may not be as generalizable as we would hope.

In contrast, the sheer volume of participants, almost 3,000, is an astoundingly large sample, one that clearly outnumbers the vast majority of empirical work in this field. (Most empirical work in Disability Studies takes a qualitative approach, e.g. one-on-one interviews, or small focus groups, where their sample sizes rarely exceeds 15 participants.) In this way, our findings may be more generalizable than most.

Regarding our predictive factors, Study 1 showed Disability Type, Severity of Condition, Visibility, Social Class, Sexual Orientation, and Age to be the most significant in predicting self-identification, and for the most part, the direction of their predictions supported our hypotheses.

Support for Study 1 findings were also found in the results of Study 2. To elaborate: first, the 11 significantly predictive themes reaped from Study 2's grounded approach matched or were related to four of the six predictive factors found significant in study 1 (Disability Type, Severity of Condition, Visibility, and Social Class). Moreover, when exploring the predictive direction of these themes, they too matched the directions proposed in our initial hypotheses.

Unfortunately, like all scholarly work, our research was limited in a variety of ways. As already mentioned, our sample may be biased in recruiting higher than average numbers of people who self-identify as a person with a disability. Our sample is also biased because we conducted our survey over the internet. This most likely led to an over-representation of individuals with high socio-economic status. Lastly, our study was cross-sectional in nature, meaning we cannot infer causality from our results.

In the future, it would be interesting to conduct a longitudinal study to see how disability self-identification changes over time. It would also be exciting to go back into our dataset and explore different sub-samples of our participants. So much of our literature review spoke to intersecting identities, it would be nice to see how disability self-identification works for those who experience multiple minority statuses. Would we find the same predictions if we exclusively examined gay, African American men? What about middle-aged Deaf persons who are in committed relationships? The possibilities are seemingly endless.

To conclude, this study's methodologies, sample size, findings, and opportunities for future research make it a most excellent contribution to the fields of medicine and rehabilitative sciences, higher education, psychology, sociology, anthropology, disability studies, and community organizing.

APPENDICES

APPENDIX A

Copy of Survey Measure

[Consent Page]

Dear Participant,

Your opinions matter! A team of researchers from the University of Michigan are gathering information about people with a variety of impairments and conditions. We have developed a snapshot survey and look forward to your participation. Your input is very important to us.

Please Note: This survey is for People with Disabilities themselves, not caretakers of or service-providers for those with disabilities.

The survey should take no more than 5-10 MINUTES to complete. If you agree to be part of the survey, you will be asked to provide basic information about yourself and your condition. Your responses are very important to the success of this initiative, which we hope will benefit people with disabilities in many communities.

Your answers will be completely CONFIDENTIAL, and you will in no way be identified with them. There are occasional and infrequent reasons why people other than the researchers may need to see information you provide as part of the study. This includes organizations responsible for making sure the research is done safely and properly, including the University of Michigan or government offices. However, only combined data in the form of averages will be used in analyses, interpretation, reports, publications, or presentations. You will NEVER be identified in any report. The data you provide will be stored on password-protected computers that can only be accessed by members of the research team. The researchers will retain an electronic database of survey responses indefinitely for use in future research studies conducted by members of our lab. However, this database will not contain information that could identify you.

There are few if any foreseeable risks associated with this survey, and no direct benefit to you, although we hope our research will benefit people with disabilities across the United States. Your participation is completely voluntary, and you may skip any question at any time. Also, you may withdraw from the study by not completing it without any consequences. If you have questions about your rights as a research participant, or wish to obtain information, ask questions or discuss any concerns about this study with someone other than the researcher(s), please

contact the University of Michigan Health Sciences and Behavioral Sciences Institutional Review Board, 540 E Liberty St., Ste 202, Ann Arbor, MI 48104-2210, (734) 936-0933 [or toll free, (866) 936-0933], irbhsbs@umich.edu. By answering the survey questions, you indicate your voluntary agreement to participate in this research and have your answers included (anonymously) in the results.

If you have any questions about this survey research, please contact our research team at Rottenstein.Lab@umich.edu

By taking a few minutes to share your experiences as a person with a disability, you will be helping us a great deal!

Many Thanks,

Adena Rottenstein, M.S.
Principal Investigator
University of Michigan
adena@umich.edu

Lorraine Gutierrez, Ph.D.
Faculty Advisor
University of Michigan
lorraing@umich.edu
Phone: (734) 936-9124

Study ID: HUM00044918   IRB: Health Sciences and Behavioral Sciences   Date Approved: 3/15/2011

Begin Survey

[Survey Page 1]

These first five questions are open-ended, that is, please feel free to write as much or as little as you would like when you answer them. Thank you!

1. What are five attributes that best describe you, that is, what are five traits, dispositions, or other descriptive features that are characteristic of who you are?

      1. _____

      2. _____

      3. _____

      4. _____

      5. _____

2. Do you identify as a person with a disability? Why or why not?

3. What do you see as the most important part of a disability identity?

4. What do you see as the most important parts of disability culture?

5. What do you see as the biggest challenge facing people with disabilities today?

[Survey Page 2]

Thank you for your responses. This next section is multiple-choice, that is, we would like you to select the one option that best represents your answer.

1. How active are you in organizations with other people with disabilities?
    - ☐ Not at all active
    - ☐ Somewhat active
    - ☐ Highly active

59

2. How involved are you in disability advocacy / disability rights?
   - ☐ Not at all involved
   - ☐ Somewhat involved
   - ☐ Highly involved

3. Which of the following conditions do you experience? (You may select more than one).

- ☐ ADD/ADHD
- ☐ Agent Orange
- ☐ Alzheimer's
- ☐ Amputation
- ☐ Amyotrophic Lateral Sclerosis (ALS)
- ☐ Anxiety/Panic Disorder
- ☐ Arthritis
- ☐ Asthma/Emphysema/Other respiratory disease
- ☐ Autism/Asperger's
- ☐ Autoimmune Disorder
- ☐ Back Injury
- ☐ Bipolar Disorder/Manic-Depressive Disorder
- ☐ Blind/Visually Impaired
- ☐ Bone/Joint Disorder
- ☐ Brain Disorder
- ☐ Brain Injury/Traumatic Brain Injury (TBI)
- ☐ Cancer
- ☐ Cardiovascular Disorder
- ☐ Carpal Tunnel
- ☐ Cerebral Palsy
- ☐ Chemical Sensitivity
- ☐ Cognitive Impairment
- ☐ Deaf/Hearing Impairment
- ☐ Dementia
- ☐ Depression
- ☐ Developmental Disability
- ☐ Diabetes

- ☐ Dyscalculia/Other math disorder
- ☐ Dyslexia/Other reading disorder
- ☐ Dysphasia/Aphasia/Other language disorder
- ☐ Emotional Impairment
- ☐ Epilepsy/Seizure Disorder
- ☐ Fibromyalgia
- ☐ Heart Disease
- ☐ HIV/AIDS
- ☐ Hypertension
- ☐ Kidney Disease
- ☐ Learning Disability
- ☐ Morbid Obesity
- ☐ Multiple Sclerosis
- ☐ Muscular Dystrophy
- ☐ Musculoskeletal Disorder/Orthopedic Impairment
- ☐ Narcolepsy/Insomnia/Other Sleep Disorder
- ☐ Obsessive-Compulsive Disorder (OCD)
- ☐ Parkinson's Disease
- ☐ Post-Traumatic Stress Disorder (PTSD)
- ☐ Post-Polio Syndrome
- ☐ Pulmonary Disease
- ☐ Short Stature/Little Person
- ☐ Spina Bifida
- ☐ Spinal Cord Injury
- ☐ Stroke
- ☐ Substance Abuse
- ☐ Other (Please Specify):_____

4. If you selected more than one condition, which would you say is your primary condition?

   _____

5. At what age did you acquire your condition? (If you have more than one condition, please use the primary condition you listed in question 4 to answer this question).

- ☐ Born with my condition
- ☐ Between 1-9 years old
- ☐ Between 10-19 years old
- ☐ Between 20-29 years old
- ☐ Older than 30 years old

6. Because of the condition(s) you listed above, do you have difficulty with...

- Seeing (even if wearing glasses)?
  - ☐ No difficulty
  - ☐ Some difficulty
  - ☐ A lot of difficulty
  - ☐ Total Difficulty (I am unable to do this activity)

- Hearing (even if using hearing aids)?
  - ☐ No difficulty
  - ☐ Some difficulty
  - ☐ A lot of difficulty
  - ☐ Total Difficulty (I am unable to do this activity)

- Walking or climbing stairs?
  - ☐ No difficulty
  - ☐ Some difficulty
  - ☐ A lot of difficulty
  - ☐ Total Difficulty (I am unable to do this activity)

- Remembering or concentrating?
  - ☐ No difficulty
  - ☐ Some difficulty
  - ☐ A lot of difficulty
  - ☐ Total Difficulty (I am unable to do this activity)

- Self-care (such as washing or dressing)?
  - ☐ No difficulty
  - ☐ Some difficulty
  - ☐ A lot of difficulty
  - ☐ Total Difficulty (I am unable to do this activity)

- Communicating (understanding or being understood by others)?
  - ☐ No difficulty
  - ☐ Some difficulty
  - ☐ A lot of difficulty
  - ☐ Total Difficulty (I am unable to do this activity)

7. Which of the following labels is most accurate when describing you?
   - ☐ Disabled person
   - ☐ Person with a disability
   - ☐ Non-disabled person
   - ☐ Able-bodied person
   - ☐ Other (Please Specify): _____

8. Were you at any point during your elementary, middle, or high school education, on an Individualized Education Plan (IEP)?
   - ☐ Yes
   - ☐ No

9. Do you receive assistance/support from any of the following sources? (You may select more than one).
   - ☐ Supplemental Security Income (SSI)
   - ☐ Social Security Disability Insurance (SSDI)
   - ☐ Medicare
   - ☐ Medicaid
   - ☐ Other (Please Specify): _____

10. Unless I disclose it, my condition(s) is/are largely hidden to those around me.
    - ☐ Strongly Disagree
    - ☐ Disagree
    - ☐ Agree
    - ☐ Strongly Agree

11. You have indicated that your condition is largely hidden from others. How often do you disclose (tell others about) your condition?
    - ☐ Never
    - ☐ Rarely
    - ☐ Sometimes
    - ☐ Often
    - ☐ Always

[Survey Page 3]

Thank you again. This last page contains a mix of multiple-choice and open-ended questions. At the end of the section, we provide you with space to give us feedback about our survey. We welcome any comments or suggestions you may have.

1. What is your age?_____

2. What is your gender?
   - ☐ Male
   - ☐ Female
   - ☐ Transgender
   - ☐ Other (Please Specify): _____

3. What is your race/ethnicity?
   - ☐ Asian, Asian American, or Pacific Islander
   - ☐ Black, African, or African American
   - ☐ Latino/a, Hispanic or Hispanic American
   - ☐ Middle Eastern, Arab, or Arab American
   - ☐ Native American or Alaskan Native
   - ☐ White, European, or European American
   - ☐ Other (Please Specify): _____

4. How would you describe your sexual orientation?
   - ☐ Completely heterosexual
   - ☐ Mostly heterosexual
   - ☐ Bisexual
   - ☐ Mostly homosexual, lesbian, or gay
   - ☐ Completely homosexual, lesbian, or gay
   - ☐ Other (Please Specify): _____

5. What is your marital/partnership status?
   - ☐ Single
   - ☐ Dating / in a relationship
   - ☐ Married or partnered
   - ☐ Divorced, separated, or widowed

6. What is the highest level of education you have completed?
   - ☐ Less than High School
   - ☐ High School / GED
   - ☐ Some College
   - ☐ 2-year College Degree
   - ☐ 4-year College Degree
   - ☐ Masters Degree
   - ☐ Doctoral Degree
   - ☐ Professional Degree (JD, MD)

7. What is your current employment status?

☐ Full-time
☐ Part-time
☐ Unemployed Student
☐ Unemployed Worker
☐ Retired
☐ Other (Please Specify): _____

8. What is the approximate combined annual income of all members of your household?

☐ Under $15,000
☐ $15,000-$24,999
☐ $25,000-$34,999
☐ $35,000-$49,999
☐ $50,000-$74,999
☐ $75,000-$99,999
☐ $100,000-$249,000
☐ $250,000 or more

9. Which of the following best describes your beliefs?

☐ Christian
☐ Jewish
☐ Muslim
☐ Spiritual, but not religious
☐ Atheist/Agnostic
☐ Other (Please Specify): _____

10. In general, how do you characterize your political views?

☐ Very Liberal
☐ Mostly Liberal
☐ Neither Liberal nor Conservative
☐ Mostly Conservative
☐ Very Conservative
☐ Other (Please Specify): _____

11. What is your current citizenship status?

☐ U.S. Citizen
☐ Resident Alien
☐ Non-resident Alien
☐ Citizen of a Different Country (Please Specify): _____

12. How did you learn about our survey? If an organization you are affiliated with, (for example: the Ann Arbor Center for Independent Living (AACIL) or the American Association of People with Disabilities (AAPD), sent you an e-mail, please list the name of that organization.

_____

13. Would you be interested in learning about the results of this survey or participating in a future survey? If yes, please provide us with your name and e-mail address. If no, please skip to question 14. (Please note that I will not use your contact information for any other purpose than my research. Thanks!)

Name:_____

E-mail Address:_____

14. If you could write a question for a future survey sent to people with disabilities, what would it be? Please feel free to write anything that may be of interest to you.

_____

_____

15. Please feel free to use this space to provide us with any feedback you have about our survey. We welcome any comments or suggestions you may have.

_____

_____

[End of Survey]

Initial Contact E-mail

Dear [contact person for organization]

My name is Adena Rottenstein, and I am a disabled doctoral student at the University of Michigan who studies how people with disabilities view their identities and their experiences. As part of my research, I have created a brief (5 minute) online survey for people with disabilities, and I am writing to ask if it would be possible to pass along information about the survey to your organization's members in the hopes that they may take the time to complete it.

The survey itself received full approval from the university's IRB (ethical review board), and any participation by your organization's members would be completely anonymous. I also did my best to make sure the survey was sensitively written, hosted on an accessible website, and gave participants many opportunities to provide feedback.

The recruitment message I would like to send to your members is written at the bottom of this e-mail. If you are comfortable with this message being sent, what would you suggest as the best way to contact your members? For example, does your organization have a list-serve, message board, or twitter account?

Thank you very, very much for your time and consideration. Please do not hesitate to contact me if you have any questions or concerns.

Kind Regards,

~Adena

Adena Rottenstein, M.S.
Doctoral Candidate
Personality & Social Contexts
University of Michigan
3256 East Hall
530 Church Street
Ann Arbor, MI 48109
adena@umich.edu
http://www.psychologyofdisability.org

---- Start Recruitment Message ----

People with Disabilities [or a specific type of condition]. We Want Your Opinion!

Please take 5 minutes to fill out this brief survey. A team of researchers at the University of Michigan have developed a short "snapshot" survey of people with disabilities to ask them about their identities and their experiences.

Go to: http://tinyurl.com/RottensteinLab

Your input will help us to better understand how people with disabilities view their lives and the society in which they live. Together, these surveys may lead to positive change for people with disabilities in a number of different ways. We appreciate you taking the time to participate in this important research effort, and please feel free to pass along this information to anyone you think may be interested!

Please feel free to contact us with any questions or concerns at Rottenstein.Lab@umich.edu

You can also learn more about who we are and this project at the following website: http://www.psychologyofdisability.org

Thank you very much for your time and input!

~Adena Rottenstein, M.S.
Doctoral Candidate
University of Michigan
adena@umich.edu
http://www.psychologyofdisability.org

Lorraine Gutierrez, Ph.D.
Faculty Advisor
University of Michigan
lorraing@umich.edu
Phone: (734) 936-9124

---- End Recruitment Message -----

APPENDIX C

Final Contact List

Table C1

Final Contact List

Organization	Location	Website (If Available)
Ability Center of Defiance (Branch)	Ohio	
Ability1st	Florida	http://www.ability1st.info/
Abledata	National	http://abledata.com/
Alliance of People with disAbilities	Washington	
American Association on Health & Disability	National	http://www.aahd.us/page.php
American Council of the Blind	National	http://www.acb.org/
Asperger Syndrome Education Network	National	http://www.aspennj.org/
Association for Airline Passenger Rights	National	http://www.flyfriendlyskies.com/
Association of Centers for Independent Living in Washington	Washington	
Blue Ridge Independent Living Center	Virginia	
BrainLine	National	http://www.brainline.org/
Capital Area Center for Independent Living	Michigan	http://www.cacil.org/
Center for Independence (CID Satellite)	California	http://www.cidbelmont.org/
Center for Independence of the Disabled (CID)	California	http://www.CIDSanMateo.org/
Center for People with Disabilities	Colorado	http://www.cpwd-ilc.org/
Cerebral Palsy International Research Foundation	National	http://www.cpirf.org/

CIL of South Florida	Florida	http://www.soflacil.org/
CIL of South Jersey, Inc.	New Jersey	
Coalition of Organizations for Accessible Technology	National	http://www.coataccess.org/
Council on International Educational Exchange	National	http://www.ciee.org/
Disability Action Center NW (Satellite)	Idaho	http://www.dacnw.org/
Disability Travel and Recreation Resources	National	http://www.makoa.org/travel.htm
Disabled Power Lifting	National	http://disabledpowerlifting.org/
Eagle Mount	National	http://eaglemount.org/
Eastern Amputee Golf Association	National	http://eaga.org/
Florida Association of Centers for Independent Living	Florida	http://www.floridacils.org/
Impact CIL	Illinois	http://www.impactcil.org/index.html
Independence Now, Inc.	Maryland	http://www.innow.org/
Independent Living Resource Center, Inc. (ILRC)	California	http://www.ilrc-trico.org/home.html
Midstate Independent Living Consultants, Inc.	Wisconsin	
DRAIL: Disability Resource Agency for IL	California	http://www.drail.org/
Muscular Dystrophy Campaign	National	http://www.muscular-dystrophy.org/
National Adult Day Services Association	National	http://www.nadsa.org
National Amputation Foundation	National	http://www.nationalamputation.org/
National Federation of the Blind	National	http://www.nfb.org/
New Vistas	New Mexico	http://www.newvistas.org/
Placer Independent Resource Services, Inc. (PIRS)	California	
Reflex Sympathetic Dystrophy Syndrome Association	National	http://www.rsds.org
Resource Center for Accessible Living, Inc. (RCAL)	New York	
Resources for Independence (Satellite)	California	http://www.ricv.org/
Resources for Independence, Central Valley	California	http://www.ricv.org/
Self Reliance, Inc.	Florida	http://www.self-reliance.org/

Services Maximizing IL & Empowerment (SMILE)	Arizona	
SILC Arizona	Arizona	http://www.azsilc.org/
SILC Arkansas	Arkansas	http://www.ar-silc.org/
SILC California	California	http://www.calsilc.org/
SILC Georgia	Georgia	http://www.silcga.org/
SILC Iowa	Iowa	http://www.iowasilc.org/
SILC Maine	Maine	http://www.mainesilc.org/
SILC Maryland	Maryland	http://www.mdsilc.org/
SILC Michigan	Michigan	http://www.misilc.org/
SILC Nebraska	Nebraska	http://www.nesilc.org/
SILC New Jersey	New Jersey	http://www.njsilc.org/
SILC New Mexico	New Mexico	http://www.nmsilc.org/
SILC North Carolina	North Carolina	http://www.ncsilc.org/
SILC IL Program	Nevada	
Silicon Valley ILC (SVILC Satellite)	California	http://www.svilc.org/
Southwest Center for Independence	Colorado	http://www.swcidur.org/
The Disability and Business Technical Assistance Center	National	http://www.dbtac.vcu.edu
The Freedom Center for Independent Living (FCIL)	Delaware	http://www.fcilde.org/
The Illinois Network of Centers for Independent Living	Illinois	http://www.incil.org/
The Independent Living Center of Eastern Indiana	Indiana	http://www.ilcein.org/
United Cerebral Palsy Association	National	http://ww.ucp.org/
WebAIM	National	http://webaim.org/
Western NY Independent Living, Inc. (WNYIL)	New York	
World Team Sports	National	http://worldteamsports.org/

Frequencies of Different Primary Disability Types

Table D1

Frequencies of Different Primary Disability Types

Code	Condition	Frequency	Percent
1	ADD/ADHD	32	1.2
2	Agent Orange	0	0.0
3	Alzheimer's	0	0.0
4	Amputation	27	1.0
5	Amyotrophic Lateral Sclerosis (ALS)	8	0.3
6	Anxiety/Panic Disorder	19	0.7
7	Arthritis	71	2.6
8	Asthma/Emphysema/Other respiratory disease	20	0.7
9	Autism/Asperger's	47	1.7
10	Autoimmune Disorder	25	0.9
11	Back Injury	32	1.2
12	Bipolar Disorder/Manic-Depressive Disorder	45	1.6
13	Blind/Visually Impaired	205	7.4
14	Bone/Joint Disorder	29	1.0
15	Brain Disorder	5	0.2
16	Brain Injury/Traumatic Brain Injury (TBI)	84	3.0
17	Cancer	15	0.5
18	Cardiovascular Disorder	0	0.0
19	Carpal Tunnel	0	0.0

20	Cerebral Palsy	148	5.4
21	Chemical Sensitivity	18	0.7
22	Cognitive Impairment	9	0.3
23	Deaf/Hearing Impairment	174	6.3
24	Dementia	0	0.0
25	Depression	68	2.5
26	Developmental Disability	30	1.1
27	Diabetes	46	1.7
28	Dyscalculia/Other math disorder	2	0.1
29	Dyslexia/Other reading disorder	22	0.8
30	Dysphasia/Aphasia/Other language disorder	0	0.0
31	Emotional Impairment	3	0.1
32	Epilepsy/Seizure Disorder	28	1.0
33	Fibromyalgia	20	0.7
34	Heart Disease	7	0.3
35	HIV/AIDS	3	0.1
36	Hypertension	0	0.0
37	Kidney Disease	0	0.0
38	Learning Disability	25	0.9
39	Mental Health Condition	31	1.1
40	Morbid Obesity	7	0.3
42	Multiple Sclerosis	96	3.5
43	Muscular Dystrophy	117	4.2
44	Musculoskeletal Disorder/Orthopedic Impairment	51	1.8
45	Narcolepsy/Insomnia/Other Sleep Disorder	7	0.3
46	Obsessive-Compulsive Disorder (OCD)	5	0.2
47	Parkinson's Disease	0	0.0
48	Post-Traumatic Stress Disorder (PTSD)	32	1.2
49	Post-Polio Syndrome	87	3.1

50	Pulmonary Disease	3	0.1
51	Short Stature/Little Person	5	0.2
52	Spina Bifida	41	1.5
53	Spinal Cord Injury	258	9.3
54	Stroke	38	1.4
55	Substance Abuse	0	0.0
56	Reflex Sympathetic Dystrophy Syndrome (RSDS) or Complex Regional Pain Syndrome (CRPS)	72	2.6
57	Paralysis/Parapalegia	36	1.3
58	Charcot-Marie-Tooth Disease (CMT)	10	0.4
59	Ataxia	9	0.3
60	Lupus / Systemic Lupus Erythematosus (SLE)	11	0.4
61	Ehlers-Danlos Syndrome	9	0.3
62	Tranverse Myelitis	13	0.5
63	Neuropathy	9	0.3
64	Chronic Pain	8	0.3
65	Spinal Stenosis	0	0.0
66	Osteogenisis Imperfecta	0	0.0
67	Fatigue/Chronic Fatigue Syndrome	0	0.0
68	Migraines	5	0.2
69	Schizoaffective Disorder/Schizophrenia	7	0.3
70	Neurological Disorder/Condition	7	0.3
71	Other	197	7.1

Note. It appears that the number 41 was inadvertently missed in the coding of disability types; thus you will see that our code numbers skip from 40 to 42 in this table.

Primary Disability Type Arranged by ICD-10 Codes

Table E1

Mental Functions/Structure of the Nervous System

Condition	ICD-10 ID	Definition
ADD/ADHD	F90.0	"ADHD is a problem with inattentiveness, over-activity, impulsivity, or a combination. For these problems to be diagnosed as ADHD, they must be out of the normal range for a child's age and development."
Alzheimer's Disease	G30	"Dementia is a loss of brain function that occurs with certain diseases. Alzheimer's disease (AD) is one form of dementia that gradually gets worse over time. It affects memory, thinking, and behavior."
Anxiety/Panic Disorder	F41	"Generalized anxiety disorder (GAD) is a pattern of constant worry and anxiety over many different activities and events."
Autism/Asperger Syndrome	F84, F84.5	"Autism is a developmental disorder that appears in the first 3 years of life, and affects the brain's normal development of social and communication skills." "Asperger syndrome is often considered a high functioning form of autism. It can lead to difficulty interacting socially, repeat behaviors, and clumsiness."

Bipolar Disorder/Manic-Depressive Disorder	F31	"Bipolar disorder is a condition in which people go back and forth between periods of a very good or irritable mood and depression. The 'mood swings' between mania and depression can be very quick."
Brain Disorder	G93	n/a
Brain Injury/Traumatic Brain Injury	S06	"Traumatic brain injury (an injury to the brain that occurs as a result of a direct impact, such as may occur after road traffic accidents and falls) is a major cause of death and long-term disability worldwide."
Cognitive Impairment	R41.8	n/a
Developmental Disability including Mental Retardation & Down's Syndrome	F70-F79, Q90	"Down syndrome is a genetic condition in which a person has 47 chromosomes instead of the usual 46."
Dyscalculia/Other math disorder	F81.2, R48.8	"Mathematics disorder is a condition in which a child's math ability is far below normal for their age, intelligence, and education."
Dyslexia/Other reading disorder	R48.0	"Developmental reading disorder, also called dyslexia, is a reading disability that occurs when the brain does not properly recognize and process certain symbols."
Emotional Impairment	F60.3	n/a
Fatigue/Chronic Fatigue Syndrome, CFIDS	F48.0	"Fatigue is a feeling of weariness, tiredness, or lack of energy." "Chronic fatigue syndrome refers to severe, continued tiredness that is not relieved by rest and is not directly caused by other medical conditions."
Learning Disability	F81.9	n/a
Mental Health Condition		n/a

Narcolepsy/Insomnia/Other Sleep Disorder	G47	"Narcolepsy is a sleep disorder that causes excessive sleepiness and frequent daytime sleep attacks." "Insomnia is trouble falling asleep or staying asleep through the night. Episodes may come and go (episodic), last up to 3 weeks (short-term), or be long-lasting (chronic)."
Obsessive-Compulsive Disorder (OCD)	F42	"Obsessive-compulsive disorder is an anxiety disorder in which people have unwanted and repeated thoughts, feelings, ideas, sensations (obsessions), or behaviors that make them feel driven to do something (compulsions).Often the person carries out the behaviors to get rid of the obsessive thoughts, but this only provides temporary relief."
Post-Traumatic Stress Disorder (PTSD)	F43.1	"Post-traumatic stress disorder is a type of anxiety disorder. It can occur after you've seen or experienced a traumatic event that involved the threat of injury or death."
Stroke	I60-I69	"A stroke happens when blood flow to a part of the brain stops. A stroke is sometimes called a 'brain attack.'"
Substance Abuse	F10-F19	"Substance abuse is the use of illegal drugs or the misuse of prescription or over-the-counter drugs for at least a year with negative consequences."
Migraines	G43	"A migraine is a common type of headache that may occur with symptoms such as nausea, vomiting, or sensitivity to light. In many people, a throbbing pain is felt only on one side of the head."
Schizophrenia/Schizoaffective disorder	F20, F25	"Schizophrenia is a serious mental illness which can cause hallucinations, fixed false beliefs (delusions) and/or apathy, slowing and less movement or thought."

Table E2

Sensory Functions/Structure of the Eye & Ear

Condition	ICD-10 ID	Definition
Blind/Visually Impaired	H53-H54	"Blindness is a lack of vision. It may also refer to a loss of vision that cannot be corrected with glasses or contact lenses. Vision loss refers to the partial or complete loss of vision. This vision loss may happen suddenly or over a period of time."
Chemical Sensitivity	n/a	n/a
Deaf/Hard-of-Hearing	n/a	"Hearing loss is being partly or totally unable to hear sound in one or both ears."
Complex Regional Pain Syndrome (CRPS)	n/a	"Complex regional pain syndrome (CRPS) is a chronic pain condition that can affect any area of the body, but often affects an arm or a leg."
Chronic Pain	R52.1,R52.2	n/a

Table E3

Voice & Speech Functions

Condition	ICD-10 ID	Definition
Dysphasia/Aphasia/Other language disorder	R47-R49	n/a

Table E4

Functions/Structure of the Cardiovascular, Haematological, Immunological, and Respiratory Systems

Condition	ICD-10 ID	Definition
Asthma/Emphysema/Other respiratory disease	n/a	"Asthma is a disorder that causes the airways of the lungs to swell and narrow, leading to wheezing, shortness of breath, chest tightness, and coughing. Emphysema involves destruction of the lungs over time."
Autoimmune Disorder	n/a	"An autoimmune disorder is a condition that occurs when the immune system mistakenly attacks and destroys healthy body tissue. There are more than 80 different types of autoimmune disorders."
Cardiovascular Disorder	I51.6, I25.0	Cardiovascular Disorder and Heart Disease are basically synonms.
Heart Disease	n/a	"Heart disease is any disorder that affects the heart's ability to function normally."
HIV/AIDS	B20-B24	"HIV infection is a condition caused by the human immunodeficiency virus (HIV). The condition gradually destroys the immune system, which makes it harder for the body to fight infections. AIDS (acquired immune deficiency syndrome) is the final stage of HIV disease, which causes severe damage to the immune system."
Hypertension	I10	"High blood pressure (hypertension) is defined as a systolic blood pressure of 140 mmHg or more or a diastolic blood pressure of 90 mmHg or more."

| Pulmonary Disease | n/a | "Chronic obstructive pulmonary disease (COPD) is one of the most common lung diseases. It makes it difficult to breathe. There are two main forms of COPD:
• Chronic bronchitis, which involves a long-term cough with mucus
• Emphysema, which involves destruction of the lungs over time
Most people with COPD have a combination of both conditions." |

Table E5

Functions of Digestive, Metabolic, & Endocrine Systems

Condition	ICD-10 ID	Definition
Diabetes	E10-E14	"Diabetes is defined as high sugar levels in the blood. There are two forms of the disease. In type 1 diabetes, the body does not produce enough insulin. In type 2 diabetes, the body becomes less responsive to insulin."
Morbid Obesity	E66.8	n/a

Table E6

Genitourinary and Reproductive Functions

Condition	ICD-10 ID	Definition
Kidney Disease	n/a	"Nephropathy is damage, disease, or other problems with the kidney."

Table E7

Neuromusculoskeletal and Movement-Related Functions & Structures

Condition	ICD-10 ID	Definition
Agent Orange	n/a	n/a
Amputee: Congenital & Acquired	n/a	n/a
Arthritis		"Arthritis is inflammation of one or more joints."
Back Injury	n/a	n/a
Bone/Joint Disorder	M20-M25,M80-M94	n/a
Charcot-Marie-Tooth Disease (CMT)	G60.0	"Charcot-Marie-Tooth disease is a broad spectrum of different types of inherited peripheral neuropathy. The most common types affect motor and sensory nerves and cause muscle wasting and sensory loss."
Carpal Tunnel	G56	"Carpal tunnel syndrome (CTS) is a condition where the median nerve, one of two main nerves to the hand, is compressed at the wrist, leading to pain in the hand, wrist and sometimes arm, and numbness and tingling especially in the thumb, index and middle finger."
Cerebral Palsy	G80	"Cerebral palsy (CP) is a non-progressive lifelong condition resulting from damage to the newborn brain. Most infants have spasms (spasticity) affecting at least one leg that prevents normal movement. It can cause muscle contractures and deformities and the affected muscles do not grow as rapidly as neighbouring bone and soft tissue."

Epilepsy/Seizure Disorder	G40-G47	"Epilepsy is a disorder where recurrent seizures are caused by abnormal electrical discharges from the brain."
Ehlers Danlos Syndrome	Q79.6	"Ehlers-Danlos syndrome is a group of inherited disorders marked by extremely loose joints, hyperelastic skin that bruises easily, and easily damaged blood vessels."
Fibromyalgia	M79.7	"Fibromyalgia is a common syndrome in which a person has long-term, body-wide pain and tenderness in the joints, muscles, tendons, and other soft tissues. Fibromyalgia has also been linked to fatigue, sleep problems, headaches, depression, and anxiety."
Multiple Sclerosis	G35	"Multiple sclerosis is an illness in which the myelin sheaths around the nerves of the brain and spinal cord are damaged, affecting the ability of nerve cells to communicate with each other."
Muscular Dystrophy	G71.0	"Muscular dystrophy is a group of inherited disorders that involve muscle weakness and loss of muscle tissue, which get worse over time."
Musculoskeletal Disorder/Orthopedic Impairment	n/a	n/a
Parkinson's Disease	G20	"Parkinson's disease is a progressive disabling neurodegenerative disease. Symptoms can include problems with movement such as being stiff, slow, and shaky, and sometimes non‑motor symptoms such as problems with communication, mood, vision, and problem solving abilities."

Post-Polio Syndrome	n/a	n/a
Reflex Sympathetic Dystrophy Syndrome (RSDS)	M89.0	This is what Complex Regional Pain Syndrome used to be called.
Short Stature/Little Person	n/a	"Short stature refers to any person who is significantly below the average height for a person of the same age and sex. The term often refers to children or adolescents who are significantly below the average height of their peers."
Spina Bifida	Q05	"Spina bifida refers to any birth defect involving incomplete closure of the spine."
Spinal Cord Injury	n/a	"Spinal cord trauma is damage to the spinal cord. It may result from direct injury to the cord itself or indirectly from disease of the surrounding bones, tissues, or blood vessels."
Paraplegia/Paralysis (all forms)	n/a	Muscle function loss is when a muscle doesn't work or move normally. The medical term for complete loss of muscle function is paralysis.
Ataxia (all forms)	R27.0, G11	"Uncoordinated movement is a muscle control problem or an inability to finely coordinate movements. This condition is called ataxia. It leads to a jerky, unsteady, to-and-fro motion of the middle of the body (trunk) and an unsteady gait (walking style)."
Transverse Myelitis	n/a	n/a

Neuropathy (all forms)	n/a	n/a
Spinal Stenosis	M48.0	"Spinal stenosis is narrowing of the spinal column that causes pressure on the spinal cord, or narrowing of the openings (called neural foramina) where spinal nerves leave the spinal column."
Osteogenesis Imperfecta	n/a	"Osteogenesis imperfecta is an inherited disorder of type I collagen characterized by low bone mass, bone fragility, and fractures with minimal or no trauma."
Neurological Condition/Disorder	n/a	n/a

Table E8

Functions of the Skin and Related Structures

Condition	ICD-10 ID	Definition
Lupus/Systemic Lupus Erythematosus (SLE)	L93,M32	"Systemic lupus erythematosus (SLE) is a long-term <u>autoimmune disorder</u> that may affect the skin, joints, kidneys, brain, and other organs."

Significant Predictive Factors of Study 1

Table F1

Significant Predictive Factors of Study 1

Factor	Variable	β	*SE*	Wald	Odds Ratio
	Disability Type Categories	0.03	0.20	0.02	1.03
	Mental Functions/Structure of the Nervous System	0.04	0.20	0.05	1.04
	Sensory Functions/Structure of Eye & Ear	-22.06	2.97[b1]	0.00	0.00
Disability Type	Voice & Speech functions	-0.60	0.31	3.80	0.55*
	Functions/Structure of the Cardiovascular, Haematological, Immunological, & Respiratory Systems	-0.29	0.35	0.69	0.75
	Functions of Digestive, Metabolic, Endocrine Systems	20.35	5.42[b2]	0.00	8.20[b3]
	Genitourinary and Reproductive Functions	0.40	0.18	4.75	1.49*

	Neuromusculoskeletal and Movement-related Functions & Structures	1.34	1.07	1.58	3.83
	Functions of the Skin and Related Structures				N/A
	Other	0.86	0.17	26.20	2.35
	Constant	0.03	0.20	0.02	1.03
	Difficulty Walking				
	No difficulty	-0.72	0.13	31.38	0.49***
Severity of Condition	Some difficulty	-0.45	0.14	10.39	0.64***
	A lot of difficulty	-0.58	0.14	0.18	0.94
	Total difficulty – I am unable to do this activity.				N/A
	Constant	1.36	0.10	188.31	3.91
	Difficulty Self-Care				
	No difficulty	-0.93	0.22	17.77	0.39***
Severity of Condition	Some difficulty	-0.56	0.23	5.85	0.57*
	A lot of difficulty	0.07	0.28	0.05	1.07
	Total difficulty – I am unable to do this activity.				N/A

	Constant	1.73	0.21	65.71	5.62
Severity of Condition	Condition Total				
	Number of conditions 1-34	0.08	0.02	25.52	1.08***
	Constant	0.74	0.07	111.95	2.11
Visibility	Hidden vs. Visible				
	Strongly Disagree	0.86	0.13	44.58	2.36***
	Disagree	0.50	0.14	12.01	1.65**
	Agree	0.33	0.13	6.29	1.39*
	Strongly Agree				N/A
	Constant	0.55	0.10	30.11	1.73
Visibility	Disclosure				
	Never	-1.66	0.58	8.37	0.19**
	Rarely	-1.46	0.37	16.02	0.23***
	Sometimes	-1.07	0.34	9.84	0.34**
	Often	-0.52	0.35	2.17	0.60
	Always				N/A
	Constant	1.66	0.33	28.56	5.27
Social Class	Employment Status				
	Full-time	-0.20	0.13	2.36	0.82

	Part-time	-0.13	0.16	0.68	0.88
	Unemployed Student	0.65	0.24	7.56	1.92**
	Unemployed Worker	0.32	0.20	2.65	1.38
	Retired	-0.11	0.16	0.47	0.90
	Other				N/A
	Constant	1.05	0.11	98.96	2.86
	Income				
	Under $15,000	0.67	0.32	4.42	1.95*
	$15,000-$24,999	0.49	0.32	2.38	1.64
	$25,000-$34,999	0.64	0.33	3.81	1.90*
Social Class	$35,000-$49,999	0.45	0.32	1.93	1.56
	$50,000-$74,999	0.36	0.31	1.34	1.44
	$75,000-$99,999	0.30	0.32	0.87	1.35
	$100,000-$249,000	0.82	0.32	0.07	1.09
	$250,000 or more				N/A
	Constant	0.61	0.29	4.28	0.04
	Sexual Orientation				
Sexual Orientation	Completely heterosexual	-0.42	0.30	1.98	0.66
	Mostly heterosexual	0.27	0.35	0.56	1.30
	Bisexual	0.70	0.39	0.03	1.07

	Mostly homosexual, lesbian, or gay	0.12	0.47	0.07	1.13
	Completely homosexual, lesbian, or gay	0.57	0.41	1.92	1.76
	Other				N/A
	Constant	1.32	0.29	20.53	3.73
Age	Age				
	18-29 years	1.02	1.42	0.51	2.77
	30-39 years	0.96	1.42	0.46	2.61
	40-49 years	0.57	1.42	0.16	1.76
	50-59 years	0.79	1.42	0.31	2.19
	60-69 years	0.53	1.42	0.14	1.70
	70-79 years	0.40	1.43	0.08	1.49
	80-89 years	0.18	1.54	0.01	1.20
	90-94 years				N/A
	Constant	0.00	1.41	0.00	1.00

Notes: (a) Reference levels used for categorical predictive variables with more than two levels are indicated by an N/A in the Odds Ratio column (b)Because of the relatively low number of participants in some of the Disability Type Categories, there were a few unusually high numbers. Due to spacing concerns, we opted to abbreviate those numbers, and put their full values here: $B1 = 40192.97$, $B2 = 23205.4$, $B3 = 686576808.20$

$*p < .05.$ $**p < .01.$ $***p < .001.$

Qualitative Themes/Codes

Theme/Code 1: Disability Type.

- Sub-Code 1.1 - **Autism Spectrum**
    a. Definition: This code indicates that the individual has mentioned autism or a disorder that lies on the spectrum.
    b. Example: *I do, I have Asperger Syndrome. I think a little different then other people, the world is more black and white to me.*
- Sub-Code 1.2 - **Blind**
    a. Definition: This code indicates that the individual has a seeing impairment.
    b. Example: *This depends upon the context. If it is meaningful that I identify my blindness, I discuss this in practical terms. If it matters not, in many situations on-line it really does not matter, I may not self-identify.*
- Sub-Code 1.3- **Brain Injury**
    a. Definition: This code indicates that the individual has mentioned a disabling brain injury, a.k.a. TBI.
    b. Example: *Yes, with severe TBI it's hard not to know my limitations*
- Sub-Code 1.4 -**Cancer**
    a. Definition: This code indicates that the individual has cancer.
    b. Example: *Yes, I have a brain tumor that causes seizures*.
- Sub-Code 1.5 - **Deaf**
    a. Definition: This code indicates that the individual has mentioned a hearing impairment.
    b. Example: *No--I am Deaf and do not consider myself a person with a disability. I view the rest of the world as missing out on an opportunity to learn another language and culture.*
- Sub-Code 1.6 - **Environment**
    a. Definition: This code indicates that the individual has a disability which makes them sensitive to the environment, such as smells or sounds.
    b. Example: *Yes, because I am forced to be aware 24/7 of contaminants in air, food, & water.*

- Sub-Code 1.7 -**Learning Disability**
    a. Definition: This code indicates that the individual has a learning disability.
    b. Example: *No, I have a learning disability which I have overcome so it does not affect me greatly.*
- Sub-Code 1.8 - **Mute**
    a. Definition: This code indicates that the individual is unable or experiences great difficulty speaking aloud.
    b. Example: *No, I can do anything except cant hear and speak. I always considered myself as invisible disability. People looked at me as normal person until they talked to me and realized that I am profoundly Deaf.*
- Sub-Code 1.9 - **Physical**
    a. Definition: This code indicates that the individual has a physical disability, including paralysis and amputations.
    b. Example: *Yes. I'm in a wheelchair, undergoing slow paralysis below the waist. I suffer from Degenerative Disk Disease from T11 to L5.*
    c. Physical Sub-code
        i. Sub-Code 1.9.1 - **Mobility**
        ii. Definition: This code indicates that the individual experiences impaired mobility.
        iii. Example: *Yes. I have difficulty walking, as well as other difficulties in day to day functioning caused by U.C.*
- Sub-Code 1.10 -**Psychological**
    a. Definition: This code indicates that the individual has mentioned a psychological disability.
    b. Example: *Yes, I have mental illness, and I am open about this condition.*
    c. Psychological Sub-codes
- Sub-Code 1.11 -**Cognitive**
    a. Definition: This code indicates that the individual has mentioned a cognitive disability.
    b. Example: *No. I have a cognitive disability and I can pass - therefore, why would I share that I have a disability and suffer stigma, segregation and other accompanying negative things associated with identifying as having a disability.*
- Sub-Code 1.12 -**Psychiatric**
    a. Definition: This code indicates that the individual has mentioned a psychiatric disability: depression, anxiety, schizophrenia, bipolar, amnesia, etc.
    b. Example: *Yes. I have Major Depressive Disorder with frequest major depressive episodes that affect my ability to live a full life and perform my work duties.*

Theme/Code 2: Difficulty and Limitations.

- Sub-code 2.1: **Diff Academic**
    a. Definition: This code is for those who experience difficulty in school.
    b. Example: *Yes, because I have problems with math, spelling and speaking .*
- Sub-code 2.2: **Diff ADL**
    a. Definition: This code is for those who experience difficulty to performing activities of daily living; this includes acts that involve self-care, such as eating or hygiene practices.
    b. Example: *Yes. It affects every aspect of my life, every day.*
- Sub-code 2.3: **Diff Communication and Social Life**
    a. Definition: This code is for those who experience difficulty communicating to others and/or has a small social life as a result of their disability.
    b. Example: *Yes. Mood Disorder that interferes with daily functioning, which results in periods of disrupted productivity and strained interpersonal relationships.*

Theme/Code 3: Assistive Technology.

- Sub-code 3.1: **AT Communication**
    a. Definition: This code indicates the individual uses a hearing aid, CART services, cochlear implants, or any other device to help them hear what others are communicating.
    b. Example: *Yes. Why? Because it took 2 seperate adaptive devices and or software(s) just so I can answer your question. My guide dog also gives it away.*
- Sub-code 3.2: **AT Mobility**
    a. Definition: This code indicates that the individual uses a wheel chair, walker, walking stick, or any other device to help them move about.
    b. Example: *I have a visual disability. (wheelchair user) My wheelchair came very close to being a CASKET.   I still have a fun filled life, and my child is grateful that his mom is still alive.*
- Sub-code 3.3: **Service Dog**
    a. Definition: This code indicates that the individual has a service dog for any purpose, be it for navigation or psychiatric services.
    b. Example: *Yes. I am legally blind and use a guide dog. Even in circumstances where it might not be advantageous to identify myself as having a disability, it is nonetheless necessary in face-to-face settings.*
- Sub-code 3.4: **White Cane**
    a. Definition: This code indicates that the individual uses a white cane (for people with visual impairments).

b. Example: *Yes, I use a white cane so I don't have a choice there. Via phone or internet, I identify as a PWD when I find it necessary to do so; i.e. when requesting an accomodation. Depends on the situation.*

Theme/Code 4: Visibility.

- Sub-code 4.1: **It is Hidden**
    a. Definition: This code indicates that the individual mentions that people cannot see, or notice, their disability.
    b. Example: *Yes, I have several "disabilities" some of which are "hidden". I identify because I often need a reasonable accommodation*
- Sub-code 4.2: **It is Visible**
    a. Definition: This code indicates that the individual mentions that their disability can be seen or noticed by others.
    b. Example: *Yes. Usually its the first thing people notice. I usually don't tell people online that I'm disabled unless I'm telling them a lot about myself.*

Theme/Code 5: Feelings.

- Sub-code 5.1: **Negative**
    a. Definition: This code is for those who mention specific feelings due to their disability that are negative (sadness, frustration, etc.)
    b. Example:*My view is "We are warriors, keep your apologies" and I hate having to accomodate to this chronic, unstable condition. No. It came late in life & I resent the impact of the disability. I am afraid that if I identify as a disabled person, it will run my life.*
- Sub-code 5.2: **Positive**
    a. Definition: This code is for those who mention specific feelings due to their disability that are positive (happy, joy, etc.).
    b. Example: *yes, with pride. it is a piece of who I am, an attribute. A part of me that has made me the person I am.*

*Theme/Code 6: Stigma and Label.*No sub codes.

*Theme/Code 7: Age or Year.*No sub codes.

*Theme/Code 8: Secondary.*No sub codes.

Theme/Code 9: Advocacy. No sub codes.

Theme/Code 10: Shaped. No sub codes.

Theme/Code 11: Symptoms.

- Sub-code 11.1: **Fatigue**
    a. Definition: This code indicates that the individual mentions fatigue.
    b. Example: *Yes. / Living with pain and fatigue that makes it difficult to walk, sit, stand, or lay in one position for very long can take a hefty physical and mental toll.*
- Sub-code 11.2: **Pain**
    a. Definition: This code is for those who experience pain.
    b. Example: *Only when my disability keeps me from doing something I want to do. And on days when there is too much discomfort/pain etc.*

Theme/Code 12: Employment.

- Sub-code 12.1: **Employ Negative**
    a. Definition: This code indicates that the individual indicated their disability negatively affects their job or employment status.
    b. Example: *I am disabled. I can no longer do the job I used to do. I am not physically able to do my job anymore.*

Theme/Code 13: Situational. No sub codes.

*Theme/Code 14: Primary.*No sub codes.

*Theme/Code 15: Accommodations.*No sub codes.

*Theme/Code 16: Treatment.*No sub codes.

Theme/Code 17: Overcome. No sub codes.

Theme/Code 18: Adapt. No sub codes.

Theme/Code 19: Entire Life. No sub codes.

Theme/Code 20: Community.
- Sub-code 20.1: **I belong**
    a. Definition: This code indicates that the individual identifies as a part of a disability community--either it is local, or the community at large.
    b. Example: *Yes, because growing up with my disability, facing discrimination, and my connections with the disability community have all significantly impacted the person I've become.*
- Sub-code 20.2: **I don't belong**
    a. Definition: This code indicates that the individual does not identify as a Spart of the disability community.
    b. Example: *I don't feel that I am part of the greater community but I do have the disability of major depression.*

- *Theme/Code 21: Dependent.*No sub codes.

- *Theme/Code 22: Chronic.*No sub codes.

- *Theme/Code 23: Diagnosis.* No sub codes.

- *Theme/Code 24: Different.*No sub codes.

- *Theme/Code 25: Accident.*No sub codes.

- *Theme/Code 26: Independent.* No sub codes.

- *Theme/Code 27: Social Benefits.* No sub codes.

- *Theme/Code 28: Everybody's Disabled.* No sub codes.

APPENDIX H

Univariate Logistic Regressions for Study 2

Table H1

Univariate Logistic Regressions for Study 2

Variable Number	Variable of Interest	Nagelkerke R-Square	Reached .01 Cutoff (Topmost Predictor)
1	Accident	0.002	
2	Accommodations	0.021	X
3	Adapt	0.088	X
4	Advocacy	0.005	
5	Age or Year	0.000	
6	Assistive Technology	0.006	
7	A.T. Communication	0.001	
8	A.T. Mobility	0.005	
9	Service Dog	0.000	
10	White Cane	0.000	
11	Chronic	0.007	
12	Community	0.002	
13	I Belong	0.006	
14	I Don't Belong	0.001	
15	Dependent	0.005	
16	Diagnosis	0.001	
17	Different	0.000	
18	Difficulty and Limitations	0.009	
19	Difficulty Academia	0.003	
20	Difficulty in Communication and Social Life	0.003	
21	Disability Type	0.012	X
22	Autism Spectrum	0.000	

23	Blind	0.003	
24	Brain Injury	0.001	
25	Cancer	0.000	
26	Deaf	0.000	
27	Environment	0.000	
28	Learning Disability	0.001	
29	Mute	0.012	X
30	Physical	0.016	X
31	Mobility	0.005	
32	Psychological	0.000	
33	Cognitive	0.000	
34	Psychiatric	0.000	
35	Employment	0.000	
36	Employment- Negative	0.001	
37	Entire Life	0.005	
38	Everybody's Disabled	0.006	
39	Feelings	0.007	
40	Negative	0.000	
41	Positive	0.004	
42	Independent	0.002	
43	Overcome	0.017	X
44	Primary	0.020	X
45	Secondary	0.004	
46	Shaped	0.017	X
47	Situational	0.109	X
48	Social Benefits	0.001	
49	Stigma and Label	0.007	
50	Symptoms	0.001	
51	Fatigue	0.001	
52	Pain	0.000	
53	Treatment	0.001	
54	Visibility	0.001	

| 55 | It is Hidden | 0.016 | X |
| 56 | It is Visible | 0.012 | X |

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