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The Role of Disability Self-Concept in Adaptation to Congenital or Acquired Disability

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### Abstract

**Purpose/Objective:** Current theories of adaptation to disability do not address differences in adaptation to congenital compared to acquired disability. Although people with congenital disabilities are generally assumed to be better adapted than people with acquired disabilities, few studies have tested this, and even fewer have attempted to explain the mechanisms behind these differences. This study tested the proposition that whether a disability is congenital or acquired plays an important role in the development of the disability self-concept (consisting of disability identity and disability self-efficacy), which in turn, affects satisfaction with life. It was predicted that disability self-concept would be better developed among people with congenital, compared to acquired disabilities, predicting greater satisfaction with life in those with acquired conditions.

**Research Method/Design:** 226 participants with congenital and acquired mobility disabilities completed a cross-sectional online questionnaire measuring satisfaction with life, self-esteem, disability identity, disability self-efficacy, and demographic information. **Results:** Self-esteem, disability identity, disability self-efficacy, and income were significant predictors of satisfaction with life. Congenital onset predicted higher satisfaction with life; disability identity and disability self-efficacy, but not self-esteem, partially mediated the relationship.

**Conclusions/Implications:** Findings highlight the distinction between adaptation to congenital vs. acquired disability and the importance of disability self-concept, which are under-researched constructs. Results suggest that rather than attempting to “normalize” individuals with disabilities, healthcare professionals should foster their disability self-concept. Possible ways to improve disability self-concept are discussed, such as involvement in the disability community and disability pride.

*Keywords:* mobility disability, self-concept, disability identity, disability self-efficacy,

satisfaction with life

## The Role of Disability Self-Concept in Adaptation to Congenital or Acquired Disability

### **Impact Section**

- Extant models of adaptation to disability focus on acquired disability and do not describe the experience of people with congenital disability. This study is among the first to demonstrate that people with congenital disability are better adapted than those with acquired, and to identify mechanisms behind differences in adaptation between these two types of disability.
- This is among the first quantitative studies to support the proposition by social psychology and disability studies scholars that a sense of disability identity benefits satisfaction with life.
- Results suggest that rather than attempting to “normalize” people with disabilities, rehabilitation practice and policy should foster a sense of disability identity and disability self-efficacy in order to improve satisfaction with life. This could be accomplished through involvement in the disability community and encouragement of disability pride.

### **Introduction**

Rehabilitation Psychologists have long sought to understand adaptation to disability, a dynamic process of affective, cognitive, and behavioral changes that gradually approach an optimal state of well-being (Livneh & Antonak, 1997). Although extant theories have provided much insight into the factors involved in adaptation to disability (see Livneh and Martz (2012) for a review), these models were conceptualized to explain the experiences of acquired disability, and research based on them has been limited to acquired disability as well. For example, many models are based on the assumption that people with disabilities grieve over a loss of functioning (e.g. Devins et al., 1983; Wright, 1963), but people with congenital disabilities have not

experienced a functional loss.

The lack of literature on adaptation to congenital conditions may reflect an implicit assumption that people with congenital conditions experience less difficulty adapting, but there are few studies directly comparing these groups. Inspecting studies that are likely to include samples of mostly congenital or mostly acquired conditions often suggests that congenital conditions are associated with better adaptation. For example, facial paralysis is most commonly acquired, and studies consisting of mostly acquired participants found these individuals experience high levels of anxiety and depression (VanSwearingen et al., 1998; 1999). However, studies focused on Moebius syndrome, which involves congenital facial paralysis, have often found no elevated levels of psychological distress (Bogart & Matsumoto, 2010; Briegel, 2012). In another population, blind individuals (more likely to be congenital) were found to be more successful in caring for their infants than individuals with low vision (more likely to be acquired; Conley-Jung & Olkin, 2000).

The few extant studies that have directly compared adaptation of people with congenital and acquired conditions found that people with congenital conditions are better adapted than those with acquired conditions (Bogart, Tickle-Degnen, & Ambady, 2012; Li & Moore, 1998). In a survey study, Li and Moore found that people with congenital conditions had greater acceptance of disability than those with acquired conditions. In the only behavioral study comparing adaptation to congenital and acquired disability, people with facial paralysis, a population which experiences threatened social functioning due to impairment in communicating facial expressions, were interviewed and videotaped (Bogart et al., 2012). Adaptation to disability was defined as use of “compensatory expression” (i.e. increased expression in the body and voice) to aid communication. People with congenital facial paralysis exhibited more of this

behavior than people with acquired paralysis.

The mechanisms resulting in better adaptation among people with congenital conditions relative to acquired conditions have not yet received examination. Understanding why people with congenital disability have better adaptation may enrich current theories of adaptation to disability and identify potential applications to improve adaptation, particularly for those with acquired conditions if they are found to fare more poorly. The purpose of this study was to examine whether people with congenital compared to acquired disabilities have better satisfaction with life (SWL) because of a stronger disability self-concept.

### **Self-Concept**

A crucial difference between congenital and acquired disability may be the extent to which people incorporate their disability into their self-concept (Smart, 2008). Self-concept is a multidimensional structure of identity which includes self-esteem, group identity, and self-efficacy (Bandura, 1977; Crocker & Major, 1989; Judge, Erez, Bono, & Thorensen, 2002; Rosenberg, 1965). Although self-concept is multi-dimensional, the vast majority of studies examining self-concept in chronic illness or disability have focused only on self-esteem. For example, a recent meta-analysis concluded that children with chronic illness have poor self-concept compared to normative data and non-disabled groups (Ferro & Boyle, 2013). Inspection of the studies included in the analysis revealed that most used self-esteem as a proxy for self-concept. Self-esteem can be characterized as the positive and negative evaluations of one's personal identity (Rosenberg, 1965). Disability-specific aspects of the self-concept, including disability self-efficacy and sense of disability identity (hereafter referred to collectively as disability self-concept) have received much less attention. Because there has been little research on disability self-concept, another goal of this study was to examine whether disability self-

concept is a unique predictor of SWL above and beyond self-esteem.

**Disability self-efficacy.** Disability self-efficacy is the belief that one can manage the tasks of one's disability in order to achieve valued goals (Amtmann et al., 2012). Disability self-efficacy affects the types of goals a person sets, the course of action a person takes, how long a person will persist, and thus, whether or not the person succeeds in attaining goals (Amtmann et al., 2012). It has been linked to SWL among several chronic conditions (Barnwell & Kavanagh, 1997), including mobility disability (Hampton, 2004). Disability self-efficacy can be distinguished from other measures of severity such as Activities of Daily Living (ADL), which measures how much assistance is needed to perform everyday tasks. Consider a person who needs extensive assistance getting ready in the morning (e.g. dressing, bathing, and eating) and relies on an electric wheelchair for transit. Although this person has little functional independence in terms of ADLs, this person may have high disability self-efficacy if she is confident in her ability to direct a caregiver and use a wheelchair, and this enables her to achieve goals such as work and participate in valued recreational activities.

**Disability identity.** A large part of our self-concept is based on our social group identity. Disability studies scholars argue that the negative aspects of disability are largely socially constructed through social stigma and a lack of accommodations (Olkin, 1999). As such, these scholars suggest that the concept of disability should be considered from a "minority model" perspective (Olkin, 1999). People with disabilities share a number of similarities with other stigmatized groups like ethnic minorities, including being subject to prejudice, discrimination, and disparities in healthcare and income (Olkin, 1999). Conceptualizing disability as a minority group allows researchers to draw from a large social psychological literature on ethnic identity which can be applied to disability (Dunn & Burcaw, 2013).



A commonly cited theory in ethnic identity research is Social Identity Theory, which states that people strive for a positive self-concept, which in turn enhances their well-being (Tajfel & Turner, 1979). Members of stigmatized groups are at risk for poor self-concept because the dominant group in society holds the stigmatized group in low esteem (Crocker & Major, 1989). Based on Social Identity Theory, there are two main ways that members of stigmatized groups (in this case, people with disabilities) manage stigma and seek to improve their self-concept (Tajfel & Turner, 1979). First, some may attempt to assimilate, or “pass” as a majority group member by denying their disability identity, distancing themselves from the minority group, and adopting the majority group’s negative evaluation of the minority group. In this case, the person with the disability would ascribe to the dominant non-disabled groups’ values, strive to be as normal as possible, hope for a cure, and feel ashamed of his or her disability (Tajfel & Turner, 1979). If individuals are able to conceal or minimize their stigmatizing characteristics, this may reduce their stigmatization. On the other hand, people with disabilities may move towards their group or “affirm” their disability identity by questioning the stigma applied by the majority group, reinterpreting stigmatized characteristics in a positive way, and developing disability pride (Darling, 2013; Dunn & Burcaw, 2013; Fernández, Branscombe, Gómez, & Morales, 2012). Aligning oneself with one’s minority group is an important strategy for individuals who experience pervasive stigma and who are unable to pass or leave the group, and is associated with protected self-esteem in a variety of stigmatized groups, including Deaf people (Bat-Chava, 1993; 1994) .

For at least a decade, scholars have been calling for research examining whether disability identity buffers well-being (Dunn & Burcaw, 2013; Olkin & Pledger, 2003), but little quantitative work has been done. A disability identity involves many facets, including a feeling

of solidarity and affinity with others with disabilities, disability pride, disability activism, and finding value, meaning, and benefits in the disability experience (Darling, 2013; Dunn & Burcaw, 2013; Nario-Redmond, Noel, & Fern, 2013; Swain & French, 2000; Wright, 1983). In one of the only quantitative studies on disability identity and well-being, Fernández and colleagues (2012) compared the effectiveness of the two strategies described by Tajfel and Turner (1979) in a cross-cultural study of people with dwarfism from the US and Spain. Individuals from Spain attempted to “pass” by undergoing arduous limb-lengthening procedures, while US participants affirmed their disability identity through activism and pride for their group. These differences reflected the norms of the dwarfism organizations within each country, with the US-based organization focusing on disability pride and the Spanish group supporting assimilation. Interestingly, well-being did not differ across groups, suggesting that either approach, when used within the context of the local support organization, can preserve well-being.

### **Satisfaction with Life**

Adaptation was operationalized as SWL in this study because it is perhaps the ultimate goal of people with disabilities and rehabilitation practitioners alike (Glass, 1999), and it has been used as the main outcome measure in previous studies of adaptation (Bishop, 2005). SWL can be conceptualized as quality of life from the perspective of the person with disability (Glass, 1999). SWL has not yet been compared among people with congenital and acquired disability, although research has found that earlier age of onset in acquired disability is associated with higher SWL (Alfano, Nielson, & Fink, 1993; Hampton, 2004; Krause & Dawis, 1992).

### **The Mediational Role of Disability Self-Concept in Satisfaction with Life in Congenital and Acquired Disability**

This study will test a mediational model (Figure 1) predicting that: disability self-concept may be better developed among people who were born with a disability compared to people who acquired a disability later in life, disability self-concept will predict greater SWL, and disability self-concept will mediate the association between congenital onset and higher SWL. Although longer duration of a disability is typically associated with better adaptation (Alfano et al., 1993; Hampton, 2004; Krause & Dawis, 1992), I expect that time of onset (congenital or acquired), an under-examined factor, will be a stronger predictor of SWL than duration of disability. People with congenital disability may be more likely to consider their disability an inextricable part of themselves because they had no premorbid identity (Smart, 2008). Indeed, people with congenital disabilities are likely to report not knowing what they would be like without the disability, while people with acquired disabilities frequently report feeling a profound sense of loss of identity (Smart, 2008). In many cases, before acquiring a disability, individuals have already internalized societal stigma about disability as an undesirable outgroup, and they suddenly find themselves members of this group (Smart, 2008). Because of these pre-existing beliefs about disability, individuals with acquired disabilities might be more resistant to developing a disability identity. Indeed, a small amount of extant research suggests that people with earlier disability onset have greater sense of disability identity (Bat-Chava, 1994; Hahn & Belt, 2004; Seligman & Darling, 2007).

Although to my knowledge, disability self-efficacy has not been compared among people with congenital and acquired conditions, I predict that people with congenital disabilities, who went through their initial development with their conditions and thus learned to function with their disabilities during their initial development, will have better disability self-efficacy. They adapted to their disability at a time when they are cognitively flexible and can easily automatize

new skills (Smart, 2008). Completing tasks may seem more natural and innate to people with congenital disabilities because they have always done them that way, fostering a confidence in ability that may not be as strong in those who must relearn how to do things that are more challenging than they used to be. Specific to the population examined in this study, much of the challenge faced by people with mobility disabilities involves navigating physical space. People with congenital disabilities have likely only experienced the part of the environment they can access, whereas people who acquired disabilities likely lose access to places they used to go. These differences in experience of the environment could lead people with congenital disabilities to feel more comfortable and confident in their ability to navigate the world, even though their accessibility may be limited.

Self-esteem is a powerful predictor of SWL (Lucas, Diener, & Suh, 1996), and as part of the self-concept, it should be related to disability self-concept. Indeed, disability identity is associated with higher self-esteem (Nario-Redmond et al., 2013). However, disability self-concept, but not self-esteem, was expected to mediate the differences in SWL for people with congenital and acquired. This is because time of disability onset would have a greater effect on disability-specific aspects of the self-concept, rather than domain-general aspects such as self-esteem, which involves other domains such as academic achievement and social support.

### **The Present Study**

This study focused on mobility disabilities because, as described above, several of the variables in the proposed model have already been tested in this population (SWL, self-esteem, and disability self-efficacy; Alfano et al., 1993; Ferro & Boyle, 2013; Hampton, 2004; Krause & Dawis, 1992). Additionally, mobility disability was ideal because it is a common condition that can be congenital or can be acquired at any age. This study tested three hypotheses. First, people

with congenital disabilities would have higher SWL and disability self-concept than those with acquired disabilities. Second, disability self-concept would be a unique predictor of SWL among people with disabilities, over and above the effects of self-esteem, disability duration, and demographic variables. Third, disability self-concept would mediate the relationship between congenital disability and higher SWL.

## **Method**

### **Participants**

This study was conducted online to better recruit individuals with congenital disabilities, since congenital disabilities are generally less common than acquired disabilities, and are less likely to be represented in disability research (Bogart & Matsumoto, 2010). Online research is becoming increasingly common in psychology, and offers a promising way to study “special populations,” such as people with mobility limitations who may have difficulty attending in-person studies (Whitehead, 2007). As internet access grows increasingly prevalent, internet-based samples are becoming more diverse and representative (Whitehead, 2007).

Participants were a convenience sample recruited from disability organizations and websites such as United Spinal, the Spina Bifida Association, and the Christopher and Dana Reeve Foundation, via newsletters, email, discussion board posts, and social media. Inclusion criteria were as follows: age 18 or older, self-reported presence of a mobility disability that impaired ability to walk to any degree, living in the USA (to control for potential cultural differences in stigma and organizational support (as found in Fernández et al., 2012), and ability to read and write in English. As progressive conditions are known to involve a particularly dynamic process involving constant change, uncertainty, and adaptation (McCulty, Livneh, & Wilson, 2004), progressive conditions such as Muscular Dystrophy and Amyotrophic Lateral

Sclerosis were excluded because of the difficulty comparing this sort of constantly changing adaptation process with congenital conditions which are unlikely to be progressive or to change as quickly. A total of 226 participants completed the survey. Participant characteristics are shown in Tables 1 and 2. Although it was unlikely that participants would complete the survey more than once because no inducements were offered, it is good practice to check IP addresses for duplicates. None were found.

Table 1 and Table 2 about here.

### **Main Outcome Measures**

**Satisfaction with Life Scale (Diener, 1985).** This 5-item Likert-type scale is the most commonly used measure of SWL. An example item is: "I am satisfied with my life." Scores were summed, with higher scores indicating more SWL. Range of possible scores is 7-35. Cronbach's  $\alpha$  for all scales with this sample are shown in Table 3.

Table 3 about here.

**Rosenberg Self-Esteem (Rosenberg, 1965).** This is a commonly used 10-item Likert-type measure of global personal self-esteem. An example item is: "I feel that I'm a person of worth, at least on an equal plane with others." Appropriate items were reverse-scored, then summed. Higher numbers indicate greater self-esteem. Possible scores range from 0-30.

**Disability Identity.** One of the only quantitative measures of disability identity, the 8-item Likert-type Personal Identity Scale was used for the current study (Hahn & Belt, 2004). It is designed to measure incorporation of disability into sense of identity, a sense of positive disability identity, as well as a sense of belonging with the disability community. Preliminary evidence for validity of this measure was supported by the finding that high disability identity scores were related to less desire for a cure among people with mobility disabilities (Hahn &

Belt, 2004). Example items include: “Being a person with a disability is an important reflection of me” and “I do not have a sense of belonging to the disability community.” Appropriate items were reverse-scored, and then all items were summed. Higher numbers mean higher disability identity. Possible scores range from 8-40.

**University of Washington Disability Self-Efficacy Scale (Amtmann et al., 2012).**

This is a 6-item Likert-type scale which shows good psychometric properties (Amtmann et al., 2012). An example item is: “how confident are you that you can figure out effective solutions to mobility disability-related issues that come up?” Scores were summed, and higher numbers mean greater disability self-efficacy. Possible scores range from 6-30.

**Covariate Measures**

**Self-Report Functional Independence Measure (Hoenig, Branch, McIntyre, Hoff, & Horner, 1999).** This is a 13-item self-report version of the commonly used Functional Independence Measure (Guide for the Uniform Data Set for Medical Rehabilitation, 1996). The ADL subscale is reported in the present study, which indicates how much, if any, assistance is needed to complete common daily tasks. Items in this scale were summed, and higher numbers indicate more independent ADL performance. An example item is “how much help do you need to move around inside your house?” Possible scores range from 13-52.

Demographic information, including type of health condition resulting in mobility disability, age, gender, ethnicity, time of onset, age of onset, duration of disability, and income was also collected. To indicate their income, participants selected from one of eight income brackets, shown in Table 1.

**Procedures**

This study was approved by the Oregon State University Institutional Review Board.

Participants gave consent and completed all measures on the Qualtrics online survey system. The questionnaire took approximately 30 minutes to complete. Participants completed other measures not reported here for the purposes of other research.

### **Data Analysis**

The purpose of the study was to compare individuals who went through their initial development with their disability to people who acquired a disability at any later point, so time of onset variable was dummy-coded, with congenital disability equal to 0 and acquired equal to 1. Gender was coded as 0 for female and 1 for male. Descriptive statistics and bivariate correlations were calculated for all measures and demographic variables.

In order to test the first hypothesis, that people with congenital disabilities would have higher SWL and disability self-concept than those with acquired disabilities, independent t tests were conducted. To test the second hypothesis, that disability self-concept would predict SWL among people with disabilities above and beyond self-esteem and demographic variables, a hierarchical multiple regression was conducted. Self-esteem and the demographic variables age of time of onset, disability duration, income, ADL performance, age, and gender were entered into the first step of the regression model. Disability identity and disability self-efficacy were added in the second step. A significant change in  $R^2$  after the second step would indicate support for this hypothesis.

The third hypothesis, that disability self-concept mediates the relationship between time of onset and SWL, was tested using PROCESS, an SPSS path analysis script to estimate direct and indirect effects (Hayes, 2013). This method is now frequently recommended over the Baron and Kenny (1986) causal steps mediation analysis method, although results are often similar (Preacher & Hayes, 2008). This method is preferable for a couple of reasons. First, it is robust to



violations of normality assumption because it uses bootstrapping to estimate confidence intervals (CIs). Second, and particularly relevant for this study, it easily handles multiple mediators and control variables.

For the mediation model, the predictor was time of onset, the outcome was SWL, and the three potential mediators operating in parallel were disability identity, disability self-efficacy, and self-esteem. Any covariates that remained significant in the final step of the regression model predicting SWL were added as control variables to the mediation model. A conventional number of bootstrap samples (5,000) were used (Hayes, 2013). CIs that do not include zero indicate significant effects. Thus, the second hypothesis would be supported if the indirect effects of disability identity and disability self-efficacy did not have CIs that included zero.

## **Results**

### **Correlations**

Table 3 shows the correlation matrix for all variables. The main outcome variable, SWL, was associated with greater duration of disability, self-esteem, self-efficacy, disability identity, ADL performance, income, and congenital onset. Participants with congenital onset had greater disability identity, disability self-efficacy, disability duration, age, income, ADL performance, and were more likely to be female.

### **Hypothesis 1**

In support of this hypothesis, t tests indicated that participants with congenital disabilities had higher SWL, disability identity, and disability self-efficacy compared to those with acquired disabilities. (See Table 2).

### **Hypothesis 2**

Table 4 shows the hierarchical regression predicting SWL. In the first step of the

hierarchical regression, which included time of onset, age, duration, gender, ADL performance, income, and self-esteem, the significant predictors were, from most contribution to SWL to least, self-esteem, time of onset, and income. This model accounted for 49% of the variance in SWL. In the second step, with the addition of disability identity and disability self-efficacy, the significant predictors were, from most contribution to SWL to least, self-esteem, disability identity, disability self-efficacy, and income. In support of the hypothesis that disability self-concept would predict SWL among people with disabilities above and beyond self-esteem and demographic variables, the second step explained a significant 6% increase in variance. The final model explained a substantial 55% of the variance in SWL.

Table 4 about here.

### **Hypothesis 3**

In the mediation model (shown in Figure 1), the predictor was time of onset, the outcome was SWL, and the three potential mediators were disability identity, disability self-efficacy, and self-esteem. Income, the only significant demographic variable in the final regression model predicting SWL, was entered as a control variable. All predicted associations in were significant and in the expected direction. The total effect, which is the effect of time of onset on SWL, controlling for income, was significant,  $b = -3.99$ ,  $p = .002$ . The direct effect, which is the effect of time of onset on SWL, controlling for income and the potential mediators disability identity, self-efficacy, and self-esteem, was reduced but remained significant,  $b = -2.05$ ,  $p = .04$ . The difference between the total effect and the direct effect is represented by the indirect effect, thus a significant indirect effect indicates a mediation relationship. Crucially, the predicted indirect effects of disability identity ( $b = -1.27$ , 95% CI [-2.40, -0.52]) and disability self-efficacy ( $b = -0.68$ , 95% CI [-1.62, -0.14]) were both significant, as indicated by CIs which did not include

zero. However, the indirect effect of self-esteem was not significant ( $b = 0.01$ , 95% CI [-1.23, 1.24]). This supports the hypothesis that the relationship between congenital disability and higher SWL is partially mediated by disability self-concept, but not self-esteem.<sup>1</sup>

Figure 1 about here.

### Discussion

The main objective of this study was to test the notion that whether a disability is congenital or acquired plays an important role in development of the disability self-concept, which in turn, affects SWL. People with congenital onset had higher disability self-concept and SWL than those with acquired onset. Supporting the importance of disability self-concept, disability identity and disability self-concept were significant predictors of SWL, above and beyond commonly studied factors such as self-esteem, disability duration, and income. Crucially, disability self-concept mediated the differences between people with congenital and acquired onset in SWL. As predicted, global self-esteem did not mediate this relationship, supporting the role of disability-specific aspects of the self-concept.

This study supports the prediction of Social Identity Theory that affirming one's disability identity protects well-being (Tajfel & Turner, 1979). However, affirmation of disability identity is still a rare phenomenon (Dunn & Burcaw, 2013). While other minority groups have managed to create subcultures of pride (e.g. Black Pride, Gay Pride), disability pride is still a foreign concept to all but a select group of disability activists and scholars (Hahn & Belt, 2004). One barrier to forming a positive disability identity is that people with disabilities are often isolated in their communities (Olkin, 2008). Unlike ethnic minorities, people with disabilities are

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<sup>1</sup> An anonymous reviewer suggested that duration of disability and ADL may affect the mediational relationship. To investigate, I repeated the mediation analysis including duration of disability and ADL as additional covariates. The indirect effect of disability identity remained significant ( $b = -0.72$ , 95% CI [-1.81, -0.02]), but the indirect effect of disability self-efficacy was no longer significant ( $b = -0.15$ , 95% CI [-0.87, 0.29]).

likely to be the only person in their family or even their community with a disability. Well-intentioned non-disabled family and community members often try to “normalize” people with disabilities so they will fit in with their majority culture (Olkin, 2008), rather than fostering a sense of disability identity.

Is going through one’s initial development with a disability beneficial to disability self-concept and SWL, or were these findings simply driven by the fact that people with congenital conditions have had a longer period of time to adapt to their disability? The first step of the regression (before the effect of the mediators was controlled for) indicated that time of onset, but not duration of disability, was significantly related to SWL, suggesting that being born with a disability may lead to better SWL, and the association between time of onset and SWL may be based on more than simply having a long time to adapt to one’s disability. Further, when disability duration and ADL were added as covariates to the mediation model predicting SWL from time of onset, disability identity, but not disability self-efficacy, remained a significant mediator. Thus, disability identity seems to be a robust mechanism explaining why people with congenital disability have higher SWL, regardless of duration and ADL. This begs an interesting question for future longitudinal research: is there a critical period for optimal adaptation to disability? Is it at birth, or within the first few years in life? There is evidence for the notion that disability identity is influenced by a critical period within the Deaf population: people who are born deaf or become deaf before the critical period of language acquisition are more likely to identify with the Deaf community than people who become deaf after this critical period (Smart, 2008).

### **Limitations**

As this was a first attempt to examine these hypotheses, there were several limitations

that may affect generalizability of the results. Recruitment involved a convenience sample and necessitated that participants had access to the Internet and be connected to disability organizations. As there are fewer congenital conditions than there are opportunities to acquire a mobility disability after birth (Bogart et al., 2012), there were fewer participants with congenital disabilities. However, the samples for each group were sufficiently large to avoid major issues with unequal cell sizes. Congenital participants were more likely to be younger, female, have better ADL performance, and lower income. Males are more likely to have early onset disability, while females are more likely to acquire disabilities as they age (US Census, 2010), but the present sample had the opposite pattern. In the present sample, the majority of participants in the acquired sample had disability resulting from injury, which is more likely to occur among men. These factors were controlled for in the regression analyses, and only income remained a significant predictor of SWL in the final model, a common finding among people with and without disabilities (Anderson et al., 2002). Income may be of particular importance to the SWL of individuals with disabilities because it affects their access to healthcare, assistive devices, and personal care attendants. Importantly, the variables of interest were unique predictors of SWL after controlling for these demographic factors.

### **Future Directions**

This research highlights the need for future studies exploring the understudied areas of disability self-concept and congenital compared to acquired adaptation to disability. Given that disability self-concept only partially mediated the relationship between time of onset and SWL, there are almost certainly other factors involved. Future research should examine other factors that may affect adaptation and interact with time of onset such as social support, socioeconomic status, visibility of disability, trauma, nature of organizational support available, and progression

of the disability. For example, it might be predicted that differences in the nature and quality of social support between those with congenital and acquired conditions affect adaptation. The quality of familial support may be particularly crucial for adaptation to congenital disabilities, as family is the main source of social support in early life, while the quality of friend support may be more important for people who acquire disability. Friends made prior to one's acquisition of disability may not be supportive after acquisition, so one may benefit from finding new friends comfortable with one's disability identity. Indeed, Jones and colleagues (2012) found that maintenance of post-injury social groups, but not pre-injury groups, predicted better adaptation to acquired brain injury.

Another factor for future study is how the visibility of the disability affects disability self-concept. It might be predicted that people with visible disabilities such as mobility disabilities, and invisible disabilities such as learning disabilities or mental illness alike may benefit from the protective effects of a disability identity, but people with invisible disabilities are more likely to try to hide their disability and identify with the mainstream culture to avoid stigma. Indeed, people with concealable stigma experience more psychological distress than those with visible stigma (Frable, Platt, & Hoey, 1998). Being in the presence others who are known to share one's stigma is protective, but is also less likely to occur if one's stigma is concealable (Frable et al.). Thus, the people who could benefit the most from disability identity and community may be the least likely to use these protective strategies.

The present study has only scratched the surface in identifying the general construct of disability identity as an important factor related to SWL. Future research should examine specific variables that may comprise disability identity and how they relate to SWL. Previous work on disability identity has identified factors such as affinity towards others with disabilities, disability

pride, reinterpreting stigmatized characteristics into valued attributes, finding meaning, and activism for disability rights (Dunn & Burcaw, 2013; Hahn & Belt, 2004; Nario-Redmond et al., 2013; Smart, 2008; Swain & French, 2000; Wright, 1983). For example, disability is often stigmatized because of the perception that it reduces independence. Part of developing a disability identity may involve changing one's value system to appreciate interdependence (Wright, 1983). Indeed, Stensman (1985) found that people with disabilities were more likely to value social relationships and interdependence, while people without disabilities were more likely to value physical competence and independence, and he suggested this may be protective of well-being.

### **Rehabilitation Applications**

The finding that disability self-concept may lead to higher SWL among people with congenital conditions suggests that interventions should focus on bolstering disability self-efficacy and disability identity among people with disabilities, and particularly among people with acquired disabilities, who may have poorer adaptation. Rehabilitation historically focused on “normalizing” people with disabilities and even advised them to avoid congregating with others, although this view is changing (Smart, 2008). This research lends validity to the notion that practitioners, support organizations, and educators should avoid such attempts to help people “overcome” disabilities because they may hamper the development of disability self-concept and lead to reduced SWL (Olkin, 2008). Norms within disability support organizations can play an important role in whether individuals with disabilities and their families feel that people with disabilities should assimilate or whether they should affirm their membership in the minority group (Fernández et al., 2012).

Disability-affirmative therapy (Olkin, 2008), a culturally affirmative approach to

psychotherapy, may be a useful example of how to support people with disabilities in the adaptation process. Disability-Affirmative Therapy assumes that disability is not inherently pathological, and that it has value and meaning. It encourages clients to develop an affirmation of disability identity by finding mentors with disabilities, becoming involved with the disability community, and engaging in positive reframing of stigmatized traits. Engaging with others with disabilities will provide a person with a disability an opportunity to learn self-management skills and find resources from others. Additionally, value changes involved with disability identity may result in changing one's goals to ones that can be accomplished with a disability, improving self-efficacy (Sharoff, 2004; Stensman, 1985). Future research should examine interventions focused on building disability self-concept to improve SWL.



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Table 1

*Participant Characteristics*

Characteristic	Congenital (n = 62)	Acquired (n = 164)
Male	19 (31)	144 (88)
Income		
Less than \$10,000	18 (29)	7 (4)
\$10,000-20,000	8 (13)	24 (15)
\$20,001-30,000	4 (7)	13 (8)
\$30,001-45,000	14 (23)	21 (13)
\$45,001-60,000	6 (10)	27 (17)
\$60,001-75,000	1 (2)	21 (13)
\$75,001-90,000	6 (10)	18 (11)
Greater than \$90,000	5 (8)	33 (20)
Ethnicity		
African American	3 (5)	5 (3)
Asian	1 (2)	1 (1)
White	50 (82)	144 (88)
Hispanic	2 (3)	6 (4)
Other or mixed	5 (8)	7 (4)
Disabling Health Condition		
Amputation	N/A	4 (2)
Cerebral Palsy	6 (10)	N/A
Infection	N/A	3 (2)
Injury	1 (2)	112 (68)
Other or more than one condition	2 (3)	15 (9)
Polio	N/A	3 (2)
Spina Bifida	53 (85)	N/A
Stenosis	N/A	17 (10)
Stroke	N/A	3 (2)
Syringomyelia	N/A	4 (2)
Tumor	N/A	3 (2)

*Note.* Values are *ns*. Percents for each column are in parentheses. Percentages may not sum to 100 due to rounding.

Table 2

*Descriptive Statistics for Variables of Interest*

Characteristic	Congenital	Acquired
Age	36.96 (12.69)	57.12 (11.73)**
Disability duration	36.96 (12.69)	20.02 (14.80)**
Age of disability onset	N/A	37.09 (15.49)
ADL	43.93 (8.04)	37.28 (10.01)**
SWL	20.53 (8.09)	17.89 (8.73)*
Self-Esteem	19.56 (6.70)	20.54 (6.52)
Disability Identity	26.67 (5.97)	22.88 (5.65)**
Disability Self-efficacy	21.03 (5.50)	18.70 (5.98)**

*Note.* SWL is satisfaction with life. ADL is performance of activities of daily living. T tests compared congenital and acquired participants for each variable. \* $p < .05$ ; \*\* $p < .01$ .



Table 3

*Correlation Matrix for Time of Onset, Satisfaction with Life, Self-Esteem, Disability Self-Concept, and Demographic Variables*

	SWL	Time of Onset	Duration	Age	Gender	ADL	Income	Self-Esteem	Self-Efficacy	Disability Identity
Time of Onset	-.14*									
Duration	.15*	-.47**								
Age	-.00	.60**	.07							
Gender	-.06	.57**	-.20**	.48**						
ADL	.23**	-.30**	.18**	-.14*	-.15*					
Income	.20**	.29**	-.04	.30**	.24**	.03				
Self-Esteem	.66**	.07	.12	.14*	.10	.16*	.24**			
Self-Efficacy	.57**	-.18**	.21**	.01	.03	.32**	.07	.60**		
Disability Identity	.54**	-.28**	.29**	-.14*	-.22**	.21**	-.02	.47**	.50**	
$\alpha$	0.89	-	-	-	-	0.95	-	0.89	0.89	0.74

*Note.* The time of onset variable was coded as 0 for congenital and 1 for acquired. Gender was coded as 0 for female and 1 for male.

ADL is performance of activities of daily living. \* $p < .05$ ; \*\* $p < .01$ .

Table 4

*Hierarchical Multiple Regression Predicting Satisfaction with Life*

Variable	Step 1			Step 2		
	<i>b</i>	<i>SE b</i>	$\beta$	<i>b</i>	<i>SE b</i>	$\beta$
Time of Onset	-3.95	1.66	-0.21*	-2.84	1.60	-0.15
Age	0.02	0.04	0.03	0.03	0.04	0.05
Duration	-0.02	0.03	-0.04	-0.04	0.03	-0.08
Gender	-0.88	1.16	-0.05	-0.7	1.12	-0.04
ADL	0.06	0.05	0.07	0.03	0.04	0.03
Income	0.39	0.20	0.106*	0.46	0.19	0.12*
Self-Esteem	0.85	0.07	.64**	0.58	0.08	0.44**
Disability Identity				0.32	0.09	0.22**
Self-Efficacy				0.24	0.09	0.16*
$\Delta R^2$		0.49**			0.06**	

*Note.* The time of onset variable was coded as 0 for congenital and 1 for acquired. ADL is performance of activities of daily living. \* $p < .05$ ; \*\* $p < .01$ .

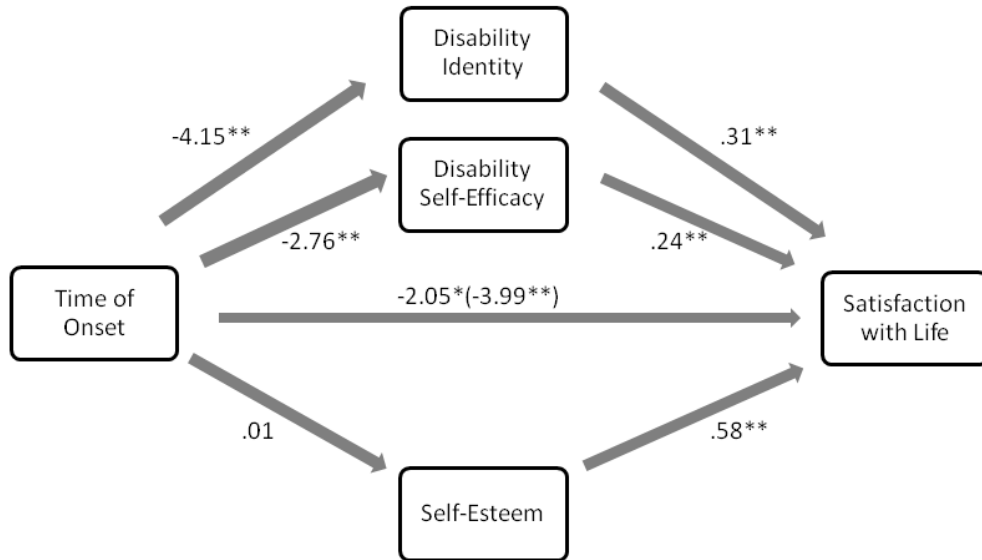


Figure 1. Model testing mediational role of disability identity, disability self-efficacy, and self-esteem in the relationship of onset and satisfaction with life. The time of onset variable was coded as 0 for congenital and 1 for acquired. Income was included as a covariate. The coefficient in parentheses is the total effect and the adjacent number is the direct effect. Values are  $b$  coefficients.  $*p < .05$ ;  $**p < .01$ .