Initial Factor Exploration of Disability Identity

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Purpose/Objective: This article describes the initial factor exploration of disability identity and preliminary psychometric characteristics based on an adult self-report tool. Disability was defined broadly, and the sample included individuals with visible and/or hidden disabilities across many disability groups (i.e., physical, intellectual, learning, mental illness).

Method: Items were developed (n = 102) and a pilot measure was administered to a sample of adults with disabilities (n = 566). An exploratory factor analysis (EFA) using the mean and variance adjusted weighted least squares (WLSMV) estimator was conducted. The resulting items were sent to expert reviewers for evaluation.

Results: Following the exploratory analyses, 37 items were retained that made up four factors: internal beliefs about one’s disability and the disability community, anger and frustration with disability experiences, adoption of disability community values, and contribution to the disability community. The pilot measure aligned well with the theoretical framework that guided its development.

Discussion/Conclusion: This factor exploration is a contribution to a growing body of literature supporting, and investigating, disability identity development. This work presents a more comprehensive understanding of disability identity development. Armed with a better understanding, this will serve as a basis to inform future scale development and validation. After this validation work is completed, there is the potential to apply findings to tailor interventions and clinical work, so that psychologists and rehabilitation professionals may be better prepared to meet the developmental needs of disabled clients.

Impact and Implications
This article provides initial factor analysis grounding for a new clinical and research tool to assess disability identity for adults with either visible/apparent or hidden/less apparent disabilities. The exploratory factor analysis identifies both internal and external dimensions of disability identity. Both internal and external dimensions are important and together represent disability identity. Rehabilitation practitioners are encouraged to consider disability identity while assessing and assisting clients in addressing issues related to their disability.

Keywords: disability identity, assessment, identity formation, exploratory factor analysis

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Introduction

Identity is socially and historically constructed and is a particularly important phenomena to understand for members of marginalized minority groups such as individuals with disabilities. Disability plays a central and unique role in one’s social identity, as individuals may become members of the disability community at any point across the life span. Social identity consists of the knowledge that one belongs to a social group and the significance that one ascribes to their group membership (Tajfel, 1974). Social identities have important positive and negative health implications, which can explain and influence “the way in which individuals understand and respond to the social structural conditions in which they find themselves” (Haslam, Jetten, Postmes, & Haslam, 2009, p. 6).

Disability identity can be described as a “sense of self that includes one’s disability and feelings of connection to, or solidarity with, the disability community” (Dunn & Burcaw, 2013, p. 148). A coherent disability identity is believed to help individuals adapt to disability, including navigating related social stressors and daily hassles (Forber-Pratt, Lyew, Mueller, & Samples, 2017; Forber-Pratt & Zape, 2017). Further, a healthy intact identity is vital for one’s physical and psychological health and contributes to a stronger sense of self and the ability to face ableism by reaffirming desired goals and personal worth (Campbell, 2008; Forber-Pratt & Zape, 2017; Mpofu & Harley, 2006). Social identities have been linked to numerous health-related outcomes that include symptom appraisal and response, health-related norms and behavior, social support coping, and clinical outcomes (Haslam et al., 2009). Specifically, disability identity is associated with positive mental health outcomes (Bogart, 2015), attitudes toward cure (Hahn & Belt, 2004), and political activism (Schur, 1998). For example, Bogart’s (2015) recent work found that a stronger disability identity was associated with lower depression and anxiety in participants with multiple sclerosis.

Past scholarship leverages Erikson’s (1968) theory of identity development and identity synthesis to examine and theorize about several types of social identities, including feminist identity development (Downing & Roush, 1985), sexual orientation identity development (Cass, 1979), and ethnic identity development (Cross, 1978; Quintana, 2007; Smith, 1991). Relative to the decades of literature that has amassed on these social identities, disability identity remains vastly understudied.

A recent systematic review of the literature on disability identity development (Forber-Pratt & Zape, 2017) identified 41 empirical articles and noted that an overwhelming majority (75.6%) were qualitative, 22% were quantitative, and only one utilized a mixed methods design (Forber-Pratt et al., 2017). This review identified five theoretical models of disability identity (Darling & Heckert, 2010; Dunn & Burcaw, 2013; Forber-Pratt et al., 2017; Gibson, 2006; Gill, 1997; Hahn & Belt, 2004; Putnam, 2005) and frequently used measures of disability identity (Chicago Center for Disability Research, n.d.; Darling & Heckert, 2010; Hahn & Belt, 2004). However, the frequently used measures of disability identity (Chicago Center for Disability Research, n.d.; Darling & Heckert, 2010; Groomes & Linkowski, 2007; Hahn & Belt, 2004) lack rigorous evaluation. One additional measure, the Attitudes Toward Disability Scale (Power, Green, & the WHOQOL-DIS Group, 2010), was found but not evaluated because of the focus on attitudes about disability in general as opposed to it being an element of identity. We discuss each measure below as a way to evaluate the need for an additional measure of disability identity development, beginning with an exploratory factor analysis (EFA), as opposed to validation of the extant measures.

The Disability Identity Scale (Chicago Center for Disability Research, n.d.) is theoretically informed by Gill’s (1997) four types of integration in disability identity development. The Disability Identity Scale is widely employed in the literature (Axtell, 1999; Darling, 2003; Valeras, 2010; Whitney, 2006); however, a systematic review of the literature (Forber-Pratt et al., 2017) revealed no documentation of its development (e.g., sample size or demographics, analysis, factor structure, etc.).

Darling and Heckert (2010) developed the Questionnaire on Disability Identity and Opportunity to assess participation and disability orientation. Item generation for this scale was informed by qualitative interviews with individuals with disabilities. Through EFA the authors identified five factors, four of which were retained, as will be discussed subsequently. Although results from the preliminary analysis are promising, this scale has yet to be validated using rigorous psychometric methods (e.g., confirmatory factor analysis [CFA]) since its initial development nine years ago.

Groomes and Linkowski (2007) adapted and revised a previous tool, the Acceptance of Disability Scale (Linkowski, 1971). This scale was not found or assessed in the previous literature review (Forber-Pratt & Zape, 2017) because the term “identity” or “disability identity” is not contained in the paper. However, upon investigation, this is a promising tool that may have application to this type of work as a component of disability identity, but likely not the only aspect. The authors (Groomes & Linkowski, 2007) used a principal component analysis and identified four domains related to the adaptation of disability: enlargement of scope of values, subordination of physique, containment of disability effects, and transformation from comparative values to asset values which connect to Beatrice Wright’s (1983) psychosocial theory on disability. Notably, the sample for this work included a variety of disability groups (learning disabilities, orthopedic injuries, substance abuse issues, mental illness, sensory impairment and traumatic brain injury). Although results from this revision are promising, this scale has yet to be validated using rigorous psychometric methods (e.g., CFA).

Hahn and Belt (2004) developed a tool that other scholars have subsequently labeled the Disability Personal Identity Scale. Using principal component analysis (not factor analysis), the authors identified four disability identity components separated into two general areas (i.e., communal attachment and personal identity). Notably, Hahn and Belt’s use of principal component analysis provides limited evidence of internal validity, as this method is not ideal for explaining complex psychological constructs like identity development (Price, 2016). Hahn and Belt provides some preliminary evidence of construct validity that suggests affirmation of disability is significantly associated with rejection of a cure for disability; however, none of the other three components were associated with this outcome (Hahn & Belt, 2004). To date, no subsequent analyses have been published to evaluate this scale. Additionally, the generalizability and utility of this measure to the larger disability community is questionable, as Hahn and Belt developed the scale using a sample of disability activists (i.e.,
individuals with disabilities who were members of a disability rights organization and demonstrated at social action events) that presumably would exhibit greater identification with the disability community than the average individual with a disability.

Rigorous scale development should include three major components: (a) definition of the theoretical constructs of, in this case, disability identity development, (b) examination of the internal relations among the items used to operationalize these constructs, and (c) examination of the external relations among these constructs and other relevant (external) constructs or subject characteristics (Benson, 1998; Price, 2016). Each of the three available disability identity measures are theory-based and meet the first criterion; however, an examination of internal relations among scale items for each of the available tools is limited to exploratory analysis (e.g., principal component analysis or EFA) and not confirmatory methods (CFA) nor do they examine the external associations between scale constructs and other constructs.

To date, there is no quantitative measure of disability identity development that has been systematically constructed, evaluated, or validated using confirmatory methods. This is significant for a few reasons. While extant research on disability identity describes the phenomenon (and its importance) qualitatively, quantitative approaches allow for statistical examination of the phenomena across different experiences of disability. In the absence of a validated quantitative measure of disability identity development, researchers and practitioners are limited in their understanding to design interventions or curriculum that address disability identity development. The construction of a validated measurement tool has important practical implications, that can equip educators, medical professionals, psychologists, therapists, rehabilitation professionals, caregivers, and, ultimately, persons with disabilities with information that may be used to improve psychosocial and other health outcomes (Forber-Pratt et al., 2017). This paper describes the initial factor exploration of disability identity including an assessment of individuals’ acceptance of their personal disability and identification with the disability community which will serve as the foundation for future scale development and validation work.

**Foundation for the Factor Exploration**

To develop the pilot version of the measure, the theoretical and empirical evidence that led to the development of a model of social and psychosocial disability identity development (Forber-Pratt & Aragon, 2013; Forber-Pratt & Zape, 2017) served as the guide for item generation. According to this model, disability identity is considered a unique phenomenon that shapes the way individuals’ look at themselves, their bodies, and how they interact with the world (Forber-Pratt & Zape, 2017).

The items were generated to represent four constructs of disability identity (i.e., essential characteristics). Table 1 presents the constructs and descriptions from a qualitative study (Forber-Pratt & Zape, 2017) with 17 college students with varying disabilities that informed the preliminary disability identity development model and was used for item generation for the measure. The results of that study led to establishing a model of psychosocial identity development for individuals with disabilities. The model highlights four developmental statuses that include acceptance, relationship, adoption, and engagement.

### Item Generation

Considering that previous qualitative work only included 17 participants, coupled with the lack of comparable existing measures, we chose to use the prior work as a foundation to inform the item generation and increased the number of participants across disability groups to determine if the model of psychosocial disability identity development in fact measured the distinct constructs. Using this model as the foundation, the research team, which included theoreticians well versed in identity development, disability, and assessment development engaged in a series of activities to create a pool of items for each domain and subdomain that represented (a) the breadth of content in each domain and (b) levels of disability identity across each domain. We developed operational definitions for each domain and subdomain to guide item identification and construction. A comprehensive review of the existing disability identity literature and assessments was conducted (Forber-Pratt et al., 2017). This review was used to generate content areas and items from other tools that could be used to seed the subdomains. For example, we used one psychometrically sound item from the Personal Identity Scale (Hahn & Belt, 2004), however, after careful review of the other items and other measures no other existing items were used to seed subdomains. This process led to the initial draft version of the measure with 102 items on a Likert-type scale, ranging from 1 (Not At All Like Me) to 4 (Very Much Like Me).

<table>
<thead>
<tr>
<th>Disability identity constructs</th>
<th>Interpretation</th>
</tr>
</thead>
<tbody>
<tr>
<td>Acceptance status</td>
<td>Become disabled and/or born with disability</td>
</tr>
<tr>
<td></td>
<td>Person accepts own disability</td>
</tr>
<tr>
<td></td>
<td>Close friends and family are accepting of the disability</td>
</tr>
<tr>
<td></td>
<td>Includes aspects of frustration</td>
</tr>
<tr>
<td>Relationship status</td>
<td>Person meets others like herself/himself</td>
</tr>
<tr>
<td></td>
<td>Engages in conversation with these individuals</td>
</tr>
<tr>
<td></td>
<td>Learns about the ways of the group</td>
</tr>
<tr>
<td>Adoption status</td>
<td>Adopts the shared values of the group</td>
</tr>
<tr>
<td></td>
<td>Feels a strong connection to the disability community</td>
</tr>
<tr>
<td>Engagement status</td>
<td>Become a role model for others</td>
</tr>
<tr>
<td></td>
<td>Help those who may be in other statuses</td>
</tr>
<tr>
<td></td>
<td>Give back to the disability community</td>
</tr>
</tbody>
</table>
Method

Recruitment Procedures

The lead author’s institutional review board provided oversight for this project. Purposive sampling techniques were used to target disability-related organizations and listservs, as we were interested in adult populations with disabilities. The lead researcher generated a list of disability-related organizations that served multiple disability populations and had national reach. The following initial organization contacts were made: ADAPT, Association of University Centers on Disabilities, American Association of People with Disabilities, National Council for Independent Living, and The Arc. Additionally, snowball sampling was employed after initial contact was made with specific individuals or organizations. The recruitment message was then shared widely including various disability-related listservs, rehabilitation hospitals, and other organizations not initially selected. Further details about the types of organizations who shared the message are provided in the online supplemental materials.

Data Collection

The measure was developed and administered online using REDCap (Research Electronic Data Capture; Harris et al., 2009) at the lead authors’ institution. REDCap is a secure, web-based application designed to support data capture for research studies and contains a survey tool for building and managing online surveys. The research team created and designed the survey in a web browser. Despite pilot and usability testing, it became apparent after data collection began that certain functionality in REDCap was not accessible via screenreader for participants with vision-related disabilities. Therefore, an additional identical version of the online measure was developed in Survey Monkey to allow for greater accessibility. A link was then provided on the online consent form to redirect participants to that link for screen reader accessibility. Both REDCap and Survey Monkey systems provide secure, web-based applications that are flexible enough to be used for a variety of types of research, provide an intuitive interface for users to enter data and have real time validation rules (with automated data type and range checks) at the time of entry. These systems offer easy data manipulation with audit trails and reporting for reporting, monitoring and querying participant records, and an automated export mechanism to common statistical packages. Participants could opt in to receive a $5 gift card to Amazon as compensation for their time.

After data collection was completed, the data from Survey Monkey was merged with the data from REDCap and prepped for analysis. The initial merged sample consisted of 621 eligible respondents (i.e., those who were over the age of 18 and reported that they had a disability). We deleted 55 cases because respondents did not complete any of the items (e.g., only provided demographic information). This resulted in a final sample of 566 respondents who completed the pilot version of the factor exploration tool.

Participants

Participants’ (N = 566) ranged in age from 18 to 78 (M = 36.1; SD = 11.76). A slight majority of respondents identified as female, 51.9%, whereas 35.9% identified as male, and 12.2% did not report any gender identity. The reported races of the participants were as follows: 70.8% White/Caucasian, 9.7% African American/Black, 3.7% American Indian or Alaska Native, 2.8% Native Hawaiian or Pacific Islander, 1.6% Asian, and 2.1% multiple races.

In terms of the types of disabilities represented, 62.5% indicated having a hidden disability and 57.8% indicated having a visible disability. The percentages do not sum to 100% because 20.3% of respondents indicated having both a visible and hidden disability. Specific disabilities included physical disability (42.9%), emotional-behavior disability (28.8%), other health impairment (21.6%), autism (9.7%), learning disability (8%), hearing loss or deafness (6.9%), vision disability or blindness (6.9%), intellectual disability (3.4%), speech-language disability (2.7%), and “other” disability (8.8%). Missing value analysis for the items revealed a range of 4%–10%. Missing data patterns did not statistically vary by demographic variables. The sample included a range of disability diagnoses and length of onset because of the variety of organizations contacted and their respective missions and reach in different communities.

Analysis Plan and Summary

Several steps were taken in the initial factor exploration of disability identity. Table 2 summarizes the total number of items and decisions that were made throughout the process.

A summary of these steps is provided here. The first step of the process consisted of the initial item construction. In this step, items were developed for each of the a priori factors based on theory and literature. There were 102 items presented to adults with disabilities. EFA is specifically suitable for scale development or factor analysis when there is little theoretical basis for specifying a priori the number and patterns of common factors (Fabrigar, Wegener, MacCallum, & Strahan, 1999; Hurley et al., 1997). The second step used the 102 items to conduct an EFA using Mplus 8.2 (Muthén & Muthén, 1998–2017). Since the items were categorical, we used the mean and variance adjusted weighted least squares (WLSMV) estimator to estimate the EFA model. All 566 participants were used in the analysis. Factor loadings of .45 or higher was used as an indicator of factor loadings to be retained. One of the most critical methodological decisions for researchers using EFA is the number of factors to retain. We used parallel analysis (PA) to determine the number of factors to retain. Research on the accuracy of determining the number of factors to retain supports the superiority of Horn’s (1965) PA approach (e.g., see Zwick & Velicer, 1986). Specifically, Zwick and Velicer conducted an evaluation of five-factor extraction and retention techniques and found PA to be the most accurate regarding the decision of how many factors to retain (i.e., correct 92% of the time). In their research, the authors also report that PA sometimes yields too many factors to retain (i.e., overfactors). Eaton, Velicer, and Fava (1999) compared PA, minimum average partial (MAP), and the K1 (Kaiser) criterion and concluded that PA was the most accurate approach, followed closely by MAP, with K1 being extremely

1 It should be noted that as a result of this project, the lead author has since worked with REDCap developers and programmers and all instances of REDCap are now screen reader compatible.
inaccurate. Finally, in reviewing the evidence on factor retention, Glorfeld (1995) and Velicer and colleagues (2000) concluded that there is little reason to choose another technique other than PA when deciding on the number of factors to retain. After running the EFA 30 of the 102 items did not load at .45 or higher and were removed leaving 72 items. The third step then removed one cross-loading which results in 71 items. In the fourth step we sent the 71 items to expert reviewers for an evaluation of their substantive importance. Using content validity ratio scores from content experts 34 items were retained and 37 items were dropped. More details about the expert reviewer process is provided after the summary of the main findings from the resulting EFA. Step 5 assessed the factor loadings or the 37 dropped items based on the content experts and nine of the items had high loading of .70 or higher and were added back into the model. Step 6 assessed the logical sense, interitem correlations, and Cronbach’s alpha reliability of the factors and items. As a result, six items were dropped that resulted in 37 items that were retained in our final EFA model. The final four distinct factors were: (a) internal beliefs about own disability and the disability community (eigenvalue = 27.880), (b) anger and frustration with disability experiences (eigenvalue = 4.473), (c) adoption of disability community values (eigenvalue = 4.543), and (d) contribution to the disability community (eigenvalue = 9.294). Table 3 presents the factor loading and standard errors for each of the four factors and Table 4 presents the correlations between each of the four factors. More details of each of these steps and findings are provided below.

Results

EFA

Results of the EFA using the WLSMV estimator available in Mplus 8.2 (Muthén & Muthén, 1998–2017) with a geomin oblique rotation are presented below. We used PA along with substantive interpretation to help guide the selection of the four-factor model that was retained. The initial EFA model pointed to a five-factor model; however, after substantive evaluations our final model retained a four-factor model with 37 loading survey items. Kaiser-Meyer-Olkin measure of sampling adequacy was .968 indicating that a large proportion of variance in the indicators may be caused by underlying factors. The Bartlett’s test of sphericity was also significant (p < .001) indicating that the correlation matrix is not an identity matrix and that the indicators are related to each other. Taken together, these results suggest that factor analysis may be a useful modeling strategy for the data. The initial EFA was conducted which yielded a five-factor model with 72 items. Using .45 as a cutoff for saliently factor loadings, one item loaded on two factors (cross-loaded) and was removed from the EFA model which resulted in 71 items. This item was, “I am able to contribute to society” and loaded on Factor 3 (0.543) and Factor 4 (0.478). Content experts were then solicited to assess the resulting 71 items.

Expert Reviewers

We sent these 71 items to content reviewers for an evaluation for their relevance and importance. Using content experts is an established method to aid in scale development process (Zaman-zadeh et al., 2015), especially in an understudied and specific content area (Lawshe, 1975; Wilson, Pan, & Schumsky, 2012). Other scale development papers have utilized this approach of a content validity ratio sometimes referred to as a content validity index (Sadeghi-Bazargani et al., 2014; Schilling, Dixon, Knaf1, Grey, Ives, & Lynn, 2007). Wilson et al. (2012) outline the many types of scales that have used Lawshe’s content validity ratio (CVR) to develop scales across many disciplines (Wilson et al., 2012; see pages 199–200 specifically). The reviewers included five doctoral-level (PhD or PsyD) researchers with disabilities who conduct disability-related research. Following the process outlined by Lawshe (1975) and Wilson et al. (2012), content experts were presented with a description of each factor and the proposed items for each factor and asked to rank each item as essential, helpful but not essential, or not essential to that factor. We calculated a CVR: 

\[ \text{CVR} = \left( \frac{N - \frac{N}{2}}{\frac{N}{2}} \right) \]

where Ne was the number of expert reviewers who stated that the item was “essential” and N was the total number of expert reviewers (N = 5). We used 0.2 or above as the criteria which identified 34 items to be retained and resulting in dropping 37 items.

We compared these results with the findings from the EFA to explicitly examine if there were any items with a high loading (over .70) that were not deemed as essential by the content reviewers. Nine items were identified, and it was decided to add them back in, bringing the item total to 43. This decision-based algorithm was used because of the recognition that we are in the scale development stage. Retaining items based on a marginal set of criteria (i.e., subjective) would only serve to produce a final scale where some set items would likely not reproduce in a cross-validation study with a complete separate independent sample. This approach was used to balance the statistical integrity of the items with high loadings (at or over .70) as well as respecting the opinion of the content experts for the items with loadings

Table 2

<table>
<thead>
<tr>
<th>Total Number of Items and Summary of Decision Processes</th>
</tr>
</thead>
<tbody>
<tr>
<td>Total number of items</td>
</tr>
<tr>
<td>102</td>
</tr>
<tr>
<td>72</td>
</tr>
<tr>
<td>71</td>
</tr>
<tr>
<td>34</td>
</tr>
<tr>
<td>43</td>
</tr>
<tr>
<td>37</td>
</tr>
</tbody>
</table>

Note. EFA = exploratory factor analysis.
between .45 and .70. We then assessed substantive interpretability of the five factors (43 items).

### Assessing the Five-Factor EFA

A detailed description of how we arrived at the final four-factor model is provided next. We assessed each of the five factors to see if the 43 items retained made logical sense based on the literature, content of the items, and input from the expert reviewers. Included in this step, we calculated Cronbach’s alphas for each factor and assessed each factor for interitem correlations. Four of the five factors made logical sense including the assessment of the content of the items, but one did not, as such, we retained four factors.

#### Table 3

**Factor Loading and Standard Errors of 37 Items Retained From EFA**

<table>
<thead>
<tr>
<th>Item</th>
<th>Factor loading (SE)</th>
</tr>
</thead>
<tbody>
<tr>
<td>1. I like (or would like) attending disability-related talks or</td>
<td>.733 (0.046)</td>
</tr>
<tr>
<td>lectures</td>
<td></td>
</tr>
<tr>
<td>2. I like (or would like) attending events hosted by</td>
<td>.730 (0.045)</td>
</tr>
<tr>
<td>disability-related organizations.</td>
<td></td>
</tr>
<tr>
<td>3. I learn about disability culture by reading books/articles/blogs/</td>
<td>.668 (0.042)</td>
</tr>
<tr>
<td>websites</td>
<td></td>
</tr>
<tr>
<td>4. Being a person with a disability is an important reflection of</td>
<td>.685 (0.038)</td>
</tr>
<tr>
<td>me.</td>
<td></td>
</tr>
<tr>
<td>5. I believe there is a disability community.</td>
<td>.635 (0.049)</td>
</tr>
<tr>
<td>6. I like (or would like) attending disability-related advocacy</td>
<td>.630 (0.047)</td>
</tr>
<tr>
<td>events (i.e., rallies, protests, policy town halls)</td>
<td></td>
</tr>
<tr>
<td>7. I identify with disability culture.</td>
<td>.805 (0.040)</td>
</tr>
<tr>
<td>8. I identify with a disability community.</td>
<td>.762 (0.032)</td>
</tr>
<tr>
<td>9. I seek out friends who have disabilities.</td>
<td>.594 (0.043)</td>
</tr>
<tr>
<td>10. I embrace the core values of disability culture as my own.</td>
<td>.645 (0.035)</td>
</tr>
<tr>
<td>11. I identify as a person with a disability.</td>
<td>.572 (0.049)</td>
</tr>
<tr>
<td>12. I have a strong sense of belonging to people with disabilities.</td>
<td>.598 (0.038)</td>
</tr>
<tr>
<td>13. I am proud to identify as a person with a disability.</td>
<td>.574 (0.038)</td>
</tr>
<tr>
<td>14. I think of my disability as a core part of who I am.</td>
<td>.560 (0.046)</td>
</tr>
<tr>
<td>15. I like (or would like) attending disability community events.</td>
<td>.722 (0.035)</td>
</tr>
<tr>
<td>16. I have a sense of belonging to the disability community.</td>
<td>.605 (0.041)</td>
</tr>
<tr>
<td>17. I believe there is a disability culture.</td>
<td>.639 (0.052)</td>
</tr>
<tr>
<td>18. I engage with the disability community.</td>
<td>.462 (0.050)</td>
</tr>
<tr>
<td>19. If there was a 'magic pill' that would take away my disability</td>
<td>.701 (0.030)</td>
</tr>
<tr>
<td>with no side effects, I would take it.</td>
<td></td>
</tr>
<tr>
<td>20. I wish that I was not disabled.</td>
<td>.479 (0.035)</td>
</tr>
<tr>
<td>21. There are some days that I wish I did not have a disability.</td>
<td>.722 (0.027)</td>
</tr>
<tr>
<td>22. When I think about my disability, I get upset.</td>
<td>.361 (0.039)</td>
</tr>
<tr>
<td>23. If I witness someone else facing discrimination on the basis of</td>
<td>.485 (0.041)</td>
</tr>
<tr>
<td>any disability, I do something about it.</td>
<td></td>
</tr>
<tr>
<td>24. I advocate for accessibility.</td>
<td>.479 (0.043)</td>
</tr>
<tr>
<td>25. I advocate for inclusion.</td>
<td>.456 (0.046)</td>
</tr>
<tr>
<td>26. If I witness someone else facing an access barrier, I do</td>
<td>.561 (0.041)</td>
</tr>
<tr>
<td>something about it.</td>
<td></td>
</tr>
<tr>
<td>27. I organize events for the disability community (i.e.,</td>
<td>.781 (0.038)</td>
</tr>
<tr>
<td>support group meetings, sporting events, advocacy events,</td>
<td></td>
</tr>
<tr>
<td>lectures).</td>
<td></td>
</tr>
<tr>
<td>28. I am a mentor to other people with my disability.</td>
<td>.451 (0.053)</td>
</tr>
<tr>
<td>29. I give advice to other people with disabilities.</td>
<td>.632 (0.040)</td>
</tr>
<tr>
<td>30. I view myself as a disability expert.</td>
<td>.619 (0.040)</td>
</tr>
<tr>
<td>31. I connect people with disabilities to the disability</td>
<td>.647 (0.042)</td>
</tr>
<tr>
<td>community.</td>
<td></td>
</tr>
<tr>
<td>32. I am a mentor to other people with disabilities.</td>
<td>.666 (0.036)</td>
</tr>
<tr>
<td>33. I am able to contribute to the disability community.</td>
<td>.599 (0.042)</td>
</tr>
<tr>
<td>34. I speak publicly about disability (in person or online).</td>
<td>.762 (0.042)</td>
</tr>
<tr>
<td>35. I donate to disability-related organizations.</td>
<td>.998 (0.040)</td>
</tr>
<tr>
<td>36. I fundraise for disability-related causes.</td>
<td>.815 (0.043)</td>
</tr>
<tr>
<td>37. I serve on disability-related panels, Boards or committee.</td>
<td></td>
</tr>
</tbody>
</table>

*Note.* EFA = exploratory factor analysis.

#### Table 4

**Correlations Between the Four Factors of Disability Identity**

<table>
<thead>
<tr>
<th></th>
<th></th>
<th></th>
<th></th>
<th></th>
</tr>
</thead>
<tbody>
<tr>
<td>1. Internal beliefs</td>
<td>1</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>2. Anger-frustration</td>
<td>-0.145*</td>
<td>1</td>
<td></td>
<td></td>
</tr>
<tr>
<td>3. Adoption</td>
<td>0.237*</td>
<td>-0.142*</td>
<td>1</td>
<td></td>
</tr>
<tr>
<td>4. Contribution</td>
<td>0.640*</td>
<td>-0.204*</td>
<td>0.125*</td>
<td>1</td>
</tr>
</tbody>
</table>

*Note.* Significant at *p* < .05.
Factor 1 is comprised of 18 items and the average of the interitem correlations was 0.48. The Cronbach’s alpha for this factor is .943.

Factor 2 initially was comprised of 13 items with an average interitem correlation of 0.45. However, upon closer examination, there were two items (“I give advice to other people with disabilities” and “I donate to disability-related organizations”) with very low correlation values ranging from .191 to .290. Based on this information from the interitem correlation table, it was decided to drop these two items. The revised Factor 2 is comprised of 11 items with an average interitem correlation of .48. The Cronbach’s alpha for this revised factor is .909. This brought the total number of items to 41.

Factor 3 initially was comprised of five items with an average interitem correlation of 0.44. However, upon closer examination, there was one item (“I am just as much a part of my community as my non-disabled peers’) with low correlation values ranging from .284 to .330. Based on this information from the interitem correlation table, it was decided to drop this item. The revised Factor 3 is comprised of four items with an average interitem correlation of 0.53. The Cronbach’s alpha for this revised factor is .815. This brought our total number of items to 40.

Factor 4 is comprised of four items and the average interitem correlation was .47. The Cronbach’s alpha for this factor is .781.

Factor 5, comprised of three items, did not make logical sense: two items related to relationships with individuals without disabilities and one related to participating in sporting events. Furthermore, the interitem correlation matrix average was .164 and the Cronbach’s alpha was .374. In alignment with Zwick and Velicer’s (1986) findings, we know that PA sometimes yields too many factors to retain. We believe that Factor 5 was an example of this phenomenon, which led to overfactorization. This factor did not make logical sense, was not supported by the average interitem correlation matrix, and had an unacceptably low alpha reliability estimate. Therefore, it was decided to drop Factor 5 including the three related items. This left us with 37 items as summarized in Table 2. Factor loadings for each item within the four factors are presented in Table 3. Correlations between the four factors are presented in Table 4. A description of the retained four factors is provided below.

Four Factors of Disability Identity

Factor 1: Internal beliefs about own disability and the disability community. This factor is about the perception the person with a disability feels of their relationship to other persons with disabilities and the disability community. It describes the internal beliefs, values, and experience of connection for the person with a disability and describes a draw toward others who share similar experiences of disability and/or impairment. These internal beliefs and values include examples of ideas about the individual (the belief that disability is a part of who they are) as well as actions that demonstrate those beliefs within passive/group-oriented disability community activities (rallies, reading online blogs, attending lectures).

Factor 2: Anger and frustration with disability experiences. Factor 2 considers an individual’s internal frustration about their disability. Frustration could be seen as a facet of acceptance, however, acceptance has a positive connotation and frustration carries a negative connotation; as such, we categorized frustrations as its own construct that has both internal and external processing components. Frustration is not considered to be a static state; rather, internal frustration over one’s disability is fluid and can change. This factor is about one’s internal frustration and wrestling with the negative aspects of one’s disability. Not all individuals with disabilities exhibit positive acceptance of or embodiment of one’s disability identity at all times. Frustration could be seen as a facet of acceptance. Anger and frustration about the negative aspects of disability is not considered to be a static state: rather, internal frustration over one’s disability is fluid and can change. This frustration and anger may occur as a result of individual factors (i.e., pain, fatigue) or external/societal factors (i.e., inaccessible environments, discriminatory attitudes, lack of support, lack of solidarity). This factor may vary based on group level differences (onset of disability, type of disability). Potentially, people who think about their disability for a longer period of time, or who have a particular disability onset (i.e., acquired vs. from birth) may have differing emotional reactions worth distinguishing.

Factor 3: Adoption of disability community values. This factor is about a person with a disability feeling a strong connection to the core value of the disability community of activism and combating ableism, and adopting this as part of their sense of self. This includes advocating and acting to remove social or physical barriers that affect other people with disabilities. An individual may actualize their values through advocacy in their local community (i.e., working to install a ramp in an inaccessible community location), or on behalf of another individual (intervening in the case of discrimination).

Factor 4: Contribution to the disability community. This factor is about the disabled person contributing to the disability community. It represents the disabled person’s lived experience and public engagement with the disability community, including taking an active role in mentorship, speaking publicly, and fundraising.

Discussion

The identification of the four factors (internal beliefs, frustration, adoption of values, contributions) represents personal experiences of people with disabilities across a wide spectrum of visible (apparent) and invisible (less apparent) impairments. These four factors map fairly well onto the proposed developmental statuses from the initial qualitative work (see Table 1). Internal beliefs (Factor 1) and frustration (Factor 2) seem to be aspects of acceptance and relationships, adoption of values (Factor 3) relates to the previously proposed adoption status and contributions (Factor 4) relates to the engagement status. To begin, the results indicated that there are common identity experiences across visible and hidden disability categories. It seems fundamentally important to further explore the potential differences between invisible and visible disability identities to see if there are distinctions based on length of time of disability interacting with the visibility of one’s disability, or if there are differences within this connection or bond group with certain hidden disability types. The challenge with these types of relationships and bonds were that they were multidimensional and therefore not able to be explored in this initial study, though is a promising area for future work.
Second, emerging factors have both internal and external components. Oftentimes interventionists design therapies and therapeutic programs to address the visible impact of one’s disability or impairment, but rarely engage with the internal processing or development of disability identity and understanding (Finkelson, 1993). Instead, there is an external problematic behavior exhibited before intervention at the psychological level to assist with processing of one’s identity or acceptance (or lack thereof). While further research is needed to further substantiate this claim, the current work suggests that disability identity is multidimensional and includes important internal and external components. Furthermore, there seems to be a fundamental difference between centering one’s own disability experience with engagement or contributing to the disability community, versus advocating more generally for other individuals and for the broader community; this is evidence of cross-disability solidarity. In considering disability identity for an individual, this factor exploration suggests the importance of disability community engagement. While internal negotiations and ideas about disability are significant in shaping disability identity, the internalization of these ideas about disability are equally important because it impacts how one participates in a broader disability community at large.

Relatedly, acceptance of disability and internalization of disability community values is not conceptualized as a simple “on and off” switch. Acceptance (especially of disability or impairment) is often viewed positively, but we must also consider the potentially negatively viewed aspects of acceptance, including occasional frustration or acknowledgment of the negative aspects of having a disability. Our findings suggest that it is possible that frustration and anger are a vital component to one’s disability identity development and may be revisited multiple times throughout one’s life span. This finding is also corroborated by the previous work from Gromes and Linkowski (2010). Particularly, given the inaccessible environments and often stigmatized social reality of disability that people navigate daily, it is natural that frustration would be a part of the dimension of disability identity. It is important to consider what is illuminated when we think of frustration as an expected phenomenon, but not the only experience in developing disability identity.

Importantly, there is not one actualized state or one monolithic disability identity; rather this preliminary exploration of the dimensions of disability identity development suggests a rejection of the “supercrip” narrative. The supercrip perspective is often lauded by nondisabled individuals, and frames individuals with disabilities as having “overcome” their disability (Hardin, Hardin, Lynn, & Walsdorf, 2001) and are viewed as “superhuman” because of achieving unexpected accomplishments (Zhang & Haller, 2013) and perhaps as having “achieved” or “reached” disability identity synthesis. On the contrary, as Shapiro (1994) stated, the supercrip model is resonated by many people with disabilities who are simply trying to lead their lives, and the complexity of disability identity development indicates a fierce rejection of this narrative. Instead, as evidenced by the frustration construct and the multiple ways of contribution to and engagement with the disability community, the message from participants was clear: there is no one way to develop a disability identity, and no “finish line” for this identity development process. Developing disability identity development, then, becomes an ongoing process of internal and community engagement that is worthy of further exploration and support.

Limitations

Notwithstanding the contributions of the current study, several limitations should be noted. First, the sample included people who were likely connected to disability organizations in some way, including membership, subscribing to disability-focused listservs, and participation in activities or activism. These participants may have had some stronger or more developed aspects of disability identity development as a result of this connection to or with disability organizations. However, participant recruitment with newly disabled participants, or participants who are entirely disconnected from disability contexts is challenging. Newly disabled participants may be in crisis and/or managing care and adjustment to disability; potential participants who do not have any connection to disability supports may have chosen this due to their own personal ideas about disability being a negative or shameful aspect of their lives which would be problematized by the participation in a study. An interesting follow-up study would be to more specifically target these sampling populations or others with less consistent access to disability community (recruitment at hospitals, doctors’ offices, rehabilitation centers, etc.).

In addition, we could not validate these findings using a CFA or to examine the construct validity. While further work is needed to assess the reliability and validity in samples that include other disabilities as well as convergent validity, the current study provides the initial construction that will be used in a future CFA study.

Future Directions

Five major directions for future research on the factor exploration of disability identity are offered. First, we plan to further validate these findings by collecting data from a new sample of adults with disabilities to perform a CFA. It is hoped that this step will lead to a valid and reliable measure of adult disability identity development. Additional analysis and data collection are also needed to assess the generalizability of the current findings with more intentional inclusion of individuals with disabilities from different racial groups and ethnicities.

Second, we plan to assess the utility of the disability identity factors for youth populations of persons with disabilities and adapt it as necessary. Currently, only adults over 18 years of age were included in this preliminary scale development. An adapted youth-oriented scale will facilitate needed research that will inform intervention designs that support individuals who are newly disabled, and support adolescents who are contending with identity formation and psychosocial adjustment. The use of such a scale will also allow for further research on psychological outcomes of youth with disabilities.

Third, as mentioned in the discussion, further exploration is needed to better understand differences in disability identity between certain characteristics of participants, such as those with invisible or less apparent and visible or apparent disability identities or length of onset of disability. There may be distinctions based on length of time of disability interacting with the visibility of one’s disability; or if there are differences within this connection or bond group with certain hidden disability types.

Fourth, we want to further explore the relationships between and among individuals with visible and hidden disabilities. It is possible that a subscale could be developed as an add-on to this tool.
to explore in more depth to account for differences or similarities of relationships with individuals with any disability or if it has to be the same shared disability. Finally, a fifth direction for future research involving a valid measure of disability identity involves rehabilitation psychologists, researchers and related professionals designing studies, such as randomized control studies, to explore effectiveness of specific interventions on disability identity.

In closing, this factor analysis demonstrates that disability identity is complex and there is no one actualized state or status. However, a better understanding of what disability identity is and what the related developmental statuses look like will allow for better assessment of how to assist individuals along their disability identity journey. The factor exploration is a first step in the process of creating a valid measure of disability identity; but as further analyses are conducted, we hope to demonstrate the importance of this phenomenon, and eventually create and tailor interventions for persons with disabilities no matter where they may be in their process of developing disability identity.

References


