Respectful Language as Perceived by People with Disabilities

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ABSTRACT

Respectfully and adequately referring to people with various disabilities is difficult due to societal norms and constantly evolving languages. In this work, we address the question of how expert researchers in the field of accessibility are referring to people with disabilities and whether this terminology corresponds to how people with disabilities prefer to be addressed. By conducting a systematic literature review of the past three ASSETS proceeding, we summarize how accessibility researchers are currently referring to people with disabilities in English. A survey of 63 people with disabilities further revealed that while researchers from ASSETS are using terms that are mostly aligned with participants' expectations, the same terminologies can be perceived both respectful and disrespectful by varying participants. Through this preliminary work, we pave the path for researchers to further explore respectful terminology and encourage researchers to improve the inclusivity and diversity of language use in our community.

CCS CONCEPTS

• **Human-centered computing** → **Accessibility**; • **disability language**;

KEYWORDS

Accessibility, Terminology, Language, Disabilities

1 INTRODUCTION

Researchers, designers, and developers of systems that target people with disabilities have a responsibility to use terminology that is respectful. However, people currently do not have a straightforward way of knowing how to best refer to people with disabilities. There

are guidelines, such as the "Accessible Writing Guide" [1] provided by the ACM Conference on Accessible Computing (ASSETS), which present best practices in the field; however, they may not be up to date, they do not include all the disabilities that are being researched, and it is not clear where the suggested phrases were gathered from.

To understand the status quo of referring to people with disabilities, we first examined how experts in accessibility (in our case, researchers publishing at ASSETS) refer to groups of people with varying disabilities. Analyzing the past three ASSETS proceedings (2018-2020) [2–4], we show that ASSETS authors share a set of commonly used terminologies when referring to people with disabilities, following either person-first language (PFL) or identity-first language (IFL) [5, 6]. To further study whether commonly used references are perceived as respectful by people with disabilities, we then conducted a survey with 63 participants falling under five disability groups. Our exploratory results indicate that (1) expert researchers are mostly using terms that people with disabilities perceive as respectful, but individuals might have varying preferences; (2) what is considered respectful and disrespectful can vary across people with disabilities, with some finding specific terms respectful while others noted the same term as an example for disrespectful terminology.

2 RELATED WORK

Until recently, the medical model of disability has been commonly used to describe people with disabilities which suggests that people are disabled by their impairments, only to be fixed with medical intervention [7]. Due to rising criticism, this view shifted in the 1980's to the social model of disability, which suggests that the disabling world is the problem by isolating and excluding people with disabilities from full participation in society [7, 8]. The social model consists of both person-first language (PFL) and identity-first language (IFL). PFL Prioritizes an individual before their disability and aims to separate a person from their diagnosis. IFL takes the opposite approach and emphasizes the disability first [5, 6]. Although these ideologies align with the accepted social model, it is argued that the use of PFL and IFL in disability research has material consequences for people including stigmatization, dehumanization, and violence. The debate in the use of PFL versus IFL should center

on disabled people's needs, autonomy, and rights to preserve their rights to self-determination [9].

A few guidelines on disability terminologies have emerged recently. For instance, "Writing About Accessibility" originally published in 2008 and updated in 2015, is a guideline for respectful terminology across various disability groups appropriate for academic publications in the accessibility field [10]. "Representing Users in Accessibility Research" is another guideline published in 2011 [11]. This source discusses common ways used to refer to people with disabilities and discusses which methods are preferred. In addition, the ASSETS conference has developed its own accessibility writing guide to introduce its community to respectful language when writing about people with disabilities [1, 10]. While these guidelines hold important and helpful material, it is often unclear where the information was gathered from. The guidelines are also not always up-to-date or inclusive of a wider range of disabilities. Constantly updated guidelines that are based on terms from the community exist for gender terminology [12], but a similar reference does not exist for people with disabilities.

3 SYSTEMATIC LITERATURE ANALYSIS

To understand the terminology used to refer to people with disabilities among expert researchers in the field of accessibility, we conducted a systematic literature analysis of papers published in the ASSETS proceedings.

3.1 Methodology

We focused on the three most recent ASSETS proceedings with a total of 106 technical papers to uncover commonly used terminology [2–4]. To systematically collect data, we first chose a few papers targeting different disability types and thoroughly read these papers to find all the terms used to refer to each population. In most cases, no more new terminology was introduced after the Abstract, Introduction and the Related Work sections of each paper; we therefore focused on reading through these sections for the extraction of terminology for the remaining papers and only skimmed the latter parts of the papers for variations of the terms we collected. We also utilized the "Find" function to (1) search for phrases that we already found in previous papers for the given population the paper was about, and (2) look up any person-first language by searching "people with" or "person with" as well as identity-first language by searching "<blank> person" or "<blank> people." For each paper, we noted down all variations of terminology used to refer to people with disabilities in general and to a specific disability group.

3.2 Results

Our analysis shows that ASSETS papers from 2018-2020 focused on five main disability types: blind & visually impaired (N=52, 49.06%), deaf & hard of hearing (N=16, 15.09%), mobility and physical disabilities (N=13, 12.26%), cognitive disabilities (N=12, 11,32%), and mental health conditions (N=1, 0.94%). Twelve papers (11.32%) targeted disability groups as a whole.

As a way to look at the data, we split the terms collected from ASSETS papers into person-first language and identity-first language, since it has been found that linguistic framing, including

the use of PFL and IFL, has material consequences for the disability community [9]. Of all papers, 12.26% used only identity-first language (e.g., blind person, deaf student), 29.25% used only person-first language (e.g., person who is visually impaired, users with learning disabilities) and 58.49% used both. Interestingly, the fraction of papers using only IFL increased from 4% in 2018 to 13% in 2019, and 16% in 2020, while the fraction of papers referring to both remained relatively stable (mean=58.89%, sd=2.41). From our analysis, we can observe that more researchers primarily choose PFL when referring to people with disabilities, but that over the past three years, more papers have used IFL. Nonetheless, the low sample size in our analysis demands future replications prior to drawing any conclusions.

Among PFL, the terms commonly used by authors in ASSETS include "people who are [X]" where X includes deaf or low vision. Authors also commonly used PFL such as "People/Person with [X]", with X representing cognitive disabilities or visual impairment. Less commonly seen PFL consists of "people who have [X]" where X is low vision, "people who use [X]" where X is wheelchair, and "people who are living with [X]" where X is intellectual disability. The most common IFL terms include "[X] people/person" where X is motor impaired, autistic, or deaf. There were additional terms interchangeably used such as "[X] individuals", and "[X] users".

4 SURVEY

To examine whether the disability terminologies used by the ASSETS community are perceived respectful by people with disabilities, we designed a survey targeting participants with various disabilities.

4.1 Methodology

The survey consisted of demographic questions including age, country, and disability (both general category they identify with, and a medical diagnosis) as well as 2 open ended questions allowing people to share phrases that they find respectful and disrespectful when referring to their disability. We specifically chose to ask about preferences for terms using open-ended questions to avoid biases from seeing specific options. Participants could identify as having more than a single disability. We posted our survey on disability-related subreddits, on Facebook, and on a university-internal mailing list.

4.1.1 Participants. We received 63 unique responses in total. Our participants identified across five main disability groups as shown in Table 1. Of the 61 participants who provided country of residence, 45 are from the United States of America, 8 from United Kingdom, 3 from Canada, 2 from Australia and 1 each from Ireland, Denmark and the Dominican Republic. Participants' ages were distributed over a wide range: 18-24 (47.4%), 25-34 (31.6%), 35-44 (17.5%), and 45-54 (3.5%).

4.1.2 Analysis. We first analyzed and grouped participants' responses into PFL and IFL and which was more respectful for each disability group. We then coded the responses, found the most common terms that participants raised, and compared those terms with the ones used in the ASSETS community.

Table 1: Participant distribution across disability groups where participants could identify with a single disability or more.

Disability Groups	N	Diagnosis
Blind and visually impaired	8	Partial vision loss (3); blind (5)
Deaf and hard of hearing	12	Partial hearing loss (9); deaf (3)
Mobility and physical Disabilities	15	wheelchair users (8), fibromyalgia (4) and autoimmune disorder (3)
Cognitive disabilities	34	Specified learning disabilities (10); ADHD (13); autism spectrum disorder (28); Acquired Brain Injury (4)
Mental Health Conditions	14	Anxiety (7); eating disorder (1); depression (9); bipolar disorder (1); avoidant personality disorder (1); post traumatic syndrome disorder (1)

4.2 Results

Our results show that the deaf & hard of hearing disability group preferred IFL over PFL, as did the autism disability group. However, most of our survey responses, such as the term "disabled", did not adhere to either structure, preventing us from finding a preference for PFL or IFL in the other disability groups. Furthermore, we explored the respectful and disrespectful terms, specifically looking for the respectful and disrespectful terms to describe a person's disability.

Among all disability groups, "disabled person" (N = 16/21) became the mostly mentioned respectful phrase for referring to people with disabilities. For the group of blind or visually impaired, the top two respectful phrases were "blind" (N = 6/8) and "visually impaired" (N = 6/8). In the deaf & hard of hearing group the most respectful terms were "hard of hearing" (N = 9/11) and "deaf" (N = 4/12). Among the mental health category, we found a recurring theme of participants preferring person first language i.e., "person with depression" or "person who has anxiety" over other terms. We did not find repeated responses in physical disability due to people's different diagnoses. In the group of cognitive disabilities, the top two respectful phrases were "autistic" (N = 23/28 people) and "person with autism" (N = 7/28). Similar to the mental health conditions, people prefer to be referred using person first languages such as "person who has ADHD".

Participants also listed several phrases that they would perceive as disrespectful. A top disrespectful term among all disability groups was "differently abled" (N = 15/21). For the blind & visually impaired, we found the most repeated disrespectful terms to be "blindy" (N = 2/8) and "blink(y)" (N = 2/8). In the deaf & hard of hearing group, the only repeated disrespectful term was "deaf and dumb/mute" (N = 4/12). In the mental health category, we found that among the various diagnoses, the most common disrespectful term was "mentally ill" (N = 3/14). In the physical impairment category, the most disrespectful terms mentioned were "crip/cripple/crippled" (N = 8/15) and "handicapped/handicapable" (N = 3/15). For cognitive disabilities, interestingly, "person with autism" (N = 11/35) showed up again as a disrespectful term as well as "retarded" (N = 9/35).

Although terminology is important, another main factor for respectful language is "the intention behind the speech" as mentioned by P54. For example, it is disrespectful to use terminology to refer to the blind & visually impaired that "implies [someone's] eyes need to be fixed ([they are] not broken)" (P39). Another example for disrespectful language to people with cognitive disabilities is "anything that implies [they are] just not trying hard enough —

it's not voluntary, not attention-seeking or wanting to be drama queens" (P22). When choosing what language to use one needs to find the balance between communicating a person's other abilities, communicating that this person may face significant barriers in their daily life and a way to signal the understanding of their needs and the willingness to accommodate them (P54).

Comparing the data gathered in our systematic literature analysis and in the survey, we found that among all terms used in ASSETS papers, roughly 30% were brought up by our participants. While those terms are perceived overall respectful, a few of them are only perceived respectful by some but not by others. As presented in Table 2, we gathered a list of terms across all disability groups that were also found in ASSETS that were found respectful and disrespectful at once by varying participants. For example, "visually impaired" and "hard of hearing" were found controversial but had more people finding it respectful and just a single person finding it disrespectful.

5 DISCUSSION AND CONCLUSION

In this paper, we reviewed 106 ASSETS papers from 2018-2020 on the use of respectful language when referring to people with disabilities and conducted a survey with 63 participants to surface terminology perceived as respectful. Our findings highlight that these preferences differ: While we identified a set of terms that is generally preferred by people with disabilities, some of our participants listed the same terms as disrespectful.

We also found that ASSETS publications generally use the terms that our survey participants deemed as respectful, with only few exceptions. When comparing our results to the ASSETS guidelines, we found that language use has only slightly shifted since they were authored. Our work validates these guidelines with a snapshot of respectful terminology that is based on the perception of people with disabilities and extends them by providing this terminology for more diverse groups of disabilities, including those most often mentioned in ASSETS publications.

What is apparent from our results is that variations in what people with disabilities perceive as respectful and disrespectful terminology are common, but that for most disability groups there is a general trend in preferred terminology. To some extent, few disagreements on the terminology used to refer to a specific disability group may suggest that this terminology is more stable over time, and perhaps that the type of disability has become more socially accepted. Those groups may have established a shared identity and preferences through exchanges in online and offline networks for

Table 2: terms found both respectful and disrespectful by people with disabilities

Disability group	Term	Respectful (N)	Disrespectful (N)	# of papers using term / Total # of papers
Blind & visually impaired (N=8)	Visually impaired	6	1	44/52
Deaf & hard of hearing (N=12)	Hard of hearing	9	1	16/16
	(partially) deaf	6	2	15/16
Learning disabilities (N=10)	Learning disability	3	1	4/6
Autism (N=28)	autistic	23	2	1/2
	On the spectrum	1	2	1/2
People with disabilities (N=21)	disabled	18	1	6/12
	Person with a disability	2	4	11/12

people with specific disabilities. In contrast, large disagreements on what constitutes respectful terminology may indicate that a disability is less socially accepted, such as the ones under the cognitive disability group.

Due to looking at only three years of research papers and a small, non-representative sample size, our work should only be seen as a preliminary step towards capturing preferred terminology and how it varies. We hope the variation in preferences for specific terminology used to refer to people with disabilities will be investigated more in the future.

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