

## Say What You Mean: Rethinking Disability Language in *Adapted Physical Activity Quarterly*

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*Adapted Physical Activity Quarterly (APAQ)* currently mandates that authors use person-first language in their publications. In this viewpoint article, we argue that although this policy is well intentioned, it betrays a very particular cultural and disciplinary approach to disability: one that is inappropriate given the international and multidisciplinary mandate of the journal. Further, we contend that *APAQ*'s current language policy may serve to delimit the range of high-quality articles submitted and to encourage both theoretical inconsistency and the erasure of the ways in which research participants self-identify. The article begins with narrative accounts of each of our negotiations with disability terminology in adapted physical activity research and practice. We then provide historical and theoretical contexts for person-first language, as well as various other widely circulated alternative English-language disability terminology. We close with four suggested revisions to *APAQ*'s language policy.

**Keywords:** history, labeling, methodological issues, sociological perspectives, wheelchair sport, dance

*Adapted Physical Activity Quarterly (APAQ)* prides itself on being "an international, multidisciplinary journal, designed to stimulate and communicate scholarly inquiry related to physical activity, which includes sport" (*Adapted Physical Activity Quarterly*, 2013a). *APAQ*'s current language policy, we argue, may undermine this mission in a number of important ways, including the degree to which research can represent international, multidisciplinary, stimulating, and rigorous perspectives on one of the major themes of research in adapted physical activity (APA): disability.

*APAQ*'s current language policy instructs authors to:

use person-first, non-sexist language in your writing . . . Refer to disabled citizens as individuals with disabilities. Avoid using characteristic and attribute. Instead, use demographic data, diagnostic criteria met, behaviors, or indicators.

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Do not assume commonalities; base language on individual assessment.  
(*Adapted Physical Activity Quarterly*, 2013b)

This policy has some significant strengths. It urges authors to use language that is respectful and recognizes the humanity of participants beyond the attributes studied. It also, importantly, warns against stereotypical assumptions of sameness and inappropriate generalizations. We commend these aspects of the language policy.

This policy also, however, has its limitations and biases. *APAQ*'s current language policy (*Adapted Physical Activity Quarterly*, 2013b) is modeled on that of the American Psychological Association. As we will detail later in this article, this policy represents a very specific cultural (i.e., American) and disciplinary (i.e., psychology) approach to talking about (and thus thinking about) disability. This language policy, and its underlying cultural and disciplinary biases, may be appropriate for a national discipline-specific organization such as the American Psychological Association, but we contend that as "an international, multidisciplinary journal," *Adapted Physical Activity Quarterly* (2013a) would benefit greatly from identifying and questioning the assumptions that underlie this exclusive person-first language policy. In this sense, our article continues conversations brought to the fore at the 1996 North American Federation of Adapted Physical Activity Symposium and expounded upon in *APAQ*'s 1998 Special Issue titled "Questioning Our Research Assumptions." Within these crucial conversations, "the expression and constructive criticism of different research assumptions and practice were [presented as] essential to the ongoing inquiry, reflection, and development processes in adapted physical activity" (Bouffard & Watkinson, 1998, p. 205). This conference and special issue included both arguments for, and practices of, clearly articulated research assumptions and generous and curious engagements in debate. It is in this spirit that we attempt to unearth some of the assumptions underlying our disability language and that we offer our own "work in progress" toward these crucial conversations.

In this viewpoint article, we maintain that universally mandating disability terminologies borrowed from American psychology may serve to either exclude research that does not share the basic cultural and theoretical assumptions of American psychology (as described in more detail below) or force researchers to adopt language that contradicts the epistemologies, theories, methodologies, ethical precepts, or cultural specificities adopted in their research. Neither the exclusion of relevant quality research that could introduce new theories and perspectives into our field nor the lack of theoretical consistency within published *APAQ* research serves *APAQ*'s intention of publishing rigorous, international, multidisciplinary, and stimulating scholarly work.

The limitations imposed by our current language policy have not gone unnoticed or unchallenged by *APAQ*'s contributors and editorial board. The recognition of multiple disability understandings and terminologies outside of the policy, for example, is evidenced by authors who explicitly articulate their rationale for their chosen disability terminology, even when it fits within *APAQ*'s current language policy (e.g., Grenier, Wright, Collins, & Kearns, in press). These limitations are also evidenced by a handful of published *APAQ* articles that include language that lies outside of the official policy, including, for example: "persons experiencing disability" (Goodwin & Rossow-Kimball, 2012); "living with a disability" (Bredahl, 2013); "adults with mobility impairments" (Morphy & Goodwin, 2012);

“wheelchair dependent participants” (Goosey-Tolfrey & Crosland, 2010); “classifiable athletes” (Spencer-Cavaliere & Peers, 2011); and “deaf children” (Hartman, Houwen, & Visscher, 2011). It is worth noting that not all of these deviations from *APAQ*’s language policy are ones that we believe should be supported. Some of these deviations read as carefully considered, respectful, and theoretically consistent. Others use terminology interchangeably or use disrespectful or theoretically inconsistent terms without a clear rationale for doing so. Our discussion below will help to elucidate these distinctions.

Given that the current language policy is neither universally accepted nor applied, we believe a dialogue around disability language in *APAQ* is long overdue. In this article, we argue for an expanded set of language standards in which authors have more choices in their disability terminology and in which all authors are held explicitly accountable for the disability terminology they use. In expanding and contextualizing disability terminology, we hope to maintain *APAQ*’s commitment to respect and rigor, all the while enabling a wider range of theoretical approaches to disability; more cultural, historical, theoretical, and methodological specificity and consistency; and, importantly, more opportunity to engage politically, ethically, and respectfully with the worldviews of individuals and communities with whom we study.

It is worth acknowledging that debates around disability terminology have not escaped criticism. Most notably Shakespeare (2013), a prominent disability scholar, argued that, “quibbling over ‘disabled people’ versus ‘people with disabilities’ is a diversion from making common cause to promote the inclusion and rights of disabled people” (p. 19). Importantly, however, this statement is contextualized within an argument about the dangers of one disability model policing and negating all knowledge, strategies, and terminologies produced outside of it. Early in the same paragraph, Shakespeare clarifies: “while terminology is important, it is not [as] important as underlying values” (p. 19). Our argument, therefore, is remarkably in alignment with this seeming critique of arguments such as ours; that is, we agree that multiple models and terminologies of disability should be enabled to coexist within *APAQ* (without unnecessary “quibbling” and silencing). Furthermore, we agree that such terminology should be judged not by one model’s claim on the universally “correct” language; rather, it should be judged within the context of the model, theories, and values that the author is articulating. Our most striking departure from Shakespeare, however, is that we place more emphasis on the ways in which terminology is directly linked to the values and ideas being articulated. This point will be emphasized most clearly later in this article when we offer an overview of the historical emergence of rights-based and social models of disability and how disability movements on both sides of the Atlantic ocean prioritized shifts in terminology as integral strategies for their respective social struggles.

We begin with three brief narratives about each of our own struggles with disability terminology in *APA*. We then offer a historical and theoretical overview of the currently mandated person-first language, to identify its theoretical and cultural biases and to clarify some of the research contexts for which such language can be a strong fit. Next, we introduce a series of other widely circulated English-language disability terminology and suggest contexts in which they may be most appropriately used. We limit this discussion to English terms because it is the journal’s language of publication and because our expertise is currently limited to these contexts. Finally,

with this historical and theoretical background in mind, we offer four suggestions for improving the current *APAQ* language policy.

## **Negotiating Disability Terminology in APA: Three Narrative Case Studies**

In this section, we each briefly explore some of the struggles and opportunities that have emerged in our own APA research and practice contexts, in relation to disability terminology. We share these experiences to demonstrate how continual engagement with research communities, and theoretical and ethical reflection, led each of us to understand the importance of, and current limitations of, disability terminology in APA (and *APAQ* in particular). We also hope to demonstrate how this process, although difficult, potentially mitigated unintentional outcomes and may have created new opportunities, theoretical insights, and relationships.

### **Alienation and Misrepresentation: Experiences of a Participant-Turned-Researcher (Peers)**

In my career as a Paralympic athlete, I was often recruited to participate in APA research, ranging from the biomechanics of wheeling to the identity effects of wheelchair sport. Although most of the researchers seemed well-meaning, their questions and resulting publications<sup>1</sup> often felt like misrepresentations, if not complete betrayals.

During my first few interviews, for example, I was fully ambulatory and using a wheelchair only for sport. I did not understand myself (and was rarely understood by others) as “having” a disability. I read in confusion and later mistrust as I and two other ambulatory athletes with minor knee or ankle overuse injuries were represented as “athletes with disabilities.” I remember feeling really uncomfortable about this nonconsensual and inaccurate representation of my sporting community and myself.

A few years later, once I had started regularly using a wheelchair, a researcher asked me: “What disability do you have?” I responded that I did not *have* a disability, but rather that the vast majority of my struggles were the result of disabling social barriers to housing and full participation in my community. I explained the terminology that I was more comfortable with, and that I felt that my diagnosis was far less relevant to the issues being studied than were social barriers. In introducing my quotes in the resulting publication, the researcher articulated me as “having muscular dystrophy.” I was also equated to this diagnosis within the accompanying demographic chart. I felt totally misrepresented and betrayed: first because my wishes for self-identification were blatantly disregarded, and second because in our very small wheelchair sports community, my relatively rare diagnosis denied me any hope of anonymity. In fact, I could identify at least half of my fellow athlete-participants from the demographic data associated with their pseudonyms. I contacted the researcher and asked how this possibly qualified as ethical research. The response was that these decisions were required for publication.

After this last of nearly a dozen experiences as a research participant, I joined the many athletes who refuse to participate in APA research. Though some of my research-participant experiences had felt really positive, these were undermined by the times when I felt misrepresented, alienated, and betrayed. It was years later, after I began doing research of my own and meeting scholars who seemed eager to hear my ethical critiques, that I came to believe that critique and dialogue is more powerful than refusal. I believe that conversations such as these can shift research in this field to become more respectful of the voices, identities, and worldviews of the individuals and communities with whom we research.

### **“With and Without Disabilities”? A Practitioner-Researcher’s Perspective (Eales)**

After a mental-illness-induced vacation from my occupational therapy degree, I found myself with a year to explore what brought meaning to my life: dance. I embarked on a research project investigating ability, disability, and integration in the dance context. As a result of this project, I cofounded an integrated dance group, which I would introduce as dance for people “with and without disabilities.” My occupational therapy training and background in psychology taught me that this was a respectful and accurate way of representing our group of diverse dancers.

Over the past 8 years of teaching dance and creating performances with this community, we have had many discussions about the language of disability and inclusion. I came to understand that diagnosis was sometimes relevant to ensure the safety of our dancers. At the same time, centering diagnoses made it harder to honor the expertise that the dancers had about their own bodies, the skills they had in mobilizing within the world, and the ways that they self-identified. Further, I struggled to find appropriate language for communicating with the media about who our group was and what we did to increase physical, social, and financial accessibility within the dance community.

As I began my graduate degree, I wondered about the unintended consequences of articulating our group as dance for people “with and without disabilities.” The term potentially (and unintentionally) undermined our program’s purpose of inclusion, as it artificially created a binary division between two groups of people. In addition, as I learned more about the social model of disability, I came to question whether our dancers *had* disabilities (i.e., dancers “with” disabilities) or our dancers were *disabled* by social structures, policies, and attitudes. At the same time, stating that we did integrated dance for dancers of all abilities was both unclear and did not accurately reflect our focus on the marginalization of people who experienced disability, as well as other forms of oppression.

We currently articulate our group as “an anti-oppressive arts non-profit led by dancers who experience disability and other forms of marginalization, along with their artistic and political allies.” This articulation aligns well with our group’s political intentions, and it is consistent with our sociocultural understanding of disability, intersectionality, and oppression. This wording is bound to shift—and I hope it does—as we come to know ourselves and understand each other in new and different ways.

## What's the Difference? Researching Across Disciplines (Spencer-Cavaliere)

"What's the difference?" (Spencer-Cavaliere & Peers, 2011, p. 298). This question emerged as the overarching theme of a study that two of us (from different disciplinary backgrounds) cowrote, in which we explored reverse integration in women's wheelchair basketball. It was also a question I (Spencer-Cavaliere) began asking myself throughout the research process, in relation to why and how different disability terminology should be used. Unlike my coresearcher, I used—and still do use, at times—person-first language. This reflected my training, teaching, and academic writing in APA, which is primarily from a psychosocial perspective. It was (and is) used deliberately on my part to be respectful. . . . but as I continue to think about my own thinking, the language I use changes.

It was uncomfortable, challenging, and enriching—finding the right words—when at times it seemed there were no right words, just words that perhaps functioned better than others. Conscious language negotiations began as early as the pilot interview for the study (which was conducted with Peers, a former wheelchair basketball athlete and my subsequent coauthor for the study). I opened the pilot interview with a question about the impact of able-bodied athletes in the sport. Although the term "able-bodied" was used straightforwardly in the existing APA literature on the subject, I soon learned that its meaning in this sporting community differed from our colloquial use of the word. It did not mean lack of disability, rather it simply meant that an athlete was not eligible to compete at an international level in the sport (e.g., Paralympic): "AB" equated to "unclassifiable." The questions I subsequently asked about athletes with and without disabilities became misleading and at times irrelevant because responses continued to indicate that able-bodied/disabled was less relevant than—and did not directly equate to—classifiable/unclassifiable in many contexts. This is not to exclude disability from the discussion. Some athletes did identify as *disabled*, *diagnosed with XXX*, or even *wheelchair dependent*. What became clear was that the term disability had multiple meanings that could change depending on context and that the athletes were the experts in communicating and understanding these uses. This expertise was evident in the interviews, pivotal in the analysis and interpretation of the data, and determined the direction of the final manuscript. We felt obligated to make this community's language use a central part of our writing.

When we submitted the article to *APAQ*, reviewers and editors challenged our choice of nontraditional terminology and our lack of diagnostic information for participants. After two rounds of review, we were able to successfully argue for our use of the community's term *reverse integration* instead of *APAQ*'s preferred term, *reverse inclusion*, our use of the descriptors *classifiable* and *unclassifiable* athletes (instead of *athletes with and without disabilities*), our use of the community's term *AB*, and our refusal to use a demographic/diagnostic table (for reasons of theoretical consistency and anonymity).

These processes of data interpretation, writing, and publishing were challenging. The constant questioning by my coauthor (not of me but of ideas) and my questioning of my own assumptions, blended with the perspectives of our study participants and feedback from *APAQ* reviewers and editors, left me at times feeling anxious about how to express myself. At the same time, it is precisely these kinds

of uncomfortable processes that lead to enriching collaborations with colleagues and communities, and that shift our work in ways that question and challenge the taken for granted in our field.

## Person-First Language: Contextualizing Current APAQ Policy

Person-first language (e.g., *individual with a disability*) is currently the mandated disability language of APAQ, as well as the most widely accepted respectful terminology for disability in the United States of America, Canada, and Australia, among other countries (American Psychological Association, 2013; Shakespeare, 2013; Titchkosky, 2001; Withers, 2012). Person-first disability language became increasingly widespread between the 1970s and 1990s, largely in the context of “rights-based” approaches to disability activism, popularized within the American disability rights movement (Shapiro, 1993; Withers, 2012).<sup>2</sup> This movement tended to model itself upon recent American civil rights struggles around race and gender, which had proved relatively successful in gaining important legal recognitions and protections. Within this movement, disability is primarily conceptualized as a biologically based trait of an individual, who should be legally protected from any unwarranted exclusion or discrimination based solely on this trait (American Psychological Association, 2013; U.S. Equal Employment Opportunity Commission, 2001).

One of the struggles of the American disability rights movement was making people understand that disability is only one trait of a whole person, not something that defines a person in his or her entirety (Shapiro, 1993; Titchkosky, 2001). Person-first language was an explicit strategic battleground for transforming these ways of thinking about disability (Withers, 2012). Whereas terms such as *a disabled person* or *an asthmatic* seem to imply that an individual is defined entirely by a diagnosis, *a person with a disability* or *a person with asthma* implies that disability is but one trait that certain people “just happen to have” (Titchkosky, 2001, p. 125).

This disability rights movement, and its related conceptualization of disability, eventually led to the emergence of the Americans with Disabilities Act (1990), the act that governs accessibility and disability-based discrimination in the United States (Shakespeare, 2013; Withers, 2012). Person-first language is used throughout this act. *Disability* is defined as an individual’s chronic, permanent, and unfixable medical condition that “substantially limits major life activities such as seeing, hearing, speaking, walking, breathing, performing manual tasks, learning, caring for oneself, and working” (U.S. Department of Justice, Civil Rights Division, Equal Employment Opportunity Commission, 2001). This person-first language perfectly articulates the understanding that underpins it. Disability is an individual trait; it is the person who *has* the disability (Titchkosky, 2001).

The language standards adopted by the American Psychological Association (2013) reflect this specifically American rights-based approach to disability:

the guiding principle for nonhandicapping language is to maintain the integrity of individuals as whole human beings by avoiding language that implies that a person as a whole is disabled (e.g., *disabled person*); equates a person with

his or her condition (e.g., *epileptic*); has superfluous, negative overtones (e.g., *stroke victim*); is regarded as a slur (e.g., *cripple*).

The American Psychological Association (2008, 2013) articulates a number of reasons for adopting person-first language. First, it helped to meet its legal obligation to comply with the Americans with Disabilities Act. Second, it showed respect for those whom psychologists studied. Third, it could easily be made to fit within frameworks that many psychologists already used to conceptualize and study human differences: "it is essential for psychologists to understand how stereotypical and stigmatizing language, attitudes, and behaviors can demean and devalue people with disabilities and have an adverse impact on self concept, self esteem, self efficacy, and relationships with others" (2008, p. 1). The American Psychological Association rationalizes their use of person-first language through their own theoretical language of stigma management, self-concept, self-esteem, and personal traits. Person-first language dovetails usefully with certain dominant psychological frameworks.

When an *APAQ* author uses a term such as *person with a disability*, the author is often drawing from American (or similar) rights-based traditions. When understood literally (and often legally), this language implies that disability is conceptualized as an individual biological trait that may result in discrimination or stigma. Person-first language is thus theoretically consistent with research that focuses on legal rights, human traits, or trait-based discrimination and stigma, including a range of psychological, physiological, psychosocial, legal, and sociological approaches. Importantly, however, because this terminology has been so widely mandated, it has come to be used in different ways by scholars with a range of different understandings of disability. It is useful, therefore, for scholars to clarify their theoretical approach to disability if their use of this terminology differs from its most widely circulated and literal meanings.

## Alternative Disability Terminology

Although the person-first language discussed above, and officially endorsed by *APAQ*, is useful for a number of researchers in the field, it does not represent the cultural, theoretical, or community-based terminologies of many other APA researchers. Disability has been thought about, and therefore talked about, from a myriad of perspectives within APA. One scholar may partake in physiological research about the optimization of power in a Paralympian's swimming form (Prins & Murata, 2008; Daly, Djjobova, Malone, Vanlandewijck & Steadward, 2003). Another scholar may use poststructuralist<sup>3</sup> or anthropological approaches to disability to inquire into the workings of power in the Paralympic Games (Howe, 2008; Peers, 2012). The list could go on. Just as the concept of *power* would be operationalized and spoken about in profoundly different ways within each of these potential studies, so too would the concept of *disability*. Many authors in our field may, therefore, find more theoretically or culturally appropriate alternatives to person-first language in the nonexhaustive list of English-language terminology below.

## General Disability Terminology

**Disabled person: the United Kingdom social model.**<sup>4</sup> The most prevalent alternative to person-first language, *disabled person*, emerged out of the United Kingdom's disability movement. In large part, this movement was based not on a civil rights model as in the United States but rather on more Marxist models of workers' unions (e.g., Union of the Physically Impaired Against Segregation, 1976). Because of its neo-Marxist roots, U.K. movements tend to conceptualize disability not as an inherent characteristic of individuals but rather as a set of socially and structurally produced relationships and processes that lead to the categorical impoverishment, isolation, confinement, neglect, and devaluation of an entire social class of people (Oliver, 1986; Shakespeare, 2013; Thomas, 1999; Union of the Physically Impaired Against Segregation, 1976). In other words, U.K. social model scholars tend to understand the state not as a protector of people *with* disabilities but rather as complicit in actively *disabling* specific groups within its population through, for example, inaccessibly designed housing and schools, policies that impoverish certain populations, ideologies and attitudes that lead to the exclusion and dehumanization of certain people, and medical models of disability that pathologize and individualize problems that stem from social oppression (Oliver, 1986; Union of the Physically Impaired Against Segregation, 1976). In Withers' (2012) words, "the rights model focused on accessing society, but the social model focused on changing society" (p. 5). In the U.K. social model, individuals do not *have* disabilities; rather, societies have actively *disabled* people.

Within this social model, nonnormative biological embodiments and capacities are called *impairments*; they are not called *disabilities* (Union of the Physically Impaired Against Segregation, 1976; Oliver, 1986). Impairments are often roughly equivalent to biomedical diagnoses and are usually acknowledged or discussed only to the extent that they affect someone's personal embodied experiences (e.g., experiences of pain); that someone seeks interventions to modify their capacities or to modify their surroundings to fit their capacities; or that individuals and populations are oppressed through disabling social structures, attitudes, or relations by virtue of their (perceived) impairment (Clare, 1999; Thomas, 1999; Thomas & Corker, 2002; Union of the Physically Impaired Against Segregation, 1976). In the majority of other contexts, the social model tends to focus on social structures, attitudes, and relations that disable classes of people, not on the impairments of individuals. In most nonmedical contexts, therefore, authors generally refer to *disabled people* rather than *people with impairments* (Barnes, 2012; Shakespeare, 2013).

In short, when an author uses the terms *disabled person* (or to a far lesser extent, *person with an impairment*), it can be expected that the author is drawing from the theoretical and cultural tradition of the U.K.'s social model of disability. Because of this model's focus on social forces over individual traits, it tends to resonate with many scholars outside the United Kingdom as well who research in the social sciences and humanities. North American disability studies scholars Clare (1999) and Withers (2012), for example, both use *disabled person* in their work because it is more theoretically compatible with their analyses of disabling social forces.

**Person diagnosed with . . . , person with impairment.** One of the most widely used models of disability is the medical model, which has tended to conceptualize disability as an abnormal and/or problematic individual trait, directly equated to diagnosis (Shakespeare, 2013). Medical model research tends to focus on bodies and/or capacities and rarely includes social, relational, or rights-based aspects of disablement (Withers, 2012). For this reason, medical models have often been conceptualized as incompatible with, and even antithetical to, both social models and social movements of disability (Oliver & Barnes, 2012). As Shakespeare (2013) notes, however, the focus on bodily capacities does not necessarily mean that medical engagements discount the possibility of, or the importance of, social oppression or discrimination occurring along with particular bodily mechanisms. The direct equation of disability with diagnosis however, can serve to erase or negate the political movements and disability models developed within disability communities.

There are at least two sets of terminology that are useful for those researching in biology, physiology, genetics, or other similar areas, and who desire to use language that is theoretically precise, respectful, and that acknowledges the existence of other disability models. As discussed above, the social model offers us the term *impairment* to connote a bodily capacity or quality that is understood to exist within the context of social disablement (e.g., Kamaraj, Dicianno, Cooper, Hunter & Tang, 2013; Mastro, Burton, Rosendahl & Sherrill, 1996). For researchers who prefer person-first language, the terminology *person diagnosed with* (for example, asthma), offers a much more theoretically precise articulation than *person with asthma*. In addition, this terminology of diagnosis can often more accurately represent the methodological sampling criteria of studies (if diagnosis rather than physical testing is used to screen participants; e.g., Krahn & Fenton, 2009). By extension, tables that list *diagnoses* or *impairments*, rather than *disabilities*, serve to acknowledge that disability has multiple meanings, and it thus does not necessarily equate to diagnosis. Although this terminology is most useful for those in the hard sciences, those in the social sciences and humanities may also find this terminology useful if they are specifically studying experiences, processes, or power effects of diagnosis.

**World Health Organization terminology.** The World Health Organization's (WHO) suggested disability language has shifted several times over the past few decades. For the most part, this terminology has centered on public health approaches, which borrow heavily from medical models of disability, but has also worked to integrate aspects of both social and rights-based models (Oliver & Barnes, 2012). The most recent World Health Organization (2013) documents treat disability as an overarching term that includes the "problem in body function or structure" (*impairment*), as well as the resulting difference in capacities to perform tasks (*activity limitations*) and challenges to full participation in life activities (*participation restrictions*). WHO terminology thus centers on problematic bodies but also acknowledges and seeks to mitigate some of the environmental and social barriers to health. This approach to disability is most useful for those who take a specifically health or public health approach to disability and has been encouraged by a number of prominent APA scholars (e.g., Hutzler & Sherrill, 2007; Tweedy, 2002). However, this terminology is generally less accepted in fields that focus on the political, social, and cultural reasons for disability-based exclusion and oppression (Oliver & Barnes, 2012).

**Person who identifies as . . . , person who experiences disability.** Medical, social, and rights-based models have all undergone significant critique from feminist, queer, and antiracist scholars of disability (e.g., Clare, 1999; Titchkosky, 2001; Thomas, 1999; Thomas & Corker, 2002; Withers, 2012). In so doing, such scholars have conceptualized more relational, intersectional, and experiential models of disability. These models draw from social and rights-based models but take much more seriously the variation of embodied experiences and identities of people whom these models purport to represent.

The phrase *person who identifies as . . .* (for example, “a queer disabled woman of color”) explicitly values how participants self-identify, acknowledging the great variety of disability experiences, understandings, and identities. It also acknowledges (as our earlier example shows) that people’s identities can be multiple and potentially shifting on the basis of context. This phrase is often related to participant selection methods that use self-identification around disability rather than diagnosis. This terminology is useful for researchers in the social sciences or related fields who work directly with research participants and who study participant life narratives, experiences, identities, and perspectives (e.g., Boyce et al., 2009).

Likewise, the phrase *person who experiences disability* is designed to acknowledge the wide variety of embodied sensations, social structures, cultural understandings, and identities that may be related to someone’s disability experience (e.g., Goodwin & Rossow-Kimball, 2012; Peers, 2012). It is a theoretically porous term in that it can be used to discuss bodily capacities and sensations as well political causes of disablement. This terminology is more often used by researchers in the humanities and social sciences but is also useful when working across disciplinary understandings of disability.

**(Dis)ability and disabled.** Poststructuralist disability scholars have also called into question some of the basic assumptions of the medical, social, and rights-based models of disability, most notably challenging the idea that impairment and diagnosis are ahistorical and objective truths about a body (e.g., Peers, 2012; Thomas & Corker, 2002; Titchkosky, 2001). Such scholars fundamentally challenge the idea of ahistorical “Truth,” and they tend to emphasize the powerful role of language in reproducing unequal and unjust relationships of power. Terms such as *(dis)ability* and *dis/ability* are generally intended to recognize that ability categories are culturally produced phenomena that are perpetually reproduced through a number of social structures, including our use of language. These terms explicitly call into question the binary of ability and disability, acknowledging instead a much more complex and shifting set of bodies, capacities, structures, and experiences (Rogers, 2001). Such terminology is most popular in the humanities and, to a lesser extent, in the social sciences.

## Community-Specific Terminology

The following are some of the terms that have been developed within specific communities, to name their own distinct experiences, embodiments, and identities.

**Cultural and linguistic models: Deaf vs deaf.** Deaf communities across the world have developed their own models to explain the unique capacities, cultural formations, and forms of marginalization they experience. Most notably, they have argued that they are not communities of disability, but rather, that they constitute a disenfranchised cultural and linguistic minority group (Lane, 2006). Activists and

scholars working within cultural and linguistic models have articulated a crucial theoretical and political distinction between the terms *deaf* and *Deaf*. Small “d” *deaf* (or person with hearing loss) refers to a medical model understanding of people with the *undesirable condition* of nonnormative levels of hearing. Capital “D” *Deaf*, by contrast, refers to individuals or communities who explicitly reject medical understandings of hearing loss (and normative imperatives to improve their hearing) in favor of conceptualizing themselves as part of a linguistic minority group with rich cultural traditions.

It is considered good practice to identify individuals and communities by the terminology with which they identify (Linton, 2006). Scholars within the natural sciences should be cautious about medicalizing individuals who do not understand their hearing capacities as a deficit. Scholars in the social sciences and humanities should be careful not to confuse or conflate these two terms and should recognize the potential theoretical, political, and ethical problems that can arise when choosing to use the terms *deaf* or *hearing loss*.

**Wheelchair user vs. wheelchair-bound.** Activists and academics who mobilize with wheelchairs have campaigned at length against the rather ubiquitous phrases *confined to a wheelchair*, *wheelchair-bound*, and *wheelchair dependent* (for a recent use of this term in *APAQ*, see Goosey-Tolfrey & Crosland, 2010; Linton, 2006). Such terms, they argue, portray the wheelchair user’s relationship to such devices as passive, tragic, and eternal, rather than active, enabling, and shifting. This terminology is thus generally understood as both disrespectful and inaccurate, and should generally be used only with an explicit rationale, such as when quoting historical sources, or—as was the case of one of our earlier narratives—when respecting how a participant self-identifies. Generally accepted alternatives to the above terminology are *wheelchair user* and *person who uses a wheelchair* (preferred in person-first approaches). Scholars should also not assume that participants who use a wheelchair in some contexts (e.g., sport or school) might not ambulate or use other mobility tools (e.g., crutches or walkers) in other contexts. In other words, *wheelchair user* is often a contextual and relative term. In cases in which scholars need to specify the degree to which a wheelchair is used for a participant’s daily mobility, terms such as *full-time wheelchair user* or even *nonambulatory* are considered more accurate and respectful than *wheelchair-dependent*.

**Classifiable, unclassifiable, “AB.”** Communities of adaptive, wheelchair, and Paralympic sport have also created terminology to describe their specific identities, embodiments, and capacities, which may or may not correspond to terms used in communities outside of sport or within other sport contexts. As we noted in one of our earlier narratives and the corresponding publication (Spencer-Cavaliere & Peers, 2011, p. 298), athletes who are deemed eligible to play a particular sport are often referred to as *classifiable*, and in most summer Paralympic sports, are thereafter assigned an alphanumeric *classification* (e.g., 3.5 or A1). By contrast, those who play the sport, but fail to meet the eligibility criteria for certain national or international leagues, tend to be termed *unclassifiable* or, within some communities and contexts, are colloquially termed *AB*. *Classifiable* should not be assumed to equate to *disabled* (or *unclassifiable* to *able-bodied*). Some classifiable athletes may not have a diagnosis or disability identity (e.g., Paralympic athletes eligible because of minor knee injuries); many medically diagnosed athletes are not classifiable (e.g.,

a person with vision impairment alone could not play wheelchair rugby); athletes have been shown to use terms such as *disabled* and *AB* in complex, contextual, and shifting ways that do not always match our definitions (Spencer-Cavaliere & Peers, 2011) and—as we have discussed at length—*disability*, in many theoretical models, cannot directly be equated to bodily difference. If selecting participants by eligibility status in sport alone, it may be more precise to articulate participants in the language of the community (e.g., *classifiable athletes* or *Paralympic Bocce athletes* rather than *athletes with disabilities*). It follows from this argument that the term *disability sport* can also sometimes be erroneous and has been explicitly rejected by some athletes in defining the sports they play (Spencer-Cavaliere & Peers, 2011). Alternative terms depend on the sports to which one collectively refers, but some include *wheelchair sport*; *parasport*; *adapted sport*; and whenever possible, simply *sport* (or the sport's name). In short, researchers should take care to learn the linguistic nuances of the communities with whom they research, rather than assuming that their disability terminologies and understandings are compatible.

**Crip, gimp, freak, mad, spaz.** These terms should be used only with explicit theoretical intention, because they are most widely used as derogatory terms (Clare, 1999). If used because one is citing historical or disrespectful sources, one should acknowledge the inappropriate use of language. These terms also, however, refer to important artistic, activist, and theoretical movements that have emerged from within disability communities (not unlike the term *queer*; Clare, 1999; Linton, 2006; McRuer, 2006). Each of these terms has its own specific history, but they share some overlapping characteristics: they reclaim words that have been used against a community; they often grow out of emerging communities of difference and their collective creation of subcultural language, values, theories, and aesthetics; and they are often used within a “pride” movement, or an explicit movement against widespread imperatives to hide, fix, problematize, shame, or normalize the bodies under question. These terms can be respectfully used by scholars who identify with them or who wish to respect the ways a participant self-identifies (Clare, 1999). They are also appropriate for referring to theories, practices, values, or aesthetics that have emerged from, and have been so-named by, disability communities (e.g., McRuer, 2006).

## Comparative Terminology

Critical disability scholars and activists have developed strong critiques of (and alternatives to) terms that refer to populations against which disability populations are often compared, including *able-bodied* and *normal* (Linton, 2006; Shogan, 1998; Thomson, 1997; Withers, 2012). They have demonstrated how these terms can often be value-laden, stigmatizing, and socially constructed. When researchers are making a comparison between a disability population, group, or individual and a group or population not affected by disability, therefore, they should be careful to choose language that is as theoretically consistent and respectful as possible.

### **Normal, average, typically developing, general population.**

Terms such as *normal*, *average*, *typically developing*, or *the general population* may well be appropriate for scholars whose research engages with statistical data, and who are thus referring to an actual statistical norm or a defined larger population

set (e.g., shooting angle was 3 degrees higher than normal). However, these same terms, in other research contexts, tend to refer more to normative ideals than definable statistical entities and thus tend to be unempirical, stigmatizing and devaluing of nonnormative embodiments and capacities (e.g., normal vs. abnormal gate; Linton, 2006; Shogan, 1998). It is also worth noting, however, that even references to statistical norms may be theoretically inconsistent for researchers who adopt a poststructuralist approach, given that scholars in that area have focused significant attention on the social construction of statistical knowledge (e.g., Shogan, 1998; Titchkosky, 2001).

**Able-bodied.** The term *able-bodied* has been problematized by many disability scholars (Linton, 2006; Withers, 2012). First, regardless of which model of disability a researcher espouses, *able-bodied* can at best be comparative only to a range of disability phenomena that is directly associated with the physical body; it accounts very poorly for diagnostic or oppressive conditions revolving around mental health and intellectual and sensory capacities (Withers, 2012). Second, the term is often understood as disrespectful because it effaces the various abilities demonstrated by people who experience disability (Linton, 2006). Third, for scholars who embrace social, rights-based, feminist, or poststructuralist models of disability, the term is likely to be theoretically inconsistent and politically problematic. The term *able-bodied* is widely understood in these models as reaffirming the disable/able-body binary and as reproducing the idea that disability and ability are natural qualities of bodies, thus effacing the social forces that create social inequality (Linton, 2006; Thomas, 1999; Withers, 2012). Finally, as discussed above, *able-bodied* should be avoided or engaged with carefully because its meaning can be highly contextual and inconsistent across disability communities.

**Person without disability, nondisabled, normate.** Disability scholars and activists have offered a number of terms to use instead of *able-bodied* (Linton, 2006; Withers, 2012). Person-first approaches tend toward *persons without disabilities*. Social model scholars tend to use *nondisabled people*. Feminist and poststructuralist scholars have coined numerous terms, most notably *normate*, a term that is intended to question the social processes that create normative ideals of embodiment and capacities (Thomson, 1997). Specific activist communities have also developed critical comparative terms similar to *normate*. Most notably, self-defined communities of neurodiversity have contested their pathologized status by referring to the comparative population as *neurotypicals*.

## Recommendations

With these contextualized understandings of disability terminology in mind, we offer four suggestions for how *APAQ*'s language policy could be rendered both more flexible and more rigorous. First, we argue that *APAQ*, as an international multidisciplinary journal, should reflect and respect that disability terminology differs by region and by discipline. As the short list of definitions above only begins to explore, "disability" is a complex and highly contested concept. We advocate that *APAQ*'s language policy should explicitly welcome contributions that approach disability

from a range of theoretical and cultural perspectives, and that it should encourage authors to use the disability terminology that is most appropriate for their research.

Second, we are recommending not only a wider range of allowable disability terminology but also a more rigorous engagement with this terminology. We believe *APAQ* should state an explicit expectation that disability terminology be consistent with, and appropriate for, the theoretical framework of the article and the related understanding of what constitutes disability (e.g., bodily problem, personal characteristic, social oppression). Although explicit articulations around disability understandings should be welcomed, we argue that well-structured and internally consistent reviews of the literature and theoretical discussions should, in most cases, adequately embed and support appropriate terminology choices within the article. In effect, a reviewer who is familiar with the theories presented in a article should be able to clearly trace the theoretical intention of the terminology used.

Our third suggestion is that authors be held accountable for using intentional participant descriptions that match their sampling criteria and their theoretical and disability perspectives. For example, if authors are approaching disability from a social model or poststructuralist perspective, they may want to think critically about whether they should be sampling participants on the basis of their diagnoses; including charts that describe participants by race, sex and diagnoses; and assuming that people sampled by diagnoses can necessarily be understood as disabled. This suggestion also encompasses our earlier example about not assuming that participants sampled by wheelchair sport participation necessarily equate to "people with disabilities."

Our fourth suggestion has us returning to, and emphasizing further, the aspect of the current *APAQ* policy that we most appreciate: the expectation of respectful engagement with, and representation of, the participants and communities with whom we study. At the most basic level, this entails acknowledging the humanity of those whom we write about: for example, not referring to a person as their diagnosis (e.g., "a CP," or "an asthmatic") and not using potentially derogatory or tragic language (e.g., "cripple," "confined to a wheelchair," or "suffering from paralysis") unless there is a compelling and explicit rationale for doing so (e.g., quoting historical sources, or quoting participants' self-descriptions). The current *APAQ* language policy includes these points but deemphasizes the need to recognize and respect how study participants understand and define their own bodies, identities, and communities. We suggest that *APAQ* authors should feel welcome, though not necessarily compelled, to engage disability through the language of participants, even if it sometimes contradicts some of the suggestions above. If choosing not to use participant's language, authors should still respect participant viewpoints by not entirely effacing or contradicting the self-understandings of participants (e.g., describing a member of the Deaf community as "hearing deficient")—at least not without a very strong explanation and/or an explicit consultation with the participants.

It is our position that *APAQ* could better fulfill its mandate as a multidisciplinary, international, and rigorous journal by revisiting its official language policy in the four above-noted ways. We suggest that such changes would enable not only higher quality research but also more diverse, more ethically engaged research with a potentially greater relevance to the communities we purport to serve.

## Endnotes

- <sup>1</sup> Identifying these publications might further undermine the anonymity of participants.
- <sup>2</sup> There is great diversity and overlap within each disability movement. American movements, for example, included civil rights approaches, Marxist approaches, and consumer-based approaches that sought to harness capitalist buyer's power (Barnes, 2012; Withers, 2012).
- <sup>3</sup> *Poststructuralism* (which overlaps with the broader term *postmodernism*) refers to a range of theories and methods used to interrogate dominant knowledge (e.g., objective truth), practices (e.g., scientific experimental methods), subjectivities (e.g., the authentic self), and power relationships (e.g., expert vs. patient) of modernity (Andrews, 2000; Thomas & Corker, 2002). Foundational thinkers include Foucault and Derrida.
- <sup>4</sup> Although we use *social model* in the singular, it is intended to encompass a range of variations, including: activist articulations (e.g., Union of the Physically Impaired Against Segregation, 1976), popular academic variations (e.g., Oliver, 1986), and feminist and queer reinterpretations (e.g., Clare, 1999; Thomas, 1999).

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