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#SaytheWord: A Disability Culture Commentary on the Erasure of "Disability"

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Purpose: To inform the field of rehabilitation psychology about the sociocultural implications of the term "disability," and explain the rationale behind the #SaytheWord movement, a social media call to embrace disability identity. Method: Review of the literature on disability terminology, the history of language use, and the relationship between attitudes toward disability and language. We reflect on the role of disability within the field of psychology and within the American Psychological Association (APA), including the underrepresentation of disabled psychologists and trainees with disabilities and the lack of mentorship opportunities available in the field. Implications: The authors argue that erasure of the word "disability" can have unintended and adverse consequences. We describe how erasure of disability identity in the context of current sociopolitical efforts to reduce and eliminate public services and supports for people with disabilities is especially threatening to members of the disability community. To move forward, the authors postulate that the disability movement must reconcile its own history of exclusion and adopt a disability justice framework. Conclusion: The field of psychology has a rich tradition of appreciation of cultural diversity and individual difference; yet, disability has largely been left out of these efforts. The disability movement is moving toward the status of a diverse cultural group with a social justice agenda parallel to those of other marginalized communities. The authors posit that psychology must play a stronger role in advancing the human rights of people with disabilities.

Impact and Implications

This commentary will inform readers about important sociocultural considerations of the use of the term "disability." The literature indicates that despite the importance of language on attitudes toward disabled people, attempts to avoid the term "disability" remain and may have unintended consequences. The authors argue that psychology and the disability movement should align in order to advance a social justice agenda.

Keywords: disability, culture, language, attitudes, disability identity

Introduction

Language choices have social, cognitive, and emotional significance (Chandler, 1994; Hunt & Agnoli, 1991). The Sapir–Whorf hypothesis, which holds that language affects perception, evolved

into a bidirectional concept wherein the social context of language is reciprocally affected by cognition (Dunn & Elliott, 2005). Perceptions about disabled people can be influenced by terminology, often through stigmatizing language and objectifying labels (Ca-

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plan, 1995; Caplan & Shechter, 1993; Gouvier & Coon, 2002). As a result, the vocabulary used to discuss people with disabilities is consequential, and rehabilitation psychologists and other providers must be aware of the sociocultural implications of language and terminology (Dunn & Andrews, 2015; Dunn & Elliott, 2005).

The impetus for this commentary resulted from the name change at the 2018 American Psychological Association (APA) Annual National Convention in which the Disability Resource Room, the hub for accommodations and other disability-related needs for convention attendees, was renamed the Multi-Abled Resource Room, in order to remove the word "disability." The Committee on Disability in Psychology (CDIP) explained that they committee decided on the name change in order to address underutilization of the room over the past several years and to be more inclusive toward attendees who could benefit from the resource room but do not identify themselves as disabled. The idea was that by removing disability from the name, users would not be "outed" as having a disability and could be protected from discrimination. This action sparked tremendous debate, conversation, and discussion over language use and language choices among psychologists with disabilities that warranted an expanded version of this critical conversation within the field of rehabilitation psychology. Subsequent conversations with APA leadership as a result of ongoing dialogue since the 2018 APA Convention have indicated that the name will be changed back to include "disability" in its name for future years. Despite this encouraging development, the authors believe this commentary is still important to highlight the salience and complexity of the issue for the disability community. The intention of this commentary is not to create chasms among vested parties; rather, our aim is to further educate the broader field about the #SaytheWord movement and the rationale behind it. All of the authors identify as disabled women and align with disability culture, so the concepts addressed in this article are of both personal and professional consequence.

Language is a means of classification that requires conceptual clarity to accurately examine the experiences of diverse groups and cultures (Cox, 1994). The language used to describe diverse communities and the words selected by different cultures to describe themselves are constantly evolving, along with the attitudes of and toward these groups. Terms once viewed as wholly negative are sometimes reclaimed by marginalized groups and repurposed as insider slang or terms of endearment, such as the use of the n-word among some Black people (Adegbembo & MacQuarrie, 2017). In other instances, terms develop over time to become more inclusive, such as the acronym LGBT (lesbian, gay, bisexual, and transgender), which has several variations, including LGBTQQIA (to include queer, questioning, intersex, and asexual people). This evolution illustrates the reclamation of the once pejorative term, "queer" among LGBT + populations, now viewed by many as a central term in relation to identity (Brontsema, 2004; Zosky & Alberts, 2016). This phenomenon has occurred in the disability community through reclaiming first the term "gimp," and subsequently the word cripple, shortened to "crip" as insider slang (Andrews, in press; Sherry, 2004). These efforts at reclamation are by no means universal, and can be controversial.

Those who are not actively involved in diversity scholarship or activism may be unaware of the complexities of terminology, and many people elect to use terms other than those used in academia (Andrews, in press). Despite the attention paid to the language used to describe many marginalized groups, very few scholarly attempts have been made to understand the evolution of disability language (Devlieger, 1999; Dunn & Andrews, 2015; Haller, Dorries, & Rahn, 2006).

History of Disability Language

The earliest models of disability, the moral and medical models, were both associated with negative and dehumanizing language (Andrews, 2016). Moral model terminology reflected pity and shame (e.g., "cripple"), while medical model vocabulary tended to describe people as impairments or medical diagnoses (i.e., "a paraplegic"). Throughout the twentieth century, the medical model was dominant, but in the latter part of the century the social model was born, and disability language started to shift (Dunn, 2015). Deemphasizing the salience of medical impairment, the social model stressed the significance of physical and attitudinal barriers. Beatrice Wright (Wright, 1983) applied the interaction between the person and the environment to medical language that she noted was dehumanizing toward disabled people. She highlighted social psychological concepts that led people to ignore personal or other identifying attributes of people with disabilities, instead referring to groups in negative and homogenous terms and equating persons with impairment (Wright, 1983). Wright was a proponent of person-first language, where the focus should be on the person, who literally comes before his or her disability (i.e., "person with a disability" instead of "disabled person"). Person-first language was widely adopted over several decades and is the predominant style in the United States (Dunn & Andrews, 2015; Gernsbacher, 2017).

Modern disability models, such as the minority and diversity models, position disability as an aspect of identity, much like race, gender, or sexual orientation. The minority and diversity models accept and even encourage identity-first language (i.e., "disabled person") as an expression of pride in a collective disability community identity (Andrews et al., 2013). Those who identify as part of contemporary disability culture often elect to identify as "disabled people," deliberately affirming and reclaiming disability identity (Andrews, in press). For example, advocates who identify with the neurodiversity movement typically rebuff the medicalization of autism and consider it a defining feature of who they are, and intentionally choose to refer to themselves as "autistic." (Collier, 2012; Kapp, Gillespie-Lynch, Sherman, & Hutman, 2012). Culturally disabled people endeavor to defy the notion that disability is intrinsically negative and undesirable by using identityfirst terminology (Brueggemann, 2013; Dunn & Andrews, 2015). In a provocative piece, Gernsbacher (2017) asserts that the use of "person-first language appears to stigmatize, rather than destigmatize, persons with disabilities" (pp. 860-861). Similar to Deaf culture, in which Deafness is seen as key aspect of culture and identity rather than an impairment, disabled people use identity-first language to show their allegiance to disability culture (Brueggemann, 2013).

There is no consensus among people with disabilities about preferences for person-first versus identity-first language, and many in disability culture are comfortable with either or both (Dunn & Andrews, 2015). Part of the lack of consensus among the disabled community is due to the variety of disabilities represented within disability culture—some are apparent, some are less appar-

ent or even both, and some individuals are born into disability culture while others enter at different stages in life. Shakespeare (2013) stressed that "while terminology is important, it is not [so] important as underlying values . . . 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).

Disability Language and Attitudes

Despite the evolution of terminology and advocacy efforts to avoid dehumanizing language, the general public and media continue to perpetuate negativistic vocabulary. Particular terms are used either to insult people with disabilities or to insult nondisabled people by calling them disabled. The terms "cripple" and "midget," for example, are considered to be offensive and insulting to people with disabilities. Many of the most common insults are derogatory terms for intellectual disability, such as "idiot" and "moron." The r-word, a slang term derived from the medical classification of mental retardation, continues to be used pejoratively as a negative label (Albert, Jacobs, & Siperstein, 2016). Efforts to educate the public on the harmful effects of the r-word, including advocacy by people with intellectual disabilities, governmental efforts (i.e., Rosa's Law), and media campaigns have done little to reduce usage of the outdated and disparaging term and in fact may actually intensify negative attitudes (Lyle & Simplican, 2015).

Words and phrases in common American vernacular reveal the diminished status and value of people with disabilities, and innumerable phrases reflect ableism in routine conversation. Insults or expressions of exasperation often evoke sensory disabilities, such as "are you deaf?" The word "blind" is frequently substituted for oblivious, and "deaf" used as an allusion to unawareness. For example, the popular metaphors "the blind leading the blind," and "turn a blind eye" represent ignorant or foolish behavior at the expense of blind people. The term "lame," is used so frequently and nonchalantly to refer to that which is uninteresting, disappointing, or lackluster, that many users may not even realize that the word originated from a person's inability to walk or gait impairment, and instead know it only as a depiction of the pathetic and inept (Andrews, in press).

Disability language in the media remains problematic. Typical media vocabulary depicts disabled people as weak and vulnerable victims through expressions like "confined to a wheelchair," "suffering from," or "afflicted with." Even if the media story content is neutral or positive, these phrases evoke distress and promulgate a perception of disability as intrinsically negative (Andrews, in press). Media terminology that describes people with disabilities as "courageous" and "inspirational" is also harmful. This language is commonly encountered in news stories about disabled people who have supposedly "overcome" disability or succeeded "despite disability." In disability culture, these depictions are considered "inspiration porn" (Grue, 2016; Young, 2012). Deliberately evocative, the term inspiration porn refers to media that objectify disabled people for purposes of inspiration for a nondisabled audience (Young, 2012). These portrayals not only provide wanton intrusion into disabled lives, but they set impossible standards for people with disabilities to mold to the stereotype of being perpetually happy and grateful (Serlin, 2015). Biased, emotionally

charged disability language reinforces problematic stereotypes and denies disabled people self-determination (Fine & Asch, 1988).

Disability as an Identity

The word "handicapped" is outdated and has largely been replaced by the term "disability." Whether person-first or identityfirst language is used, the term disability is widely used and universally accepted (i.e., World Health Organization International Classification of Functioning, Disability, and Health; National Institute on Disability and Rehabilitation Research; National Council on Disability). Regardless, various terms have been proposed as alternatives to the term disability, such as "differently abled," "special needs," "physically challenged," and "handicapable" (Hojati, 2012; Marks, 1999). Such terms are meant to counteract the negative associations of disability by accentuating the strengths of people with disabilities. Despite good intentions, these labels are considered euphemisms in disability culture, and have largely received scorn among disability advocates (Longmore, 1985). Disability euphemisms are often, although not always, developed by nondisabled people; in particular, nondisabled parents of children with disabilities commonly utilize the term "special needs" (Galvin, 2003). Disabled people often find these terms infantilizing and patronizing (Linton, 1998). "Special needs" is commonplace in the educational system and among nondisabled parents of children with disabilities. Disability advocate Lawrence Carter-Long (2017) explained, "A need isn't special if it's something everyone else takes for granted." Although couched in positive terminology, euphemisms reveal discomfort with disability and reinforce the implication that disability is a negative and undesirable state. Further, there is potential for these terms to undermine social justice goals; by making disability sound more positive, it is as if the reality of social oppression is erased (Gilson, Tusler, & Gill, 1997; Linton, 1998). In truth, the complexity of marginalization is not trivial, and no replacement word can eradicate the prejudice and discrimination faced by the disability community (Galvin, 2003).

Technology and social media have invigorated the disability rights movement, and activists have been outspoken about the use of the word disability. Major news outlets (i.e., BBC, NPR) covered the #SayTheWord campaign, a viral hashtag on social media created by people with disabilities to claim the term and encourage nondisabled people to stop attempting to avoid and replace disability as an identity. Disabled activists have been motivated by the work of other oppressed groups to educate the general public about identity erasure. For example, the Black Lives Matter movement seeks to correct the narrative that race is insignificant by highlighting instances of social injustice. The disability community also claims and celebrates a shared history and identity. Yet, a common sentiment toward disabled people is, "I don't think of you as disabled." These efforts to avoid using the word disability paradoxically reveal actual prejudices and biases against people with disabilities. Expressions of surprise upon learning about disabled people's accomplishments and abilities or denial of disability identity are microaggressions, covert social experiences that indirectly or subtly insult the recipient (Keller & Galgay, 2010). The implication is that disability is negative, and the individual defies the undesirable stereotypes held by the observer. This phenomenon is consistent with social psychological research on atti-

tudes toward people with disabilities; when disabled people are inconsistent with outsiders' stereotypes, they are considered to be a distinct subtype or an exception (Dunn, 2015). As a result, outsiders often sensationalize disabled people who are perceived as successful, and disabled people who engage in ordinary activities such as employment may be met with attitudes of astonishment and admiration (Andrews, in press).

Self-Identification

It is painfully obvious that many disabled people do not identify as such, and there are several factors that contribute to whether or not one chooses to identify oneself as disabled. Presence of objective impairment and functional limitations do not predict selfidentification as disabled, and a significant portion of people with disabilities do not identify themselves this way (Kelley-Moore, Schumacher, Kahana, & Kahana, 2006; Nario-Redmond et at., 2013). Self-identification is believed to be essential to the formation of a positive disability identity, which is associated with better self-esteem and well-being (Bogart, 2014; Darling & Heckert, 2010; Nario-Redmond, Noel, & Fern, 2013). However, several factors serve to limit self-identification as disabled, including perception of stigma (Bogart, Rottenstein, Lund, & Bouchard, 2017). People with severe and obviously apparent disabilities more readily self-identify as disabled, as do those who are economically disadvantaged, perhaps because they have no option to "pass," and are likely marginalized in multiple ways (Bogart et al., 2017; Nario-Redmond & Oleson, 2016). Stigma is the most consistently cited and measurably the most powerful predictor of selfidentification as disabled; while perceived stigma can discourage identification, those who do self-identify may use their collective identity to protect themselves as individuals against stigma by externalizing rather than internalizing disability prejudices. (Bogart et al., 2018; Nario-Redmond & Oleson, 2016). In order for disabled people to forge the type of solidarity and pride seen with other diverse identities, they must be able to self-identify as a member of the group; given the isolation faced by so many in the disability community, socialization and contact with other disabled people is imperative (Bogart, Rottenstein, Lund, & Bouchard, 2017; Darling & Heckert, 2010).

The Deaf community has long held that they have a specific cultural identity, marked by the use of American Sign Language (ASL) and notated by the capital 'D' (Sheppard, & Badger, 2010). Some Deaf people consider themselves to be a discrete cultural and linguistic minority, and do not identify as disabled; others have joined in solidarity with the broader disability community to highlight the social construction of disability and challenge societal definitions of normality (Branson, & Miller, 2002). One problem with a Deaf versus disabled differentiation is that some people are both Deaf and disabled in other ways; some Deafdisabled advocates have argued that the stance of "Deaf not disabled" is inherently ableist (Ruiz-Williams, Burke, Chong, & Chainarong, 2015).

Disability Language in Psychology

Disability has historically faced significant discrimination in the field of psychology. People with physical, emotional, and cognitive functioning outside socially constructed and prescribed norms

have been severely pathologized in psychology. The very field that now promotes the mental health recovery model is in part responsible for the labeling and stigma of mental health disabilities. The American Psychological Association (APA) has had a somewhat tumultuous relationship with its disabled constituency. Advocates have often argued that disability issues have been overlooked in psychology and that the inclusion of disability in APA diversity efforts has been merely cursory. Over the past several decades, several disabled psychologists have become involved with APA through advocacy and governance roles to increase the presence of disabled people and disability issues within the organization. The Publication Manual (American Psychological Association [APA], 2010) requires the use of person-first disability language, and the APA Guidelines for Assessment of and Intervention with Persons with Disabilities (APA, 2012) recommends use of person-first language, although it acknowledges that it is not necessarily the consensus of people with disabilities. Results of advocacy have included American Psychologist and APA Monitor articles focused on disability, and disability culture training at APA Board meetings and to APA Council. While the APA manual (and numerous other style guides) still require person-first language, one of the top cited academic publications justifying the use of identity-first language appears in the American Psychologist (Dunn & Andrews, 2015).

Disability Identity in Professional Psychology

People with disabilities are underrepresented in psychology, among trainees, health service providers, and academics. Even more troubling, unlike those who are racial, ethnic, sexual, or gender minorities, disability representation has not increased over recent years among psychology students and trainees (Andrews & Lund, 2015), suffering from both systemic and individual discrimination and a lack of access to resources and mentorship (APA, 2009; Lund, Andrews, & Holt, 2014). Psychology trainees may desire disability mentorship but avoid seeking it out because of fear of negative repercussions steaming from self-disclosure or association (Andrews & Lund, 2015; Lund, Andrews, & Holt, 2016). Although trainees consistently identify the importance of pursuing mentorship and support, they are also aware of the possible negative repercussions of disability disclosure and frequently choose not to disclose (Lund et al., 2014, 2016). Indeed, disabled trainees consistently report experiencing disability-related discrimination during their training (Lund et al., 2014). Although the concerns expressed by trainees about negative repercussions associated with disclosure of disabilities are understood, the authors believe choosing alternative words to identify disability needs will not ameliorate them. In fact, research supports the view that increasing representation and exposure to individuals with disabilities who are utilizing resources, especially those who are in leadership roles or viewed as experts in the field, can serve to promote a positive shift in attitudes toward persons with disabilities (Shannon, Tansey, & Schoen, 2009).

What does it mean within the field that we are so afraid to be known as disabled or even possibly disabled that we will not access resources? We believe this is not only a product of the shame and fear elicited by prejudice, but also speaks to how little disability as diversity is valued in the field of psychology. Psychologists with disabilities have long perceived a lack of status and equal representation of disability within APA and the broader field; it often feels like psychologists with disabilities must constantly ask to be invited to sit at the table, rather than just being expected and welcomed there. Removing "disability" can increase internalized stigma and shame by validating the negative, undesirable connotation of the word. Eliminating or avoiding the word disability can have unintended consequences; it risks erasure of an identity, counter to the message of equality and human rights. APA must not be complicit in using language that even inadvertently reinforces stigma or indicates a lack of welcome for disabled individuals.

As described above, many efforts over the years have been promoted to distance people from the stigma of disability, including euphemisms like "handi-capable" and "differently-abled," but these superficial attempts are not useful in effecting change. Replacing the disability identity with a euphemism would portray an organization completely out of touch with disability culture, which is not a fair assessment of the totality of efforts made by the organization. We do not want to lose the vast institutional knowledge that has been gained over the years by taking a step backward to use euphemisms in place of disability. Inclusivity and cultural identity are not at odds with one another. Disability culture is a by nature a cross-disability phenomenon, and those with nonapparent disabilities make up a significant proportion of disabled people (Erickson, Lee, & von Schrader, 2019). The disability community embraces those with nonapparent disabilities and advocate to protect collective rights (e.g., not to be judged or criticized when parking in a disabled space).

The Future of Disability Culture: Disability Justice

The disability rights movement is not without flaws. For the most part, disability studies scholarship has largely been the domain of disabled White people. Although people of color have always played an important role in activism, their contributions have been largely overshadowed by attention paid to White activist efforts (Bell, 2010). It is a fair criticism to conclude that the disability movement has historically been noninclusive and that minority voices and perspectives from the intersections of diverse identities have not been heard. Traditional disability rights activism has focused narrowly on a monolithic concept of disability, missing opportunities to join with other social justice movements, and neglecting the role of power and privilege across several domains of identity (Sins Invalid, 2016). Historically, the movement has been led by those who prioritize experiences of Whites, and those with mobility impairments and readily apparent disabilities, who are able to engage in traditional means of protest and activism, such as legal action (Sins Invalid, 2016). In summary, "while a concrete and radical move forward toward justice, the disability rights movement simultaneously invisibilized the lives of peoples who lived at intersecting junctures of oppression (pp. 11-12, Sins Invalid, 2016)." As a result, many of these individuals have had to make difficult choices to integrate into other social justice movements, sacrificing involvement in disability activism and facing marginalization of disability issues in other communities (Sins Invalid, 2016).

More recently, work in particular areas of intersection have gained traction. Examples include disability and feminism (Hall, 2015), disability integration with queer theory (Kafer, 2013), the

emergence of a parallel crip theory (McRuer, 2006), and Dis/Crit, an examination of critical race theory and disability studies (Annamma, Connor, & Ferri, 2013). These developments, led by disabled voices that have been historically silenced in the disability movement, led to the emergence of disability justice. The concept of disability justice is a paradigm shift in disability rights; instead of promoting independence, disability justice advocates for interdependence and collectivism (Mingus, 2011). The disability justice paradigm rejects hierarchy within the disability community and actively promotes solidarity among different groups and types of disability, as well as with other social justice movements (Mingus, 2011). Disability rights activist Mia Mingus stated, "We don't want to simply join the ranks of the privileged; we want to dismantle those ranks and the systems that maintain them" (Mingus, 2011, para. 5). If disability rights is going to move forward in contemporary society, we believe disability justice will be the vehicle.

Implications

We argue that the loss of the term "disability" risks diminished visibility, which results in waning services and opportunities. The current push to center disabled voices in disability rights conversations is certainly not a new phenomenon (see the work of Sins Invalid, 2016 for a more comprehensive overview); however, there has been a surge of disability activism particularly since 2017 both in the trenches and through cyber protests and activism (Mann, 2018). In a growing body of popular media articles from outlets such as TIME Magazine, MSNBC, the Huffington Post, as well as a small but expanding body of scholarly literature on the topic (Ginsburg & Rapp, 2017; Mann, 2018; Sangaramoorthy & Olson, 2018; Trevisan, 2018) disability rights are asserted as civil rights. National online advocacy efforts such as the Disability Visibility Project have catapulted disability issues to the forefront, marked by viral hashtags including #cripthevote, #iamapreexistingcondition, and #thisiswhatdisabilitylookslike. Central to these aforementioned pieces is disability identity. Disabled activists are reclaiming and reasserting our identity and demanding equal access to rights and services as well as to be included in the broader social justice movements.

At the same time that the voices of the disability community are resounding, disability rights and services are being rolled back systematically on a national level; erasure of the term disability may be construed as part of that effort. Legislation such as the Patient Protection and Affordable Care Act of 2010 (ACA), Americans With Disabilities Act (ADA), the ADA Amendments Act of 2008 (ADAAA), and the Individuals with Disabilities Education Act (IDEA) are central to the survival of the disability community. Efforts to dismantle elements of these legislative gains for people with disabilities have jeopardized many aspects of life for disabled Americans, including access to medical care and education (Kennedy, Wood, & Frieden, 2017; Lindner, Rowland, Spurlock, Dorn, & Davis, 2018). Disability advocates face impending legislation meant to weaken, de-fund, or eliminate services that are relied upon disproportionately by people with disabilities. Despite our status as the largest minority group in the United States, people with disabilities are significantly underrepresented among voters (Belt, 2016). It is in this sociopolitical and cultural context that disability erasure is so threatening.

Recommendations

Nondisabled psychologists can be disability allies by supporting efforts to normalize the word disability by recognizing and speaking out against offensive language and efforts to replace disability with euphemisms. Allies can advocate by identifying and calling out instances of inspiration porn. Nondisabled allies who are committed to learning about the disability justice movement and the importance of intersectional identities can support efforts toward greater equality and social justice. For a more in-depth discussion of allyship to the disability community, refer to Forber-Pratt, Mueller, and Andrews (in press) in this issue. Psychologists should honor patient language preferences in culturally appropriate ways, while opening up dialogue with patients about the underlying attitudes and beliefs that shape their selection of preferred terms. Allies must advocate for systemic advancements to increase disabled access to appropriate educational, occupational, and medical resources. Finally, future research should center disabled voices by focusing on disability identity, collective activism around social justice issues, and the impacts of legislation and policy.

Conclusion

Decisions about language have important sociocultural meanings in the disability community, and erasure of the term "disability" can evoke fear and frustration among those who claim a disabled identity and align with disability culture. In bringing up other diverse groups, it is not our intent to make comparisons or to equate experiences. Conversely, the importance of intersectionality is that multiple identities interact in complex ways in the lives of individuals. When we face injustices in other areas of psychology, however, we do not invalidate the identities of other diverse groups. We do not support #MeToo by distancing ourselves from womanhood. We do not stand in solidarity with Black Lives Matter by saying "all lives matter." And we do not march in a LGBTQ pride parades with signs that refer to people with "alternative lifestyles." Disabled people are reclaiming our identities, our community, and our pride. We will no longer accept euphemisms that fracture our sense of unity as a culture: #SaytheWord.

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