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Insight Article

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Scientific discoveries and technological advances, in combination with evolving sociocultural understanding of health and ability, continue to reshape the definition and perspectives of disabilities around the world. New discoveries about variations in brain structure and function within the general population, and technological advances that may influence brain activity, can impact the range and continuum of conditions that are viewed by society and experienced by a child or adult as disabling. The World Health Organization (WHO) estimates that about 15% of the global population lives with a form of disability, of which 2–4% experience "significant difficulties in functioning" (World Health Organization 2011). In Canada, where we are writing, the disability rate in 2006 was 14.3%, accounting for about 1 in 7 Canadians; 8.6% of Canadians were found to experience mild to moderate disabilities, and another 5.7% severe to very severe disabilities (Statistics Canada 2013). While the medical model of disability focuses largely on biological factors, more integrated approaches such as social and cultural models recognize the complex interactions of biology with environment and societal attitudes.[1] This implies that in both policy and practice, society and government must uphold the rights of people with disabilities, not only by implementing appropriate environmental supports and accessibility, but also by promoting positive attitudes and an inclusive society. The United Nations Convention on the Rights of Persons with Disabilities (CRPD), for example, ratified by 174 countries as of July 2017, is grounded in such a model (Office of the United Nations High Commissioner for Human Rights 2015).

The language around disability can offer a barometer to gauge and a potential tool to guide social attitudes and perspectives. In a similar way to racism or sexism, ableism can manifest in negative attitudes and stereotypes that lead to prejudice of members of the affected group (Miller et al. 2004). These negative attitudes and stereotypes can directly affect the way that disabled individuals are treated and perceive themselves, and may limit their expectations and negatively influence their self-concept and determination, which in turn affect societal views and expectations of a disabled individual (Barnes et al. 2000).

Over the past years, concerted efforts have been made to reduce, if not eliminate, harmful terminology from general usage, academic discourse, and policy, although perspectives around which terms society views as stigmatizing or elevating are both contested and continually evolving. Stigmatizing words are assumed to not only reflect but also to propagate and magnify negative perceptions. In contrast, some terms have positive connotations that empower individuals or destigmatize pejorative perspectives of the deficit, and can be considered elevating. For example, in 2010, Rosa's Law in the United States mandated that two terms related to neuro-disabilities, "mental retardation" and "mentally retarded," be replaced with the terms "intellectual disability" and "individual with intellectual disability," respectively, in federal policies (Mikulski 2010).

These policies and recommendations signify critical interest in word choices among stakeholders. However, they do not reflect consensus on use of the terminology. While some words are generally considered stigmatizing and unacceptable, such as use of the term "Mongoloid" to refer to individuals with Down syndrome, much of the conversation around disability terminology is nuanced and varied. Proponents of person-first terminology, for example, advocate respect for persons by emphasizing the person instead of the deficit. In contrast, critiques of this view have promoted the identity-first view. They suggest that the disability is an integral part of the phenomena of identity and individuality, and that attempts at deemphasis propagate a narrative that disability is a misfortune. Some members of the

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1. Myopia or nearsightedness is an impairment that affects a significant percentage of the population globally and is generally not considered disabling where prescription eyeglasses are accessible.

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autism community hold the neurodiversity view that defines the condition as an example of human diversity rather than as a disorder that requires a cure. In the world of journalism, the British Broadcasting Corporation (BBC) issued guidelines for which English words should be used to refer to people with disabilities just ahead of the 2012 Paralympics (British Broadcasting Corporation [BBC] 2012). Perhaps unsurprisingly, however, international journalists reported challenges in applying or adapting these guidelines while conducting interviews in languages other than English, speaking to the need to recognize the subtleties of how language is used to refer to individuals with disabilities (Public Radio International 2012). While different perspectives about which words should be used are likely to persist, the very existence and prevalence of these conversations speak to the importance of disability terminology for people with disabilities, their families, and society in general.

This discussion is only a glimpse into the disability terminology conversations within an English-speaking Western context. What of the terminologies across other parts of the world and within multicultural communities in countries with significant cultural minority populations? To this end, we generated a sample of disability terms from around the world, and applied a pragmatic framing inherent in the field of neuroethics to examine our findings.

We identified 103 unique descriptive terms for study from 24 countries (Table 1). Our method for data generation involved mining the peer-reviewed literature and dissertations, and advocacy and health policy websites, as well as consulting with multilingual individuals. The final list included terms that refer either to a disability in general, to neurodevelopmental disorders specifically, or to persons with any of these conditions.

Using a consensus approach, we organized all terms into *descriptive* categories—aside from *nominative* terms, which are based on the name of a person, such as Down syndrome—that emerged organically from the list of terms and discussion, taking into consideration the context of the terms provided by each source (Figure 1). Identified categories were *relating*, which indicates social perspectives of how the person relates to the world, and included subcategories of *internalizing* (e.g. social withdrawal) and *externalizing* behaviors (e.g. hyperactivity); *valuing*, which denotes the valence of the terms and was further subcategorized based on whether the term had *elevating* (positive) or *stigmatizing* (negative) connotations; and *medicalizing*, which represents a clinical or biological description of the condition. Forty-six percent of the terms were assigned into the category of stigmatizing, 14% into the category of elevating—either independently or in context of its evolution from prior use of more stigmatizing terms—and 39% into the category of medicalizing (Figure 1). Categories are not mutually exclusive; for example, a term can be classified as both *stigmatizing* and *medicalizing*.

We found seven terms that were categorized as *relating*, including the *internalizing* Chinese term for autism directly translated as "the lonely disease," which describes the difficulties that some individuals with autism experience with socialization, and the *externalizing* Japanese term "KY," an abbreviation of the term "kuki ga yomenai," which describes a difficulty in relating to the world around them. This term is commonly used in referring to individuals with autism, but can be used to describe "neurotypical" people who have trouble "reading the room or situation" (Teruyama 2014).

In total, 63 terms were identified under the category of *valuing*. This includes *elevating* terms such as "jang-ae-in," a Korean term described as an uplifting term for disability and disabled people, as compared to the *stigmatizing* Korean term "michin aeja," which translates to "crazy disabled people; or those whose minds change erratically" (Hwang and Charnley 2010). Indeed, we found that a majority of elevating terms were adapted as a response to or against stigmatizing language against disabilities and those who are affected by them. For example, in Indonesia the term *diffability,* abbreviated from the English phrase "differences in abilities," encompasses individuals who are visually impaired or sighted, deaf or hearing, those who move differently, and those who learn differently (Suharto et al. 2016). This term has emerged as part of grass roots advocacy movements to emphasize differences in abilities as normal variations of humanity, as opposed to disabling deficits.

In contrast, we also identified 48 terms that were classified as *stigmatizing* in nature. This includes Bayat's description of the term *snake children,* which can be used to describe children with Down syndrome in the Ivory Coast (Bayat 2015). The use of this term reflects the community perspective that given the psychomotor deficits of these children, they "crawl longer, like a snake … So, they [children] are bothersome, just like snakes are bothersome." These stigmatizing views of disability can sometimes come with tragic consequences; Bayat (2015) goes on to describe children with disabilities being referred to in Ghana as *spirit children*, who are believed to be spirits sent to harm the family and community and are ritually killed as a consequence.

We identified 41 *medicalizing* terms, some of which encompass a definition different from our Western cultural understanding of conditions and diagnosis. In Japan, the term *hattatsu shōgai*, translated as "developmental disability," is currently used to encompass learning disability, attention deficit/hyperactivity disorder, and autism spectrum disorder as described by the *Diagnostic and Statistical Manual of Mental Disorders* (DSM). Historically, in Japan, a related term *keido hattatsu shōgai*, translated as "mild developmental disability," was used, but has been largely replaced because "this term came to be criticized for its connotation suggesting that the suffering and the level of challenge faced by those with *hattatsu shōgai* is 'mild' (i.e., not significant)" (Teruyama 2014). Those more familiar

Table 1. Disability terminology from around the world.

Country	Term	Meaning	Source	Usage[a]
Armenia	*Hokegan hivantutyun*	"Illness of the soul": psychological problems, mental or emotional problems.	Consultation	Unknown
Bangladesh	*Protibondhi*	Disabled	Consultation	Current
Bhutan	*Kukpa*	Dumb	(Schuelka 2014)	Current
	Lengo	Dumb		Current
	Tsagay	Stupid or simple; used both as a term of endearment, "my stupid little one," or negatively toward older children or adults; loosely translated as "retarded"		Current
	Tsagyem	Dumb		Current
	Tschow	Handicapped		Current
Brazil	*Autismo*	Autism	(Rios and Costa Andrada 2015)	Current
	Deficiência	"Deficiency"; disability, mental suffering		Current
China	*Guduzhen*	"The lonely disease"; refers to autism	(Bie and Tang 2015)	Current
	Shen jing bing	"Nerve disorder"; intellectual or mental disorder; also used as an insult	Author contribution	Current
	Zibizheng	Autism	(Bie and Tang 2015)	Current
Cook Islands	*Katu neneva*	Crazy head; someone who has a problem with their mind; someone who has a mental health issue or is easily upset	(LeVa 2014)	Phased out
	Kite kore	Same as *neneva*		Phased out
	Makimaki	Similar to *paki*		Phased out
	Neneva	Crazy or dumb; refers to those with a mental illness or impairment; intellectually disabled		Phased out
	Paki	"Sick people"; people with a sickness or disability; someone who is not "normal"		Phased out
	Pakipaki tai''	People with a disability; those not as capable as others or who struggle to live independently		Current
	Pirikoki	Physical and mental health are not fully functioning		Current
Canada; United States; United Kingdom; Australia	Autism	Clinical term based on the Greek word *autos*, meaning "self"	(Special Learning Inc n.d.)	Current
	Cerebral palsy	Clinical term	Author contribution	Current
	Fetal alcohol spectrum disorder	Clinical term		Current

(*Continued*)

Country	Term	Meaning	Source	Usage[a]
Canada; France	*Attaque; épisode; faire une attaque*	Attacked	(Government of Ontario, 2004)	Phased out
	Autisme	Autism		Current
	Crise - être en situation de crise	In crisis		Current
	Désordre	Disorder		Phased out
	Handicapé(e)	Handicapped or disabled; commonly used and does not have the negative connotation like in English; primarily refers to physical disability	Consultation	Current
	Incapacité	Incapacity	(Government of Ontario, 2004)	Phased out
	Invalidé	Invalid		
	La paralysie cerebrale	Cerebral palsy	Consultation	Current
	Limitation	Disability	(Government of Ontario, 2004)	Current
	Limitation fonctionnelle	Functional disability		
	Personne handicapée; personne ayant un handicap, déficience ou limitation	Handicapped person; person with a handicap, impairment, or limitation		Current
	Un retard mental	Mental retardation; replaced with learning disability	Consultation	Phased out
	Syndrome de Down	Down syndrome		Current
	Trisome 21, Trisomy 21	Down syndrome		Phased out
	Un trouble envahissant du developpement	Pervasive developmental disorder (alternative to autism)		Current
	Trouble de; problèmes en matière de	Impairment; disabilities	(Government of Ontario, 2004)	Current
Country	Term	Meaning	Source	
Ghana (Northern)	*Spirit children*	Children with disabilities; believed to be spirits sent to harm the family and community; ritually killed	(Bayat 2015)	Current
Greece	*Chighere khankarvadz en*	"Her nerves are bothered"; referring to anxiety	Consultation	Unknown
Hungary	*Befele fordulas*	Looking inward; referring to autism	Consultation	Unknown
India	*Jeep zodh aasa*	"The tongue is thick"; intellectual disability	(Desai et al. 2012)	Current
	Mooley illai	"No brain"; intellectual disability	(Narayan 2015)	Current
	Mundh buddhi	"Slow brain"; intellectual disability		Current

Country	Term	Description	Citation	Status
Indonesia	*Anak luar biasa*	Special children	(Suharto et al. 2016)	Current
	(Anak) berkebutuhan khusus	(Children) with special needs; (children) who require assistance due to physical, mental, behavioral, or medical disabilities or delays		Current
	(Ber)cacat	(With) defect		Phased out
	Berkelainan	Abnormal		Current
	Difabel	Abbreviation for "differently abled people"		Current
	Orang yang dalam keadaan kekurangan jasmani atau rokhani	Persons who have physical or mental deficit		Phased out
	Penderita cacat	Persons suffering from a defect		Phased out
	Penyandang cacat	People who have a defect		Phased out
	Penyandang disabilitas	Persons who have disabilities		Current
	Penyandang kelainan	People who have abnormalities		Phased out
	Terganggu atau kehilangan kemampuan untuk mempertahankan hidup	Ability for survival is disturbed or lost		Phased out
Ivory Coast (West Africa)	*Tuna*	Broken, loss, deficit		Phased out
	Snake children	Children with Down syndrome	(Bayat 2015)	Current
	Asupe-ppoi; asupeposa	Aspie-ish, Aspie-ness (quality of Asperger's)	(Teruyama 2014)	Current
	Asuperugā shōkōgun	Asperger's syndrome		Current
	Bogenbyō	Illnesses caused by the mother		Phased out
	Chie-okure	"Wisdom backwardness"; intellectual disability	(Bryce et al. 2014)	Current
	Chiteki shogai	Intellectual disability or person with a disability	(Teruyama 2014)	Current
	Chui kekkan tadōsei shōgai	Attention deficit hyperactivity disorder (ADHD)		Current
	Chūto shindansha	People who are diagnosed with *hattatsu shogai* (see above) as adults		Current
	Gakushū shōgai	Learning disability	(Gottlieb 2001)	Current
	Hakuchi	Imbecility		Phased out
	Hattatsu shogai	Developmental disability; includes learning disability, ADHD, and autism spectrum disorder	(Teruyama 2014)	Current

(Continued)

Country	Term	Meaning	Source	Usage[a]
Japan	*Hinin*	"Not human"		Phased out
	Jiheisho	Autism; social withdrawal (in schizophrenia); autosymnoia; social isolation	(Jisho.org n.d.; Teruyama 2014)	Current
	Jiheishō supekutoramu shōgai	Autism spectrum disorder	(Teruyama 2014)	Current
	Jōcho shōgai	Emotional disability		Current
	Keido hattatsu shogai	Mild intellectual disability		Phased out
	Kichigai	Crazy	(Gottlieb 2001)	Phased out
	Kokino jiheisho	High-functioning autism	(Teruyama 2014)	Current
	Kosei	Personal quality or character		Current
	Kosei jushi	Personal quality or character		Current
	Kuki ga yomenai (KY "kay-wye")	Autism; cannot read air (translates to reading the atmosphere or situation)		Current
	Mienai shōgai	Invisible disability		Current
	Seijin tōjisha	"Adults who are concerned," referring to adults with hattatsu shōgai		Current
	Seishin shogaisha	Intellectual disability or person with a disability		Current
	Shogaisha	Disabled person		Current
Korea	*Aeja*	Like disabled people; people with mental problems	(Hwang and Charnley 2010)	Current
	Chapae; japye-ah	Being closed in on yourself; autism		Current
	Gyonggye-seon aideul	Term used to avoid a diagnosis of autism; "border children"; children who do well in school but have developmental difficulties;	(Grinker and Cho 2013)	Current
	Jang-ae	More positive term for disability and disabled people	(Hwang and Charnley 2010)	Current
	Jang-ae-in	More positive term for disability and disabled people; more positive than *Jang-ae* (see above)		Current
	Jangea	An autistic child		Current
	Kkoma cheonjae	Child genius; children who perform well academically but have abnormal behavior		Current
	Michin	Crazy		Current
	Michin aeja	Crazy disabled people; those whose minds change erratically		Current

Country	Term	Definition	Source	Usage
Nepal	*Apanga*	"Missing organs"; disability	(Simkhada et al. 2013)	Current
Samoa	*Le atoʻaatoa le malosi o le tino poʻo le mafaufau*	Physical and mental health not fully functioning	(LeVa 2014)	Current
	Tagata mamaʻi or maʻi	"Sick people"; people with a sickness or disability or to someone who is not normal		Phased out
	Tagata ua le atoʻatoa le malosi	People with a disability; people who are not as capable as others		Current
	Ulu leaga	Crazy head; someone who has a mental health issue or is easily upset		Phased out
	Vale	Crazy or dumb; refers to anyone with a mental illness, mental impairment, or intellectual disability		Phased out
Somalia	*Waali*	Those with mental health or emotional issues; those affected by the evil eye	(Miller-Gairy and Mofya 2015)	Current
Tonga	*Faingataʻaʻia fakaeʻatamai* *Faingataʻaʻia fakaeongo hangee koe moleʻene vakai pe fanongo* *Kakai* *faingataʻaʻiaʻfaingataʻaʻia fakaesino*	People with physical, intellectual, or sensory disabilities	(LeVa 2014)	Current
Zimbabwe	*Batufwida luzyalo* *Siamunganda* *Undivubide*	Expression implying deep feelings of pity (Disabled people are) Hidden from sight Reared or domesticated (like animals)	(Munsaka and Charnley 2013)	Current Current Current

aUsage was categorized based on information obtained from the sources only and may not reflect consensus among stakeholders. Usage was defined as "phased out" if the source either specifically indicates a past usage of the term or if it recommends against its continued use. Otherwise, terms were categorized as "current." All sources were published within the last 15 years.
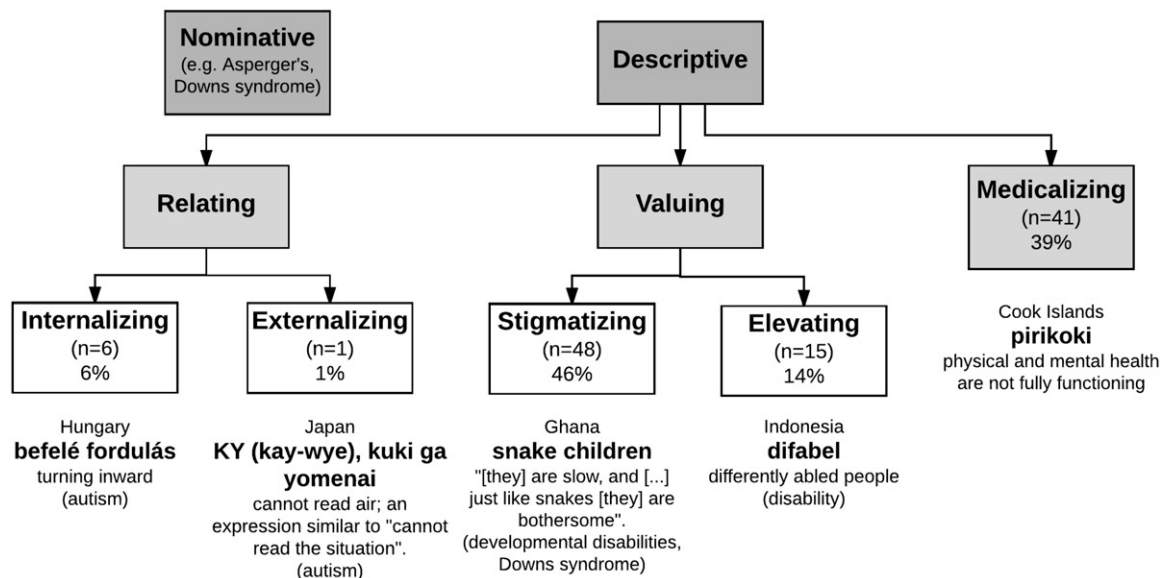
Figure 1. Descriptive categories.

with disability conversations in places such as Canada or the United States may find this rationale to be counterintuitive, given the negative connotation often associated with the valence of the concept of suffering. Teruyama (2014) compares the term "bogenbyo," or "illnesses caused by the mother," to the English term "refrigerator mother," which emerged from Leo Kanner, the first to diagnose children with "infantile autism" in 1943; until this point, autism had largely been used to describe adults with schizophrenic symptoms. Kanner suggested that autism was caused by a lack of "maternal warmth" (Kanner 1949), a theory that he later rejected and that has since been debunked in both Japan (which leads autism research in Asia) and the United States, but still sees support in some parts of Europe and has been viewed as a predominant cause of autism in South Korea (Cohen 2007; Grinker, 2008).

Many questions arise from the database of disability terms we have assembled here. Among them, we ask: Given that language can be empowering or disabling, what place should cultural terminologies for disabilities have within disability conversations globally and in multicultural and pluralistic nations in the context of fostering an inclusive society? Are dialogues around disability terminology unique to the English language, Western nations, or high-income countries? To what extent are dialogues around disability terminology representative of or responsive to the viewpoints of children of culturally diverse backgrounds? Are affected children from minority groups able to engage with and benefit from the conversations taking place either in their place of origin or in the countries to which they have migrated?

The term neuroethics was initially used to refer to ethical issues associated with the treatment and enhancement of the human brain, but as the field has expanded in scope, it has become increasingly clear that the changing understanding of the brain is having a profound influence on many more aspects of human life (Marcus 2004). The cross-cultural element brings to the foreground a departure from Western-oriented ethics and highlights the importance of diversity in perspective and values, and the way that these are expressed from the research context to daily life (Di Pietro et al. 2016; Di Pietro and Illes 2016; Stevenson et al. 2013). It is likely that over the next few years, the conversation around linguistic appropriateness for disabilities will, and we argue should, begin to envelop cross-cultural considerations even more than in the past. Given the relevance of neurodevelopmental and neurological conditions as contributors to various forms of disabilities, the history of neuroethics in tackling ethical challenges with both clinical and sociocultural relevance, and the impact of scientific discoveries and technologies on the human condition, the lens of cross-cultural neuroethics is well suited to focus pluralistic dialogues about the use of language and human rights goals such as those set forth in the CRPD. Situating the cross-cultural disability terminology dialogue within the field of cross-cultural neuroethics offers synergistic opportunities between the field and the topic (Illes 2017).

Practical challenges around the accessibility and acceptability of new and costly technologies, including cultural perspectives of health, ability and normalcy, and policies around accessible services, have led to a world in which an individual with a specific impairment can have significantly different experiences of disability. Resource allocation can influence which impairments remain disabling, as the fruits or consequences of scientific, clinical, and technological advances are not equitable across different parts of the world, and even when resources are available, their application may need to be

negotiated within the context of the local social and cultural norms to optimize their use.

In multicultural and pluralistic nations such as Canada and the United States with progressively diverse populations, the interplay of different cultural perspectives in the health of the population can influence service utilization and acceptability (Lombera and Illes 2009). Whether strategic efforts through advocacy, legislation, or education to modify terminology correlate with improvements in social perspectives and attitudes remains unclear and difficult to establish, and emergence of empirical evidence for which terms are preferred by whom is at its infancy. Concerted efforts to identify and bridge cultural challenges in cross-cultural medicine—which have, for example, led to increased ethical and more effective health care delivery through development of culturally appropriate accessibility services and assessment tools—provide a model to identify and address opportunities to utilize the knowledge around culturally diverse terminology.

Words matter not only for how social perspectives of disability are tailored but for how they define beneficence and nonmaleficence across cultures. Engaging in conversations about disabilities openly confers benefit to children, adults, and societies overall, and can increase opportunities for cultural minority groups who have disabilities to advocate for themselves. To this end, cross-cultural neuroethics, with a history of tackling similar challenges, brings a fresh lens to this dialogue.

ACKNOWLEDGMENTS

FUNDING

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