

Defining Disability Internationally: Implications for Rehabilitation Service Provision within Immigrant Populations in the United States

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Abstract

This paper presents multiple perspectives on disability that exist in the global context and their significance as necessary components of cross-cultural ethnic awareness. The author proposes engaging in cultural humility and integrating cultural brokers into rehabilitation service provision, to more effectively meet the needs of rehabilitation clients from diverse ethnic backgrounds. The goal is to support rapport-building and facilitate client engagement while removing differences in culture as potential barriers. Comparison of and insight into disability terminology, disability perceptions, and implications of disability legislation in several countries provide practicalities for forming therapeutic alliances with clients globally.

Keywords: disability, international, language, cultural humility, legislation

Defining Disability Internationally

Almost 45 million immigrants reside in the United States (Batalova et al., 2020). While immigrants tend to congregate in major cities, enclaves of immigrants are increasingly residing in many suburban and rural communities (De Graauw et al., 2013; Farrell, 2016; Lichter, 2012; Lowenhaupt, 2016). This trend makes it more likely for rehabilitation professionals and disability experts to interact with clients from ethnically diverse and international backgrounds across geographic landscapes. This characteristic of assimilation should not compel us to diminish the significance of the nuanced experiences of being an immigrant in America. This phenomenon can compound issues faced by immigrant groups who need health and rehabilitation services, by isolating them and perhaps even diminishing their access to resources. Immigrant status, particularly when the immigrant comes from a non-English-speaking nation or a developing country, presents a variety of barriers to acculturation and access to rehabilitation services. These barriers are distinct from those faced by American ethnic minorities (Akande, 2013; Akande, 2017; Clerge, 2014).

Rehabilitation professionals who work in transnationally diverse contexts must work diligently to appreciate just how much depth diversity can have. Concepts concerning health, able-bodiedness, sickness, or disability vary in interpretation across cultures, religions, and languages. These variations are critical to acknowledge and require a sense of humility on the part of the clinical experts. Cultural humility takes the concepts of cultural awareness and cultural sensitivity a step further. According to Tervalon and Murray-Garcia (1998), cultural humility positions us to acknowledge the existence of power differentials. Unfortunately, these exist in society and to a degree are inherent in therapeutic relationships (Capawana, 2016; Ottemiller & Awais, 2016; Stewart, 2019). Ethically-speaking it is the burden of the clinician to mitigate such disparities in power and to become ego-less (Commission on Rehabilitation Counselor Certification, 2016; American Counseling Association, 2014). Studies show that immigrants are more susceptible to falling victim to power differentials (Heffron et al., 2018; Ryo, 2018). In addition, cultural humility promotes self-awareness and purposeful self-reflection and self-critique when engaging with individu-

als from diverse backgrounds (Tervalon & Murray–Garcia, 1998). Culturally humble life care planners and other rehabilitation professionals should look to highlight what they don’t know, what they need to learn, what they have been wrong about, and what they have been doing incorrectly. This mindset makes the clinician primed and ready for the growth that is ethically mandated. In my opinion, this concept is linguistically and conceptually the antithesis of the phrase cultural competence, a common notion which seems to imply in its literal definition, sufficiency or satisfactoriness. No such standing should exist in this ever–changing world of social services, and this further emphasizes that language and definitions matter.

An important aspect of cultural humility may be the fact that we are called to see ourselves through a critical lens with individuals from diverse backgrounds – not only with individuals from *different* backgrounds. In other words, some of us assume that we already understand the plight of clients and patients who share the same cultural labels as we do. But perhaps, we need to practice humility more in these situations and embrace the individuality that autonomy brings. Social constructionism prevails here. “Each of us creates our own worlds from our perceptions of the actual world” (Galbin, 2014, p. 82). So, an individual who looks like me, speaks my language, and comes from the same place that I do, can be quite different from me.

The third component of the cultural humility model is institutional accountability (Tervalon & Murray–Garcia, 1998). At the micro–level, we have personal responsibilities as practitioners to self–reflect, learn, and evolve. But at the macro level, the organizations within which we work can either facilitate or impede this process. The powers in an organization (i.e., directors, CEOs, owners) that influence work culture, norms, procedures, interventions, and standards for training, hiring, and advancement (Baylor Media Communications Team, 2020; Sharp & Garcia–Pittman, 2021; Stewart, 2019; Tai, 2020). The institution must buy into cultural humility as a foundational principle. One primary example would be an organization’s engagement with cultural brokers in rehabilitation practice.

Cultural brokers

It is not realistic nor expected for rehabilitation professionals and clinicians to endeavor to know everything about every cultural perspective that their clients or patients hold. This is particularly true in cases of rapid assessments for single visits, where a therapeutic alliance can be difficult to build, for the simple fact that the client and practitioner will never see one another again after the initial meeting (Martin, 2018; Yi, Martyn, Salerno, & Darling–Fisher, 2009). The limited time that is available leads to the prioritization of treating the matter at hand. However, even in situations where service plans span months and years, issues like language barriers, differences in cultural health beliefs, or a lack of citizenship status can significantly decelerate the pace at which rehabilitation progress is made. Anthropologists first introduced the concept of the cultural broker, as they observed particular individuals arise as interpreters, negotiators, delegates, or brokers between colonial governments and the people that they governed (De Jong, 2016; Jezewski & Sotnik, 2001). The goal was to bridge the cultural divides, to resolve conflict or to bring about change. Moreover, the cultural broker serves as an advocate for a person or a group of people (Brar–Josan et al., 2020).

If we transfer this concept over to the rehabilitation field, there are a number of potential ways that we could support and advocate for consumers in settings where their cultural differences are presenting hardships for their rehabilitation journeys. In a field where resources may be limited, it is important to note that the incorporation of cultural brokers in clinical practice does not have to be expensive or extensive. Currently, there is no formalized training or credentialing required to take on this role. Simply put, expertise

as a cultural broker is typically rooted in a person's cultural identity. How and where a person was raised, the languages that they speak, and their related cultural experiences make them qualified to advocate for and support people with similar backgrounds. Although formal training is not required, it is a plausible substitute for first-hand experience. Therefore, a cultural broker can embody a paraprofessional role, as well as a professional role. This person can have a high school level of education or a doctoral degree in a variety of related fields, be a native or a non-native of a client's particular country of origin, and be unpaid or paid (Brar-Josan & Yohani, 2014; Reyes, 2019). Volunteer opportunities, service-learning, internships, and part and full-time jobs can all be fashioned into cultural broker roles. Cultural brokers can also be recruited from settings such as places of worship, community boards, schools, universities, and government offices. Identify community gatekeepers or respected leaders for insight. It is important to note that cultural brokering is ultimately a professional role adhering to ethical standards of practice. Therefore, children and family members should never be asked to take on the role of cultural broker for a client or patient (Boston Children's Hospital, 2018; National Center for Cultural Competence, 2004).

Regardless of the level of formal training that a potential cultural broker may have, in-depth, on-the-job training should be a standard first step in the onboarding process for a role that is so nuanced (Chang et al., 2020). Training cultural brokers in how to take on the perspective of cultural humility is critical. The following additional skills and knowledge areas should also be requirements or included in the training of cultural brokers: (a) the significance of the establishment of trust; (b) principles of client advocacy and mediation; (c) oral and written communication and translation; (d) awareness of the service system and connection to community resources; (e) the ability to impart contextual and historical knowledge on both client and clinician; (f) destigmatized views of chronic health conditions, disability, and related treatments; (g) capacity-building within the community; (h) holistic perspectives toward treatment, and (i) ethical values and integrity (Boston Children's Hospital, 2018; National Center for Cultural Competence, 2004).

It is also pertinent for the cultural broker to maintain neutrality (Gustafsson et al., 2013). This may appear contradictory for an individual who also has the role of an advocate, but it is not. The cultural broker should promote client autonomy and not impose their views, while also ensuring that they know and understand their client's rights, and work to ensure that those rights are not being violated. For these reasons, it's also expected that cultural brokers do not have agendas that are blindly in support of what medical or rehabilitation professionals are proposing. Lastly, under the current circumstances involving race, culture, and health care access in America, ensuring that cultural brokers understand and practice anti-racism is imperative. To be anti-racist and to be a non-racist are distinctly different, and this aspect of social justice cannot be separated out of advocacy for immigrants in America. The self-reflective work essential to a culturally humble stance reveals implicit biases and complacencies that can thwart racist tendencies. But, anti-racism actively works against structures, systems, ideas, and policies that continue to marginalize oppressed peoples, and understands that systemic racism is a public health crisis among minority groups (Cahn, 2020; Carlezon, 2020; Matsuzaka & Knapp, 2019). It is not sufficient to recognize what is wrong, but anti-racists are compelled to act (Crear-Perry et al., 2020; Farias & Simaan, 2020).

Defining disability

An example of the ability to impart contextual and background knowledge to both client and clinician is the cultural broker seeking to understand the client's definition of disability and sharing that with members of the clinical team. These definitions will frame how a client or patient will approach treatment and reha-

bilitation. As rehabilitation professionals in the United States, many of us will approach the clinical setting and view health and disability through an American lens. This lens can be colored by many things, such as American perspectives on beauty, quality of life, religion and other influential aspects of our identities and worldviews. One source of our perspectives could be the legal definition of disability, as outlined by the Americans with Disabilities Act (ADA).

To be protected by the ADA, one must have a disability, which is defined by the ADA as a physical or mental impairment that substantially limits one or more major life activities; a person who has a history or record of such an impairment; or a person who is perceived by others as having such an impairment. (ADA.gov, n.d.)

To approach a client or patient with a culturally humble perspective, we must understand that their definition of disability may be different. We cannot assume that immigrant clients come from countries that have laws supporting people with disabilities or laws that define disability. In addition, if a legal definition is present in their country, it might be very different – more inclusive and empowering or less. Also, if there is related legislation in their country, we cannot assume that our clients are aware of it, or aware of the ADA for that matter. Furthermore, how might the ADA apply to someone in America who is not American – assuming that they are employed by an entity obligated to the ADA? The legislative definition of disability is just one potential source from where an individual may extract meaning from the term disability.

In the field of rehabilitation, we also understand the different models of disability – such as the medical model, the social model, and the biopsychosocial model. These models can be another source for definitions and perspectives on disability and health. The model with which we view disability is determined by education level, geographic location, personal experiences, and other factors. While rehabilitation practitioners generally embrace the biopsychosocial and the International Classification of Functioning, Disability and Health (ICF) models of disability in practice, some of our immigrant clients and patients may hold to the religious model of disability. This model provides us with the perspective on health and disability that is the oldest and longest lasting in human history (Retief & Letšosa, 2018). Under this model, we attribute aspects of our physical, mental, and psychological functioning to extrinsic, supernatural forces. Disability, and chronic health conditions are also more likely to carry negative connotations under this model – leading to greater stigma, issues with self-consciousness, or depression. For instance, under the religious model of disability, conditions such as migraine headaches and seizure disorder have been attributed to demon possession. Even symptoms of certain anxiety disorders, such as post-traumatic stress disorder (PTSD) have been attributed to being a witch (Martin, 2018). Disabilities and conditions like HIV/AIDS and substance use disorder, which are behavioral health conditions, can also be seen as punishments from God (Aghaei et al., 2020; Anand, 2016; Etieyibo, & Omiegbe, 2016). Beliefs like this can make one less likely to trust, appreciate, or accept certain therapies, preventative measures, and interventions that are medical or pharmacological in nature. And according to the Standards of Practice for Life Care Planners (2015, p.7), “The life care planner considers cultural and linguistic factors that may influence the assessment, development, and implementation of the plan” (International Association of Rehabilitation Professionals).

Another issue to be mindful of when working with individuals from diverse backgrounds is the role that the visibility of a disability plays in believability. Physical conditions with symptoms that can be seen or “proven” are more digestible than conditions that are psychological or somatic (Kirmayer et al., 2011). The presence of conditions in the latter category, such as major depressive disorder, fibromyalgia, or generalized anxiety disorder, may not be regarded as disabilities, or may not be taken seriously (Amri

& Bemak, 2013; Donnelly et al., 2011). This is also attributed in part to the stigma associated with these conditions. Engaging these individuals or their families in treatment for the long run can be difficult but may benefit from cultural brokering as well.

Anecdotes from Research and Exploratory Travel

Research into the experiences of people with disabilities will indubitably produce stories of marginalization at multiple levels – within the microsystem, macrosystem, exosystem, and chronosystem (Onwuegbuzie et al., 2013). These experiences with discrimination throughout a person's development can be difficult to effectively address – depending in part on the system in which these attitudes exist. Bronfenbrenner's ecological systems theory describes how different aspects of our environments have direct and indirect impacts on our personal development. This includes legislation, historical events, cultural practices and views, school and work settings, and relationships with family members and members of our communities.

While spending time in Southern India, to establish a short-term study abroad program for undergraduate students, I had the opportunity to investigate disability legislation with a colleague at an Indian medical school. While exploring the Indian Rights of Persons with Disabilities Act (RPDA) of 2016, the framework stood out to me immediately, as compared to the Americans with Disabilities Act. The ADA provides a formula, by which to deduce whether or not a health condition is a disability. However, the RPDA provides a somewhat finite list of conditions that can qualify as disabilities. For instance, in a section of the document titled Specified Disability, several categories of disabilities are followed by a list of related, specific diagnoses (Legislative Department, 2016). Under Physical Disability is listed the sub-categories of locomotor disability, visual impairment, hearing impairment, and speech and language disability. Under each sub-category, several specific disabilities are listed with their definitions. See the following example.

1. Physical disability.— A. Locomotor disability (a person's inability to execute distinctive activities associated with movement of self and objects resulting from affliction of musculoskeletal or nervous system or both), including—... (c) "dwarfism" means a medical or genetic condition resulting in an adult height of 4 feet 10 inches (147 centimeters) or less... (Legislative Department, 2016, p. 16)

Other specific disabilities include acid attack victim, leprosy cured person, autism spectrum disorder, and sickle cell disease. While there are arguments for and against having a fixed list of conditions that prequalify as disabilities from a legislative perspective, the greater issue from an American practitioner standpoint is the possibility that an Indian immigrant in America may have a vastly different perception about what qualifies and does not qualify as a disability than his or her American health care provider. Conditions like substance use disorder, obesity, or HIV/AIDS are just a few examples of chronic health conditions that Indian law excludes, but American law encapsulates. Qualifying which perspective is right or wrong in this case is secondary to the necessity of acknowledging that the two cultures have perspectives that are different. The difference may warrant a bridging that will facilitate mutual understanding, empathy, treatment plan development and adherence, and successful rehabilitation strategies.

While researching in Sri Lanka in 2018 and exploring the rehabilitation needs of women with disabilities, an issue that arose there was the lack of enforcement of disability legislation – which was also an issue in India. One might agree that the first step in fighting disability discrimination is the creation of laws to protect the human rights of people with disabilities in a particular country. We may take for granted in the U.S. that in some countries the simple presence of a law is the extent to which it serves the public. In other words, some laws are present, but not enforced. In some capacity, this is true of disability legislation

in both India and Sri Lanka.

For instance, Indian law endeavors “to ensure that the women and children with disabilities enjoy their rights equally with others...” (Legislative Department, 2016, p. 8) and to ensure “specific measures to promote and facilitate inclusive education...” (Legislative Department, 2016, p. 11). However sociocultural inclinations, gender norms, and limited resources make these goals impossible for some. A family with limited financial means will likely not use their resources to fund the education of their child with a disability, especially if that child is a girl (Janardhana et al., 2015; Wilbur et al., 2019). There is also no widespread training and credentialing for teachers of students with disabilities, accessible education for students with disabilities, nor academic accommodations (Das, Kuyini, & Desai, 2013; Das & Shah, 2014; Price, 2011), although legislation promotes inclusive education (Legislative Department, 2016; Singh, 2016).

The circumstances are similar in Sri Lanka. The Protection of the Rights of Persons with Disabilities states that “No person with a disability shall be discriminated against on the ground of such disability in recruitment for any employment or office or admission to any educational institution” (Democratic Socialist Republic of Sri Lanka, 1996, p. 6). However, the experiences of many contradict this statement. There is also no specific annotation regarding women’s rights, and the plight of the female in Sri Lankan society is burdened by sexism, and further by having a disability (Kandasamy et al., 2017; Krishnan, 2011; Samararatne, & Soldatic, 2014).

Laws shape practices and can also dictate everyday language. For instance, the Social Security Administration replaced the term mental retardation with intellectual disability and acknowledged that this change had already occurred formally and informally in other areas of government, as well as in the private and public sectors (Change in Terminology, 2013). This issue leans into the preference for person-first language in the rehabilitation realm, as compared to the disability-first language inclinations in medical and social settings in American society (Jensen et al., 2013). The underpinnings for the attention to language constitute a perspective that, simply stated, words can hurt. Taboo labels create perceptions of diminished value, implications of a lesser quality of life, and hazardously attempt to establish a definition of human normalcy outside of which people with disabilities reside (Back et al., 2016; Broyles et al., 2014; Davis, 2013; Illes & Lou, 2019; Martin, 2012; Wasserman et al., 2016).

I witnessed an example of this while serving in a day program for young adults with developmental disabilities in Córdoba, Argentina in 2015. I observed a group of young people spend their days engaging in arts and crafts activities, musical instruction, and a variety of therapies over the two weeks that I was there. Semi-fluent in Spanish, I was able to interact with participants and staff. After suggesting the possibility of the establishment of a vocational training program for the participants to one of the staff members, I was met with a response that I was discouraged by. Referring to the participants as “animalitos” (meaning little animals), the staff member simply explained to me that these individuals would not be capable of engaging in any meaningful employment activity. Fully understanding my role and my setting, I let the conversation end. However, I was quite aware of how much differently that scenario would have played out in the United States. Firstly, vocational training and job readiness programs do exist in the U.S. for individuals with developmental disabilities, and they are entitled to have access to employment opportunities that they are qualified for while receiving accommodations when necessary. Secondly, a service provider who publicly refers to a client or patient with a derogatory term is prime for termination and subject to possible further penalty (i.e., loss of a license to practice, lawsuit). Denying services, causing harm, or acting in a discriminatory manner, by using insulting language, is ethically prohibited for Bachelor’s, Master’s, and

Doctoral level clinicians in rehabilitation, counseling, and human services fields (ACA, 2014; CRCC, 2016; National Organization Human Services, 2015).

A word for disability in Spanish is “discapacitado,” literally meaning without capacity. However the English word “disability” – meaning without ability – is equivalent. Some people in the disability community prefer the term “differently-abled,” which can be seen as more positive. Others prefer disability-first language and embrace disabled identities. Some simply are not concerned either way with which terms are used, so long as they are not deliberately offensive (Lister et al., 2020; Peers et al., 2014). From a practitioner’s perspective, the best practice is to utilize person-first language, unless the individual indicates that they would prefer otherwise.

Final Thoughts

For the life care planner, culture and language have direct implications on the process of developing life care plans with their clients (Collins, Zoucha, Lockhart, & Mixer, 2018). Specifically, cultural differences among immigrant communities, and language barriers that bring about poor communication and comprehension lead to greater likelihoods of unmet life care plan goals, as compared to White, non-immigrant clients (de Vries, Banister, Dening, & Ochieng, 2019; Garrido, Harrington, & Prigerson, 2014). Additionally, life care planning as a discipline and resource is more likely to be unknown to ethnic minority groups, especially immigrants (Biondo, Kalia, Khan, Asghar, Banerjee, Boulton, Marlett, Shklarov, & Simon, 2017). Beliefs that are rooted in the cultures of the country of origin (i.e., taboos, superstitions, religious beliefs related to life and death) may further minimize the likelihood that ethnic minorities will engage in such services.

The perpetuation of societal perceptions of people with disabilities is associated in part with the language that is used to define, describe, and understand the disability experience. The use of certain terms can be based in cultural norms, legislative standards, or candid sentiments that people possess. As rehabilitation professionals who serve diverse peoples on paths with diverse perspectives, we must establish effective ways in which to meet them halfway – or beyond. Cultural brokers can act as liaisons for this necessary task. And this can be accomplished in a variety of settings and at multiple skill levels.

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