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WORLD HEALTH ORGANIZATION

IMPROVING ACCESS TO HEALTH SERVICES FOR THE DISABLED:

Rights of Indigienous Peoples with Disabilities

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"Everyone has the right to a standard of living adequate for the health and well-being of himself and of his family, including food, clothing, housing and medical care and necessary social services, and the right to security in the event of unemployment, sickness, disability, widowhood, old age or other lack of livelihood in circumstances beyond his control."

Committee Brief

Often, when able-bodied individuals discuss improving access to healthcare, their discussions are limited to issues within their own community. The needs of the disabled, or less able-bodied individuals, are often not at the forefront or readily understood. This realization may be a bit hard to believe, considering WHO estimates upwards of 15 percent of the population – or, roughly, one billion people – are afflicted with some kind of disability. As WHO notes, "Disability is extremely diverse."

In order to improve access to health services for disabled or less-abled persons, careful observers must first take a broad-based approach to understanding the different types of afflictions that can impact people during their day-to-day lives. Because not every disability can be readily noticed by a layperson, a greater awareness for different types of disabilities and their various manifestations is crucial to improving access to treat these issues; if more people are aware of the problems that can face different members of their community, not only can they work together to improve the treatment thereof, but also work to reduce any and all stigmatization associated with those disabilities.

WHO reported in 2021 that people with disabilities are "three times more likely to be denied health care, four times more likely to be treated badly in the health care system," and "50% more likely to suffer catastrophic health expenditure." These disparities in access to health care and in health outcomes are unacceptable, and, in an alarming number of cases, may also be illegal. While it may not always be possible to achieve fully equitable health outcomes, based on a wide variety of factors and intervening variables, it is absolutely essential that equitable access to health care facilities, providers, and services be achieved as quickly as possible.

One area where public attention is sometimes intentionally drawn to the health problems and lack of adequate and appropriate health care facilities for people with disabilities is the treatment of wounded military service personnel. In the United States, recent scrutiny has focused on delays in treating the injuries suffered by military veterans⁴ in recent combat operations in Afghanistan and Iraq as well as on non-governmental organizations (NGOs), such as the Wounded Warrior Project, that provide financial and other assistance to wounded and disabled veterans, including for those suffering from post-traumatic stress disorder (PTSD). The United States, the United Kingdom (UK), and other countries have also pointed to serious needs

¹ United Nations, Universal Declaration of Human Rights Article 25 Section I, 10 December 1948, https://www.un.org/en/about-us/universal-declaration = of-human-rights.

² Disability and Health, 24 November 2021, https://www.who.int/news-room/fact-sheets/detail/disability-and-health

³ WHO, "Disabilities and Health" 2021. Found at: https://www.who.int/en/news-r oom/fact-sheets/detail/disability-and-health

⁴ Abby Goodnough, "Many Veterans Praise Care, But All Hate the Wait" New York Times May 31, 2014.

for improving access to mental health care and facilities for wounded and disabled veterans.⁵

Where do we go from here?

WHO differentiates between impairments, disabilities and handicaps, as each is a type of limitation that can impact the day-to-day lives of individuals. They are as follows:

- <u>Impairment</u>: Any loss or abnormality of psychological, physiological, or anatomical structure or function.
- <u>Disability</u>: Any restriction or lack (resulting from an impairment) of ability to perform an activity in the manner or within the range considered normal for a human being.
- <u>Handicap</u>: A disadvantage for a given individual, resulting from an impairment or disability, that, limits or prevents the fulfillment of a role that is normal, depending on age, sex, social and cultural factors, for that individual.⁶

Systemic approaches to improving healthcare access for disabled persons should not focus solely on one aspect of these limitations, but rather should take a multidisciplinary approach to incorporate the necessities of all communities.

To help address the needs of the disabled, the United Nations drafted a Convention on the Rights of Persons with Disabilities, which received the most signatories of any convention on its first day of availability of any previous UN convention, indicating a wide level of support. The Convention entered into force in 2008, and outlines a set of rights and privileges to be afforded to those affected by a disability. The UN notes the Convention should be considered analogous to a human rights treaty specifically focusing on the needs of the disabled community. 8

One article of the Convention specifically addresses the need to improve access to healthcare for those who have disabilities. Article 25 of the Convention requires signatories to ensure the level of healthcare afforded to the disabled is of equal quality and value to that which is offered to the able-bodied, as well as the inclusion of further treatment to prevent the disabilities in question from progressing, if possible. But this article's lofty goals have yet to be universally met. For example, a study from the United States notes that 28 percent of persons with health insurance and one or more disabilities report not being able to receive necessary treatment for such disability/ies through their insurance plan, despite the fact the United States

⁵ BBC News, "Veteran mental care 'inadequate'" July 21, 2009.

⁶ WHO, "International Classification of Impairments, Disabilities and Handicaps (ICIDH)," 1980, as quoted in United Nations, "World Programme of Action Concerning Disabled Persons," https://apps.who.int/iris/bitstream/handle/10665/41003/9241541261 eng.pdf?sequence=1&isAllowed=v.

⁷ As of 5 January 2022 there are currently 164 signatories and 184 states which have ratified or acceeded to the Convention on the Right of Persons with Disabilities; the European Union (EU) and State of Palestine have also signed on to the Convention.

⁸ United Nations, "Convention on the Rights of Persons with Disabilities," https://www.un.org/development/desa/disabilities/convention-on-the-rights-of-persons-with-disabilities.html. ⁹ Convention on the Rights of Persons with Disabilities, Art. 25.

¹⁰ It should be noted the United States has signed but not ratified the Convention.

¹¹DREDF, "Disability healthcare access brief," 2007, https://dredf.org/public-policy/health-access-to-care-old/disability-healthcare-access-brief/.

spends the most money per capita on healthcare in the world.¹² If a country with an advanced (by western standards) healthcare system still has more than a quarter of disabled persons not receiving adequate healthcare, it stands to reason this could be a challenge for developing and Least Developed Countries (LDCs) as well.

Invisible disabilities

Not every disability is outwardly apparent to the casual observer; mental health issues, for instance, do not readily present themselves in a physically manifesting way, yet still require the same dedication and attention in the health sector. Currently, WHO estimates that between 35 and 50 percent of those impacted by mental health issues in developed countries have not received proper treatment; that number skyrockets to between 76 and 85 percent of those affected in developing countries. Further outside research corroborates WHO's findings; a study in *Acta Psychiatrica Scandinavica*, a Scandinavian psychiatry journal, suggests that mental health services are underutilized in Western European countries, even among those who self-identified as having been diagnosed with a mood and/or anxiety disorder. ¹⁴

Too often, those who do not suffer from mental health issues stigmatize them, and a lack of understanding of these issues may lead to complications when treating them. Mental health practitioners, government officials and NGO representatives should work in concert to ensure public awareness of these issues increases, in concert with improving access to treatment. With an increase in education of these issues, the likelihood of stigmatization decreases as more people become aware of the impacts mental health issues have on both individuals and on communities.

Another less noticed disability is hearing loss, ranging from persons who are hard of hearing to those who are completely deaf. Although the Convention on the Rights of Persons with Disabilities specifically mentions those afflicted by hearing loss in article 30, adequate health coverage for them – either related to or separate from their disability

– is lacking. A study from the United Kingdom found that less than ten percent of deaf women felt they received and/or fully understood proper healthcare advice from their general practitioners, irrespective of whether it was related to their hearing loss, because their doctors had difficulty communicating properly with them.¹⁵

Rights of Indigenous Peoples/Persons With Disabilities

Over 1 billion people, or approximately 15 percent of the world's population, are persons with disabilities. ¹⁶ While no global data exists regarding indigenous persons with disabilities,

¹² California Healthcare Foundation, "Health care costs 101," July 2014, http://www.chcf.org/publications/201 4/07/health-care-costs-101.

¹³ WHO, "Disability and health."

¹⁴ J. Alonso, et. al.,"Use of mental health services in Europe: results from the European Study of the Epidemiology of Mental Disorders (ESEMeD) project," *Acta Psychiatrica Scandinavica*, 109: 47–54.

¹⁵ J. Ubido, et. al., "Inequalities in access to healthcare faced by women who are deaf," 2002, *Health & Social Care in the Community*, 10: 247–253. doi: 10.1046/j.1365-2524.2002.00365.x.

¹⁶ World Health Organization and the World Bank, World Report on Disability (2011).

available statistics show that indigenous peoples/persons are often disproportionately likely to experience disability in comparison to the general population.¹⁷ Factors that make indigenous persons more likely to experience disability include: high levels of poverty, increased exposure to environmental degradation, the impact of large projects such as dams or mining activities, and the higher risk of being victims of violence.¹⁸

Indigenous persons with disabilities often experience multiple forms of discrimination and face barriers to the full enjoyment of their rights, based on both their indigenous identity and disability status. This has been recognized in the preamble of the Convention on the Rights of Persons with Disabilities, which stresses that persons with disabilities "are subject to multiple or aggravated forms of discrimination on the basis of race, colour, sex, language, religion, political or other opinion, national, ethnic, indigenous or social origin, property, birth, age or other status." ¹⁹

The 2014 World Conference on Indigenous Peoples presented a new and historic opportunity for Member States and indigenous peoples to commit to the inclusion of the voices and concerns of indigenous persons with disabilities in all efforts towards the realization of the rights of indigenous peoples and the objectives of the UN Declaration on the Rights of Indigenous Peoples (UNDRIP),²⁰ altogether with the rights of even more vulnerable sectors of both populations, such as women and children.

In its "Study on the situation of indigenous persons with disabilities, with a particular focus on challenges faced with regard to the full enjoyment of human rights and inclusion in development," the Permanent Forum on Indigenous Issues (PFII) presented key considerations in relation to indigenous peoples/persons with disabilities, including the following:

- 1. Indigenous peoples/persons with disabilities face discrimination and exclusion in all areas of life, preventing realization of their rights and resulting in extreme inequalities.
 - a. Exclusion may be compounded by multiple dimensions of discrimination, for example, in situations where education or other services are neither culturally appropriate nor accessible. Circumstances such as sex, age, location and ethnicity can aggravate such forms of exclusion
- 2. The right to self-determination is a central right for indigenous peoples and includes rights to autonomy or self-government and also to participate and be actively involved in

¹⁷ For example, in 1991 over 20 percent of Canada's indigenous population aged between 25 and 34 reported a disability, the rate going even up to 30 percent concerning the people aged between 34 and 45 (See www.statcan.ca/english/studies/82-003/archive/1996/hrar1996008001s0a02.pdf). In the United States 20,7 percent of all Native Americans and/or Alaska Natives aged 16 to 64 reported a disability in 2007 (See: http://www.ilr.cornell.edu/edi/disabilitystatistics/acs.cfm), while in 2002 over one third of Australia's Aboriginal and Torres Strait Islander people aged 15 years or older reported a disability or long term health problem, spread relatively evenly over remote and non-remote areas. (See http://www.healthinfonet.ecu.edu.au/health-facts/overviews/disability).

¹⁸ Permanent Forum on Indigenous Issues. Study on the situation of indigenous persons with disabilities, with a particular focus on challenges faced with regard to the full enjoyment of human rights and iclusion in development. E/C.19/2013/6 of 6 February 2013. par. 7.

¹⁹ Convention on the Rights of Persons with Disabilities. UNTS, vol. 2515, p.3. See preamble paragraph (p)

²⁰ United Nations, "UN Declaration on the Rights of Indigenous Peoples (UNDRIP)," https://www.un.org/development/desa/indigenouspeoples/wp-content/uploads/sites/19/2018/11/UNDRIP_E_web.pdf

²¹ United Nations Economic and Social Council, Permanent Forum on Indigenous Issues Twelfth Session, 20-31 May 2013 https://digitallibrary.un.org/record/744625?ln=en

external decision-making processes.

- a. The right to self- determination should be respected by all external stakeholders, and while supporting elaboration and implementation of all laws, policies and programmes, the needs and rights of indigenous peoples/persons with disabilities should be taken into account.
- b. Specific disability rights legislation, policies and programmes aimed for the whole population, should also be respectful of the right of self-determination.
- 3. The right to participate in decision-making processes is reaffirmed by both the UNDRIP and the CRPD.
 - a. This right should be respected in relation to relevant decision making processes by all governments. Similarly, consultation processes taking place in indigenous communities should include the participation of persons with disabilities.
 - b. The right of indigenous peoples to determine their political or organizational systems should be exercised with the full participation of those members with disabilities, taking into account the cultural barriers that women tend to face in such processes.
 - c. Many indigenous peoples/persons with disabilities are excluded from participating in and benefiting from culturally and otherwise appropriate development.
- 4. Many live in poverty and lack equal access to appropriate quality education; health services; work and employment; social protection, sanitation; assistive devices including mobility aids and health and rehabilitation services; as well as to food and clothing, among others.
 - a. Existing services may lack adequately trained providers, as well as physical or other accessibility, and may be located at great distances from those living on indigenous lands, or in rural or remote areas.
 - b. Lack of appropriate services can also contribute to higher rates of institutionalization of indigenous peoples/persons with disabilities, removing them from family, culture, traditions, community and society.
- 5. Lack of support and services for families with indigenous children with disabilities has led to the displacement of families from their communities and often to the separation of children from their families and communities.
 - a. In many societies in which indigenous peoples suffer intergenerational trauma caused by, among other things, forced assimilation and the removal of children from their families, indigenous children with disabilities continue to be at a high risk of being separated from their families.
 - b. Available evidence shows that girls and women with disabilities are at higher risk of violence than girls and women without disabilities and that indigenous women are often disproportionately victims of sexual violence.
 - c. In terms of realization of their rights, as well as access to redress and remedies for human rights abuses, indigenous women with disabilities often face a complex set of barriers relating to gender, indigenous identity and disability.

Taking steps forward

In order to address the issues disabled persons face, WHO adopted a global plan of action in 2014 to focus on strategic needs both governments and NGOs need to address for the better part of the next decade. The Global Disability Action Plan 2014- 2021 aims to make it easier for persons with disabilities to access healthcare, both related and separate from their afflictions, as well as to strengthen existing healthcare regimes and to further study the impacts of healthcare on the disabled throughout the world. By coordinating efforts between doctors, their patients and governments, WHO hopes this plan begins to reduce some of the limitations the disabled face in their attempts to receive adequate healthcare.²²

The Global Disability Action Plan 2014-2021 focuses on three primary areas of improving healthcare for people with disabilities. First, the plan aims at removing barriers and improving access to health care for people with disabilities. Second, WHO and its member states and relevant civil society partners committed themselves to strengthening and extending rehabilitation, assistive technologies, and community-based rehabilitation (CBR). Finally, the Action Plan seeks to improve the collection of "relevant and internationally comparable data on disability support research on disability and related services."²³

Ensuring that these three primary areas are addressed must be paramount for the delegates to the World Health Organization (WHO) but they may find it quite useful to address related issues within their respective resolutions.

A further step toward bridging the coverage gap includes the potentially obvious solution of consulting with persons affected by the disabilities in question that treatment schemes and programs seek to mitigate. By promoting a more inclusive model of treatment, both in discussing different treatment possibilities and in implementing them, the disabled and healthcare providers can work together to try and improve access to healthcare.²⁴

In May of 2021, WHO passed Resolution EB148.R6 "The highest attainable standard of health for persons with disabilities." In the resolution, WHO set out to ensure inclusivity in the health sector by increasing access to effective health services, protection during health emergencies, and access to public health interventions.²⁵ These three goals will help frame the actions that will help eliminate the disparities in the health sector. The resolution contains numerous actions that the WHO Secretariat will take on the matter, including composing a "report on the highest attainable standard of health for persons with disabilities by the end of 2022."26 This report is the most recent step in the WHO's goal towards improving healthcare for people with disabilities, and member states have the opportunity to craft what the report should

²² WHO, "WHO Global Disability Action Plan 2014-2021," https://www.who.int/publications/i/item/whoglobal-disability-action-plan-2014-2021.

²³ WHO, "Disabilities and rehabilitation: WHO Global Disability Action Plan 2014-2012" 2015.

²⁴ Michael Ashley Stein, et. al., "Health Care and the UN Disability Rights Convention," 2009, *Popular Media*, Paper 34. http://scholarship.law.wm.edu/popular_media/34.

²⁵ A new landmark resolution on disability adopted at the 74th World Health Assembly," World Health Organization, 27 May 2021, https://www.who.int/news/item/27-05-2021-a-new-landmark-resolution-on-disa bility-adopted-at-the-74th-world-health-assembly.

²⁶ WHO Resolution EB148.R6 20 January 2021

include, highlight where the United Nations has excelled, and note where more work needs to be done, both on a national and international scale.

The Committee on the Rights of Persons with Disabilities shall continue to consider the situation on indigenous peoples/persons with disabilities in its dialogues with State parties to the CRPD and maintain and expand its recommendations related to indigenous peoples/persons with disabilities in its Concluding Observations. Moreover, relevant United Nations mechanisms and funds, including the United Nations Partnership to Promote the Rights of Persons with Disabilities and the multi-donor trust fund of the United Nations-Indigenous Peoples' Partnership should include indigenous peoples/persons with disabilities in projects at the country level, in cooperation with indigenous peoples/persons with disabilities and their representative organizations. Civil society actors should include indigenous peoples/persons with disabilities in their respective areas of work in a cross-cutting and coordinated manner, ensuring space for meaningful participation of indigenous peoples/persons with disabilities both when issues related to persons with disabilities and indigenous peoples are discussed.

National governments and their respective civil society partners, including health care providers, need to address the situations within their own countries as well as participate in WHO's Global Disability Action Plan. Governments need to enact appropriate legislation as well as devote the requisite resources, financial, legal, and political, to achieving equal access to health services for people with disabilities. In October 2014, Jamaica passed a disabilities act banning workplace discrimination and setting up a tribunal to address the grievances of peoples with disabilities; the Bahamas and Guyana recently passed similar legislation and schools and other facilities are becoming more accessible for people with disabilities.²⁷ All governments need to expand upon their existing legislation regarding people with disabilities to ensure that health care facilities are fully accessible, including ramps, restroom facilities, and that healthcare workers are properly prepared and trained to address the needs of people with disabilities.

Conclusion

Although the Convention on the Rights of Persons with Disabilities has been in force since 2008, its presence should not be treated as a panacea, and with it, all problems are solved. Instead, it is a first step toward a systematic overhaul and evolution of healthcare systems throughout the world to better address the needs and the rights of those with disabilities. Because healthcare systems were often designed by able-bodied persons to help able-bodied persons, the needs and the rights of the disabled have often been neglected.

What happens next can vary. Institutional support for nongovernmental organizations that assist in liaising between disabled communities and their public and/or private healthcare providers may be worth exploring; as Stein, et. al. noted, because these grassroots communities have more experience working with disabled groups, they may know the needs of their members more effectively than a larger institution might.

Similarly, the somewhat obvious step of including disabled persons in conversations

²⁷ Associated Press, "Long Neglected, Disabled Make Gains in Caribbean" October 16, 2014

about their healthcare would be an easy first step to ensuring their rights and needs are represented by their healthcare systems.

Guiding Questions:

Has your country ratified the Convention on the Rights of Persons with Disabilities? Why or why not? What further steps can the UN System, including the World Health Organization, take to ensure universal ratification of the Convention on the Rights of Persons with Disabilities?

How many disabled persons are in your country's healthcare system? Do they receive adequate treatment?

What strategies has your country undertaken to improve access to healthcare? Are these strategies inclusive of multiple types of disability?

Has your country passed any new legislation or updated existing legislation in recent years to improve access to healthcare for the disabled? How effectively is your government and/or your healthcare system collecting and analyzing data about access to healthcare for the disabled?

Has your country include indigenous peoples/persons with disabilities in their respective areas of work and should support the creation, strengthening and capacity development of organizations of indigenous peoples/persons with disabilities?

World Health Assembly Resolutions:

World Health Assembly (WHA), WHA 66.9, "Disability", May 27, 2013. A66_R9-en.pdf (menlosecurity.com)

This resolution provides support to Member States, intensifying collaboration with a broad range of stakeholders including organizations of the United Nations system, academia, the private sector and organizations of persons with disabilities, in the implementation of the Convention on the Rights of Persons with Disabilities

World Health Organization Reports:

World Health Organization and The World Bank, "World Report on Disability", 2011. The entire report may be accessed at: http://who.int/disabilities/world_report/2011/en/

The first ever World report on disability, produced jointly by WHO and the World Bank, suggests that more than a billion people in the world today experience disability. People with disabilities have generally poorer health, lower education achievements, fewer economic opportunities and higher rates of poverty than people without disabilities. This is largely due to the lack of services available to them and the many obstacles they face in their everyday lives. The report provides the best available evidence about what works to overcome barriers to health care, rehabilitation, education, employment, and support services, and to create the environments which will enable people with disabilities to flourish. The report ends with a concrete set of recommended actions for governments and their partners.

United Nations General Assembly Resolutions:

United Nations General Assembly resolution A/71/165, (A/RES/71/165), "Inclusive development for persons with disabilities", December 19, 2016. N1645292.pdf (menlosecurity.com)

This resolution provides the progress that marginalized groups take part in and benefit from, regardless of their gender, ethnicity, age, sexual orientation, disability or poverty. It seeks to address the deepening inequality across the world that has arisen despite unprecedented economic growth.

United Nations General Assembly resolution A/70/170, (A/RES/70/170), "Towards the full realization of an inclusive and accessible United Nations for persons with disabilities", December 17, 2015. A RES 70 170-EN.pdf (menlosecurity.com)

This resolution provides accessibility issues as they relate to human resources, the physical facilities on the United Nations premises, conference services and facilities, and information and documentation, and offers options for improving accessibility. It also includes best practices and views of Member States, organizations of the United Nations system and other relevant stakeholders concerning accessibility at the United Nations. In addition, the report provides recommendations for next steps towards making the United Nations premises more inclusive and accessible.

United Nations General Assembly resolution A/46/119, (A/RES/46/119), "The protection of persons with mental illness and the improvement of mental health care", December 17, 1991. A RES 46 119-EN.pdf (menlosecurity.com)

This resolution provides an important international standard is the United Nations Principles for the Protection of Persons with Mental Illness and for the Improvement of Mental Health Care. It has proved to be particularly valuable in applying human rights recognised in other instruments to people with mental illness and to situations affecting them.

Statistical Research

Zero Project, "International Study on the Implementation of the UN Convention on the Rights of Persons With Disabilities: Zero Project Report 2014", 2014. zero-project-report-2014.pdf (menlosecurity.com)

The mission of the Zero Project is to work for A World Without Barriers in accordance with the principles of the U.N. Convention on the Rights of Persons with Disabilities (CRPD).