Notes from the Field: Disability Inclusion in the Healthcare Sector in Jamaica

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The 2030 Agenda for Sustainable Development is an internationally negotiated set of goals unanimously adopted by the United Nations in 2015. The Agenda outlines the objectives and vision for progress and development around the world by the year 2030 and is described by the UN as "a plan of action for people, planet and prosperity" that "seeks to strengthen universal peace in greater freedom" (Transforming Our World: The 2030 Agenda for Sustainable Development | Department of Economic and Social Affairs, n.d.). The agenda comprises 17 Sustainable Development Goals (SDGs), which will be used as benchmarks and targets for development worldwide. These goals span a wide range from abolishing poverty to promulgating health, well-being, peace, justice, and sustainable development. Additionally, at the end of each year, a progress report will be issued to assess the completion of these goals. The 2030 Agenda also categorizes persons with disabilities, the elderly, people living with HIV/AIDS, indigenous people, refugees and internally displaced persons, and migrants as vulnerable people who must be empowered, placing a particular emphasis on their marginality. Of the SDGs, one in particular best applies to specific vulnerabilities and needs of people with disabilities: SDG 3, which is focused on health and well-being. During my time abroad through the Law, Societies, and Justice/ Jackson School of International Studies Disability, Aging, and Development in Jamaica Study Abroad program during the summer of 2023, I had the opportunity to conduct research on disability in Jamaica and the implementation of the 2030 Agenda for Sustainable Development. This paper will analyze disability in Jamaica based on these observations and field notes, Sustainable Development Goal 3 (SDG 3), and Jamaica's progress in implementing the 2030 Agenda for Sustainable Development overall.

What is SDG 3?

The overarching goal for Sustainable Development Goal 3 is to enact the UN's mission to prioritize healthy living for all countries participating in the 2030 sustainable development plan. In the Agenda, the UN states that "ensuring healthy lives and promote[ing] well-being is important to building prosperous societies" (UN Photo / Hien Macline, n.d.). SDG 3, which is broken down into specific targets, each with its own indicators, aims to uplift healthcare systems by tracking the progress that centers on global mortality rates, a limitation in the spread of diseases, promotion of mental health, a reduction in substance abuse, a decrease in global deaths and injuries, and an overall push to broaden the scope of universal healthcare coverage and improve existing healthcare systems (UN Photo / Hien Macline, n.d.).

The Place of Disability in SDG 3

While disability rights may not be explicit goals in the 2030 Agenda, the UN emphasizes the principle of "Leave[ing] No One Behind," including historically marginalized groups such as persons with disabilities ((Leave No One Behind, n.d.)). Thus, in 2018, three years after the 2030 Agenda was written, the UN Flagship Disability and Development Report was created to outline how each SDG should be adapted to apply to persons with disabilities.

In the 2018 Disability and Development Report, the UN recognizes that access to good quality, effective, and affordable healthcare services is necessary for anyone to achieve a certain acceptable standard of health. However, this standard of health is not often achieved for persons with disabilities due to inaccessibility, lack of financial resources, and stigma as the most prominent barriers faced by persons with disabilities who are seeking healthcare services. According to the UN Flagship Report on Disability and Development (2018), persons with disabilities are more likely to be unable to transport themselves to a healthcare facility due to either the lack of accessible public transportation or the high costs of private transport, or both. The same report (2018) notes that in addition to transport barriers, the healthcare facilities themselves are also often inaccessible due to physical barriers, like a lack of ramps or elevators, or the healthcare staff are inaccessible due to communication barriers, such as the lack of information in simple language, which presents comprehension issues for someone who with an intellectual disability , the lack of sign language interpretation for Deaf and hard of hearing persons, or the lack of Braille texts or audio files for someone blind. Finally, persons with disabilities are more likely to be unable to afford healthcare services due to a lower level of employment and earnings amongst persons with

disabilities. Affording healthcare services and insurance is one of the most prevalent issues for persons with disabilities seeking healthcare access. People with disabilities are also more likely to be treated with less legitimacy and respect by healthcare personnel due to the ever-prevalent stigmas regarding disability status and feel fearful of seeking medical treatment due to possible discrimination or other adverse outcomes due to the stigma surrounding disabled persons (UN Flagship Report on Disability and Development, 2018).

All these factors are intrinsically connected to the fact that persons with disabilities have more healthcare needs than their able-bodied counterparts but are often unable to obtain the care they need to help support these healthcare needs. Disability is not inherently "unhealthy," but because persons with disabilities are often excluded from quality education, formal employment opportunities, and other fundamental rights due to the lack of access or simply outright discrimination, they are simultaneously at higher risk of poor health outcomes and having unmet healthcare needs. This results in catastrophic health outcomes for persons with disabilities. According to the UN, Persons with disabilities have an overall shorter life expectancy with a much higher chance of developing additional medical complications, such as depression, pain, and osteoporosis, compared to their non-disabled counterparts. Further, in countries with lower levels of GDP per capita, as many as 80 percent of persons with disabilities report poor health (UN Flagship Report on Disability and Development, 2018).

SDG 3 was created to promote healthcare for all, which, though not explicitly stated, according to the UN, includes persons with disabilities. In order to reinforce this, the 2018 Flagship Disability and Development Report provides the basis for ensuring the implementation of this goal in the specific case of people with disabilities. Because of this intersection between persons with disabilities and SDG 3, interpreted in the light of the 2018 Disability Development Report, this application of SDG 3 is a vital area for research to determine what is happening in practice.

Why Jamaica?

Jamaica is a small country in the Caribbean that experiences poverty and is still trying to find its footing after gaining independence from the United Kingdom in 1962. It is home to a rapidly aging society with a relatively high number of persons with disabilities estimated to be as high as 18% (Jamaica - Country Profile, 2023). Jamaica was also a prominent participant in the negotiation of the Convention on the Rights of Persons with Disabilities (CRPD) and the very first country to sign and ratify it in 2007 (UNTC, 2007). Therefore, it is an ideal location to learn about disability rights in the context of a government and country still establishing many policies and learning to advocate for their vulnerable populations. The University of Washington's three-week study abroad program in Jamaica aims to educate students on the various existing disability rights advocacy groups active in the country and their advocacy work promoting health and well-being on the island.

Vision 2030 Jamaica & SDG 3

Jamaica's own Vision 2030 plan is Jamaica's blueprint for implementing the 2030 Agenda for Sustainable Development, and other fundamental rights and development goals. Jamaica's Vision 2030 was created in response to overall poor conditions in the country since its independence in 1962. The plan sets out to "provide quality and timely healthcare for the mental, physical and emotional well-being of [the] people; provide full access to efficient and reliable infrastructure and services" and contains a promise to "fully integrate" persons with disabilities and ensure they "have access to appropriate care and support services and are treated as valuable human resources" (Vision 2030 Jamaica National Development Plan, n.d.). The national strategies can be categorized into three main themes for improvement in the healthcare sector when specifically discussing persons with disabilities: accessibility, finances, and the successful implementation of equitable healthcare systems and infrastructure addressing disability stigma. Although Vision 2030 Jamaica does not provide a specific section to address goals for persons with disabilities within the healthcare sector, like the United Nations Agenda for Sustainable Development and Vision 2030. The initiative strives for persons with disabilities to be included in all goals, national outcomes, and national strategies.

Observations from Jamaica in Barriers to Accessibility

There are many barriers to accessibility for people with disabilities that can be observed in Jamaican society, generally categorized as follows: Physical, financial, institutional and social barriers, stigma and associated systemic barriers, and communication barriers. In the following section this paper will analyze each of these within Jamaican society utilizing both research done in the field during the UW's Disability, Aging, and Development in Jamaica, and supplementary research done before and after the program.

Physical Barriers

Barriers to accessibility can take many forms. However, physical barriers to access are the most tangible, visible and easily remedied through adding accessible infrastructure.

Throughout my time in Jamaica, it was apparent that one of the most significant barriers to persons with disabilities obtaining healthcare services is the lack of physically accessible infrastructure.

The most fundamental solution for any accessibility issue is the availability of transportation, especially public transit. People need to be able to transport themselves to facilities and doctors' offices to receive any kind of care. Sidewalks and roads are extremely underdeveloped; many have numerous potholes, uneven surfaces, and sometimes a complete lack of structure, making the surfaces challenging to navigate. Additionally, some of the pathways have added obstacles, such as light poles in the middle of the sidewalk, making it nearly impossible for someone who may have a disability to navigate without having to go onto the road. When speaking to the Jamaican Council for Senior Citizens, one person remarked that for some people with physical disabilities, the sidewalks are so inaccessible that it's "the road or nothing," posing an extreme risk for those persons to experience a fatal traffic accident. Further, the sidewalks and roads are not functional, and the transit and transportation systems that run upon them are not as well.

When speaking with the Jamaica Council for Persons with Disabilities (JCPD), we were told that out of the 50 new buses the city of Kingston received, only five were wheelchair accessible, a mere 10% out of the new buses, which does not encompass the dozens already running in the system. It is also vital to note that there is no island-wide transportation, which makes it very difficult for people living in rural areas to navigate to the capital and receive care that may only be available in the city. The inaccessibility and hardships do not end with physical barriers, however. Once inside the healthcare facility, there are additional barriers to accessibility while they may not be explicitly physical.

Financial Barriers

While physical barriers are a considerable portion of the problem in Jamaica, one could argue that financial barriers are even more insurmountable. Seventy-eight thousand Jamaicans are classified as multidimensionally poor, and 141 thousand Jamaicans are seen as vulnerable to multidimensional poverty ("Multidimensional Poverty Index 2023," 2023). People with disabilities are even more likely to suffer multidimensional poverty because of the high rate of unemployment and underemployment of people with disabilities (UN Flagship Report on Disability and Development, n.d.). Even though healthcare in Jamaica is free and anyone can access public health clinics and hospitals for no charge, many people experiencing multidimensional poverty, such as people with disabilities, still encounter several financial restraints when seeking comprehensive care. For example, according to several Jamaican residents we met across several locations, including the John Golding Rehabilitation Center, public health clinics and hospitals cover most medical needs but do not provide services such as diagnostic testing. In order to receive these services, patients have to navigate private medical centers, which are often less accessible financially and physically. Certain specialists are often only available in Kingston, posing a significant barrier for persons living in other parts of the country. A prime example of how this issue relates to persons with disabilities is the Sir John Golding Rehabilitation Center in Kingston, which is the only center on the entire island that provides rehabilitation services to those who have recently become disabled.

These patients are taken to a hospital where they are often turned away due to the lack of rehabilitation services in public hospitals. They are usually then referred to the Sir John Golding Rehabilitation Center to receive rehabilitative care, where they may not even be admitted due to the months-long wait or the inability to pay since the center is a private rehabilitation center. It is also important to note that this rehabilitation center does not accept patients at risk of houselessness or do not have sufficient income. It is unsurprising, then, why so many disability advocacy groups and disabled persons on the island stated that financial accessibility was a significant barrier to those with disabilities due to many of the additional services they may have to access due to their disability that they are not able to because these services are only available in private centers.

Financial capabilities are also restricted on a structural level. A recurring issue I observed throughout my time in Jamaica was the lack of resources to fund the actual efforts being made around the island. For example, although the John Golding Rehabilitation Center is the only of its kind able to house Jamaicans with new physical disabilities. However, the equipment in the center is extremely outdated and insufficient for comprehensive care of some of the health issues the center manages. The center manager expressed her frustration with the inability to obtain new resources, both due to the lack of funds and the process of obtaining the equipment. She recounted to us that she has been trying to order a new piece of equipment that would benefit her patients for over a year now, but the process and prices to obtain said equipment are constantly changing and never stay the same for a long enough period of time to obtain the equipment. As Gloria Goffe of the Combined Disabilities Association remarked, "We do not lack vision or drive, but the resources to achieve them."

Finally, transportation is also highly inaccessible to most Jamaicans due to the unreasonably high prices, which impact persons with disabilities more since, according to the UN, they are more likely to be unemployed (UN Flagship Report on Disability and Development, n.d.). In Jamaica, more often

than not, the only way to be transported around the island is through a private mode of transportation, such as a taxi or a bus with a ticketing system. Both of these systems are costly and thus inaccessible to most persons with disabilities financially, besides being inaccessible physically.

Institutional and Social Barriers

Once inside a treatment facility, a person with a disability must now face even more barriers to healthcare access, such as long queues or waiting lists to access the care they need. For example, at the John Golding Centre for Rehabilitation, the head of the physical therapy department informed us that the waitlist for physical therapy was booked three months out. The manager of the Centre informed us that there is a long waitlist for those who seek long-term admission as well, stating that the waitlist is "indefinite" and depends entirely on the recovery rate of existing patients. Even if there is no waitlist to join, proper documentation is often required, which in and of its own can pose a barrier to access as a large percentage of elderly people with disabilities do not have birth certificates, which are necessary to receive care. Unfortunately, this lack of birth certificates among people with disabilities is due to the stigma surrounding disability in Jamaica. Historically, the parents of persons born with disabilities have chosen to forego getting their children birth certificates due to a belief that persons with disabilities are not active members of society and thus have no need for proper documentation such as a birth certificate. Therefore, in addition to the societal stigma, institutional and social barriers become a salient factor that impacts the persons with disability negatively.

Stigma and Associated Systemic Barriers

In a predominantly Christian country like Jamaica, disability is often seen as a sin or a punishment from God. Multiple stories were shared by parents, community members, friends, family, etc., who were ashamed to be associated with someone who has a disability. The extent of this stigmatization of people with disabilities became incredibly clear to me when we visited UNICEF Jamaica. The visit included a presentation that included a quote from a mother of a child with a disability who "wished and prayed" that her daughter would "just be normal." Parents or family members who feel this way about their children or relatives are much less likely to take someone with a disability to receive the care they need because they have a "what's the point" mentality. Unfortunately, this is a common mindset in Jamaica.

This non-acceptance of persons with disabilities is so ingrained throughout Jamaican society that even medical personnel still have biases towards persons with disabilities and do not treat these persons with the respect and care that is required when inside a medical facility. Several persons with disabilities and advocates expressed that when someone with a disability goes to the doctor, they are hardly actually addressed, but the person with them at the appointment is addressed instead, even though it is the person with the disability who needs care. The attitudinal barriers that persons with disabilities face in Jamaican society are still as ever prevalent, and the discrimination they face makes establishing impactful, equitable, and accurate healthcare much more difficult.

Communication Barriers

Communication barriers can be less noticeable or visible and more difficult to address since they often require education or technological solutions. However, these barriers are just as damaging and alienate persons with disabilities from their communities. Persons with various disabilities may be unable to access accurate, comprehensive, and timely healthcare due to impairments in understanding information. For example, a blind person may be unable to see an infographic about COVID-19, or a Deaf person may be unable to hear a town crier communicating local mask suggestions. Persons with learning disabilities, too, may be unable to understand complex medical language used to communicate public health messages. This is an issue because it serves as yet again, another additional barrier to accessing and understanding how to utilize healthcare. All of these barriers – and even more that have not been discussed – make accessibility to healthcare for persons with disabilities extremely difficult to achieve.

Conclusion

In the face of many seemingly insurmountable barriers, Jamaica has still shown significant progress, including implementing the Jamaican Disabilities Act (JCPD The Disabilities Act 2014, n.d.). Though the act was passed in 2014, it has recently been officially established and begun to be implemented in Jamaican law in February of 2022. This new act will force newly established buildings, roads, and other public spaces to be physically accessible for persons with disabilities. This new act also contains a Disability Rights Tribunal, which will be able to prosecute those who do not comply with the act and those who discriminate against persons with disabilities, including medical personnel.

Professor Stephen Meyers remarked that while he was initially worried that some of these organizations might be shut down because of the pandemic, he was surprised and thrilled to see that not only have many of these organizations "survived, but [they] thrived." The work that organizations such as the Combined Disabilities Association, the Jamaica Council for Persons with Disabilities, the Jamaican Society

for the Blind, UNICEF, USAID, and many others have done for persons with disabilities has been exceptional. Whether it is the JCPD establishing Operation Birthright, which provides birth certificates to those with disabilities who were never given one at birth, or the CDA launching a new HIV + AIDs campaign to spread awareness to those with disabilities about the danger of these diseases, or the Jamaican Society for the Blind providing subsidized specialty low vision eye care to those who cannot afford it, these organizations are getting things done.

Despite barriers to achieving the full potential of healthcare, such as lack of accessibility, financial barriers, and stigma, the direction of disability advocacy in terms of healthcare in Jamaica is headed in the right direction. With the continued trend of disability rights, Jamaica is on the right track to ensuring accurate and accessible healthcare options for those with disabilities.

References

Disabilities Act 2014. Ministry of Labour and Social Security. (2014). https://www.mlss.gov.jm/wp-content/uploads/2021/11/JCPD-2017_Disabilities-Act-8hx1 1-fin.pdf

United Nations. (2018). Disability and development report: Realizing the sustainable development goals by, for and with persons with disabilities: 2018. United Nations. https://www.un.org/development/desa/disabilities/wp-content/uploads/sites/15/2019/10/U N-flagship-report-on-disability-and-development.pdfJamaica - Country profile. (2023, August 23). Health in the Americas. https://hia.paho.org/en/countries-22/jamaica-country-profile

Leave no one behind. (2015). https://unsdg.un-.org/2030-agenda/universal-values/leave-no-one-behind.

Multidimensional Poverty Index 2023. (2023). In Jamaica, Unstacking Global Poverty: Data for High Impact Action [Report]. HDRO and OPHI. https://hdr.undp.org/sites/default/files/Country-Profiles/MPI/JAM.pdf

Transforming our world: the 2030 Agenda for Sustainable Development | Department of Economic and Social Affairs. (2015). https://sdgs.un.org/2030agenda

UN Photo / Hien Macline. (2018). Good Health and Well-Being: Why It Matters. https://www.un.org/sustainabledevelopment/wp-content/uploads/2018/09/Goal-3.pdf

United Nations. (2006) Convention on the Rights of Persons with Disabilities (2006). https://treaties.un.org/Pages/ViewDetails.aspx?src=TREATY&mtdsg_no=iv-15&chapter=4&clang=_en

Vision 2030 Jamaica - National Development Plan. Jamaican Information Service. (2019.). https://jis.gov.jm/media/vision2030_popular_versionsmallpdf.com_.pdf