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Breaking Barriers: Ensuring Equitable and Non-discriminatory Healthcare Access for Persons with Disabilities

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#### BREAKING BARRIERS:

# Ensuring Equitable and Non-discriminatory Healthcare Access for Persons with Disabilities

# Saheb Chowdhury<sup>1</sup>

Abstract: Access to Healthcare is a matter of human rights. However, healthcare needs of persons with disabilities still remain unmet. This is, apart from the usual barriers to access as faced by persons with disabilities, also due to the usual understanding that resources do not translate into actual benefits derived by persons with disabilities. Hence, quite often States are disinclined to adequately spend on and prioritise healthcare access of persons with disabilities. This raises serious concerns about equity and justice in access to healthcare. Therefore, in this paper I firstly provide an explanation for equity and non-discrimination in access to healthcare for persons with disabilities from an utilitarian perspective based on the works of Mark Stein. I then look at the existing laws and policies in India that affect the healthcare access of persons with disabilities and provide suggestions as to how the same should be improved to provide greater access to healthcare to persons with disabilities.

**Keywords:** *Healthcare, Persons with Disability, Equity, Non-discrimination.* 

T.

#### Introduction

It is now an accepted idea that people are disabled not by their differences or impairments but by the barriers in the society. The idea is that there has to be changes made in various spheres of the society itself to ensure equal participation of persons with disability. In other words, this model is based on the basis of substantive equality i.e. we ensure equal participation of all by taking into consideration the variable needs of people to ensure a level playing field for all. Healthcare is a particular social good of great concern which is not equally accessible to all and in particular to the vulnerable and marginalised sections of the world and one such major vulnerable group is the persons with disabilities. Then our above understanding of disability would require that we take the healthcare access of persons with disability seriously and ensure that our healthcare laws and policies are designed in such a way so as to ensure that persons with disability have equal access to such care. This may require that we prioritise the healthcare needs of persons with disabilities when they also benefit more.

Right to health, which is a human right, imposes legal obligations on the States to provide affordable and quality healthcare goods, services and facilities to all

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without any discrimination based on people's social or other status.<sup>2</sup> However, it is also known to us that in reality how accessible healthcare is to one does in fact depend on the social and economic status of individuals and groups.<sup>3</sup> Equity in healthcare requires us to address this injustice of unequal access to healthcare. According to the World Health Organisation "Equity is the absence of unfair, avoidable or remediable differences among groups of people, whether those groups are defined socially, economically, demographically, or geographically or by other dimensions of inequality (e.g. sex, gender, ethnicity, disability, or sexual orientation)."4 So this definition of equity means that if there is unequal access to healthcare, among others, due to one's disability then equity requires to address such to address such remediable unequal access. Furthermore, it also says, "Health equity is achieved when everyone can attain their full potential for health and well-being." Therefore equity, which is essentially the idea of substantive equality, would require us to take positive measures to ensure that persons with disability can also attain their full potential for health and well-being. Such concern for equity in healthcare access is particularly important for persons with disabilities who, due to their greater vulnerability when combined with a lack of sufficient means, suffer even more due to unaffordability and inaccessibility of healthcare. Moreover, catastrophic healthcare expenses are one of the most concerning causes of poverty which may have an even worse effect on persons with disability further worsening equity.<sup>5</sup> Therefore, when it comes to access to healthcare of persons with disabilities, equitable and non-discriminatory access are two important principles worth considering. So how must we understand them? Let us consider and unpack each of these two principles

<sup>&</sup>lt;sup>2</sup> Human rights, https://www.who.int/news-room/fact-sheets/detail/human-rights-and-health (last visited Feb 14, 2024).

<sup>&</sup>lt;sup>3</sup> World Bank and WHO: Half the world lacks access to essential health services, 100 million still pushed into extreme poverty because of health expenses, https://www.who.int/news/item/13-12-2017-world-bank-and-who-half-the-world-lacks-access-to-essential-health-services-100-million-still-pushed-into-extreme-poverty-because-of-health-expenses (last visited Feb 14, 2024).

<sup>&</sup>lt;sup>4</sup> Health equity, WORLD HEALTH ORGANIZATION, https://www.who.int/health-topics/health-equity#tab=tab\_1 (last visited Sep 10, 2023).

<sup>&</sup>lt;sup>5</sup> Shyamkumar Sriram & Muayad Albadrani, A STUDY OF CATASTROPHIC HEALTH EXPENDITURES IN INDIA - EVIDENCE FROM NATIONALLY REPRESENTATIVE SURVEY DATA: 2014-2018 F1000RESEARCH (2022),

https://www.ncbi.nlm.nih.gov/pmc/articles/PMC9005991/#:~:text=Catastrophic%20pay ment%20headcount%20informs%20the,10%25%20of%20household%20consumption%20expenditure. (last visited Sep 10, 2023).

<sup>&</sup>lt;sup>6</sup> Jae Woo Choi et al., *Medical Security and Catastrophic Health Expenditures among Households Containing Persons with Disabilities in Korea: A Longitudinal Population-Based Study*, 15 Int. J. Equity Health 119 (2016), https://doi.org/10.1186/s12939-016-0406-9 (last visited Feb 14, 2024).

II.

# What Equity in Access to Healthcare is:

Equity in health and equity in access to healthcare are distinct but related ideas and one can inform the understanding of the other. Paula Braveman and Sofia Gruskin<sup>7</sup> defined equity in health in terms of absence of systemic disparities in health among groups in terms of their differences based on social advantages and disadvantages. They look at equity as a health right consonant principle that operationalises the right to the highest attainable standard of health understood in terms of the health status of the most disadvantaged. On equity in health, Paula Braveman and Sofia Gruskin have tried to propose a definition of 'health equity' that may be used for its operationalisation and measurement, which they say is the absence of disparities in health or its major social determinants between different groups that enjoy different levels of social advantages or disadvantages that includes wealth, power and prestige.8 So as can be seen from above their approach focuses on the entirety of health and therefore understand equity in terms of systemic disparities in health and therefore define it in terms of absence of such disparities based on disadvantages or advantages groups enjoy. When it comes to access to care, equity can then be defined in terms of absence of disparities in such access based on disadvantages and advantages groups may enjoy. When it comes to persons with disabilities, equity in access to healthcare can then be understood in terms of absence of disparities in access due to one's disability. Therefore, any such disparity that can be avoided or remedied must be so remedied. This would firstly require that there is no discrimination in such access based on one's disability and secondly that positive steps are taken to ensure that equal access is available to persons with disability through prioritisation in healthcare laws and policies. While the above definition of equity is understandably clear we need clear reasons as to why we must do so and explanation as to how that is to be achieved.

#### An Explanation for Equity in Access to Healthcare

As defined above equity requires some kind of prioritisation of healthcare needs of persons with disabilities. However, the question then arises as to why there should be any such prioritisation. Is prioritisation just because of one's greater vulnerability a sufficient reason. What if the resources can be used for others who may be at a higher level of wellbeing from such access. So for instance, if the limited resources available could be used either to provide a person who doesn't have legs with prosthetics or a bald person with hair transplant, one may say that we should do the latter as that bald person would be at a higher level of wellbeing.

<sup>&</sup>lt;sup>7</sup> P Braveman, *Defining equity in health*, 57 JOURNAL OF EPIDEMIOLOGY & AMP; COMMUNITY HEALTH 254–258 (2003).

<sup>&</sup>lt;sup>8</sup> *Id*.

This is usually the criticism of the utilitarian approach to healthcare allocation i.e. that utilitarianism, that intends to maximise the wellbeing or benefits may ignore the concerns of individuals who are at a lower level of wellbeing. Broadly, it is said that the utilitarian approach doesn't address our concerns for equity in access to healthcare as it doesn't necessarily prioritise the worse off.

It shall be seen that as a matter of general policy utilitarianism provides more than sufficient reasons for not only prioritising the healthcare concerns of the poor and vulnerable. Which means that this approach shall correctly and justifiably prioritise the right to healthcare access of persons with disabilities. However, in specific healthcare micro-allocative decisions utilitarianism shall also require that we consider the relative benefits derived. Before we get to the details of how utilitarianism will be able to do so, let's lay out briefly what utilitarian approach to healthcare is essentially all about.

As a theory on distributive justice, utilitarianism requires us to distribute resources in such a way that maximise the benefits or wellbeing derived out of such resources. Moreover, the benefits or wellbeing here is to be understood not in the classical sense of subjective pleasure one derives but in terms of that which is objectively beneficial for someone. In the context of allocation of resources in healthcare, the utilitarian approach holds that access to basic health care is necessary because most people who do not have sufficient access to the basic healthcare or have no such access will benefit greatly from such access and thus clearly increasing the net social benefit or well-being. So in healthcare allocation such an approach would require us to distribute healthcare resources in such a way as to maximise the benefits and wellbeing. However, this maximising approach raises concerns about equity and justice. The worry is that a maximising approach of the sort as mentioned above would have the effect that the concerns of the vulnerable and marginalised, who are considered not to derive high benefits, would be ignored. In other words there are concerns as to whether utilitarianism would also address the concern of equity in health. In this regard the position from utilitarianism is that it can be said with reasonable certainty that the poor, vulnerable and marginalised who do not have adequate access to basic healthcare would also generally benefit more from such access than the well off or groups who already have adequate access to the basic healthcare. When understood in the context of persons with disability, the usual understanding is that from an utilitarian approach their access to healthcare would not be considered sufficiently as they will not be able to convert such resources into benefits as others who are not persons with disabilities would.

The utilitarian approach suggests broadly and clearly that the well-being of a society of people in good health will be higher and therefore, among other ways of promoting health, requires providing healthcare to all those people who are in need and would benefit. Healthcare prevents, protects and ameliorates people's

pain and suffering from disease and sickness and prevents early loss of lives and thus increases the net benefit or wellbeing of the society. Therefore, the utilitarian approach requires providing healthcare to individuals and groups in a society. Human flourishing, which is the maximum human wellbeing and development, is only possible in a society where people do not have to majorly struggle with the consequences and effects of sickness, diseases or disabilities. These are therefore more than sufficient reasons to justifiably assert that the society, which the State represents, has an obligation to make healthcare available and accessible to all its individual members irrespective of their capacity to pay for such healthcare and to those who do not have adequate access to healthcare goods and facilities due to factors vulnerability and marginalisation and this majorly includes persons with disabilities. The broad justification, as we have argued earlier, is that those who are in greater need, in our case persons with disabilities, also in general would benefit more from such access to healthcare. However, usually the assumption is that persons with disabilities derive less benefits from access to resources.9 Criticising Sen, Mark Stein says that while a person with disability may be at a lower level of wellbeing, that doesn't mean that such a person would also derive low marginal welfare from access to resources. 10 So for instance, in the healthcare context, if we were to make a policy on allocation of healthcare resources, it would not be correct to assume that a person without any disability would necessarily benefit more than a person with disability. In fact it is more likely that a person, who due to their disability, doesn't have access to basic healthcare facilities would in fact benefit more from such access. Therefore, a healthcare policy should prioritise the healthcare needs of persons with disabilities, for instance through improving both physical access and economic access for those who need, in order to increase overall benefit.

While as a matter of general policy we can conclude this, what about micro allocative decisions? Should disability itself be the reason for either prioritisation or de-prioritisation? The utilitarian approach comes with the condition that in specific cases of allocation or micro-allocative cases the worse off is to be prioritised if they also derive relatively greater benefits. In other words, disability itself cannot be the reason for either. So, if a person with disability doesn't derive greater benefit in a micro-allocative decision than a person without disability, then we will not have the reason to prioritise that person, Similarly, if the person with disability does in fact derive greater benefit from a micro-allocative decision, it would be wrong to not prioritise that person merely because of their disability. For instance, in an organ transplant decision if we could give one kidney available to

 <sup>&</sup>lt;sup>9</sup> Amartya Sen & James Foster, On Economic Inequality 16 & 17 (1973), https://doi.org/10.1093/0198281935.001.0001 (last visited Feb 15, 2024).

<sup>&</sup>lt;sup>10</sup> Mark S. Stein, Distributive Justice and Disability: Utilitarianism against Egalitarianism 47 (2008).

either a person with disability who would live for seven years after such a transplant or to another person without any disability but would live only for six months, we have to allocate the kidney to the person with disability who derives higher benefit. Disability in itself is not the reason to not do so.

#### Non-discrimination in access to healthcare

While above we have provided an explanation for how equity is to be achieved, another aspect of healthcare access is non-discrimination. Non-discrimination is not only to be understood as prohibition of discrimination but also as an obligation to take positive steps to remove barriers in access to health care by redressing discriminatory laws, practice and policies.<sup>11</sup> Non-discrimination is therefore a much more substantive value. Non-discrimination in access to health care has been defined to mean that health facilities, goods and services are accessible to all in practice and through law and especially to the most vulnerable and marginalised population without discrimination on the prohibited grounds including "race, colour, sex, language, religion, political or other opinion, national or social origin, property, birth, physical or mental disability, health status (including HIV/AIDS), sexual orientation, civil, political, social or other status."12 Furthermore, the Convention on the Rights of Persons with Disabilities 13 talks, among other rights, about the right to health as is to be specifically guaranteed to persons with disabilities. Article 25 of the Convention recognizes the right of persons with disabilities to the enjoyment of the highest attainable standards of physical and mental health without any discrimination on the basis of disability.14 It also requires the States to ensure access to appropriate rehabilitation services. More specifically, it requires the States to provide on a non-discriminatory basis access to quality, affordable and free healthcare and programmes as is available to others and also provide those health services which are required specifically because of disability. Providing such services within local communities is emphasised to improve physical accessibility. Further, non-discriminatory care of similar quality is to be provided respecting freedom, consent, human rights, dignity, autonomy, and needs of persons with disability. Non-discrimination in health and life insurance is also emphasised. Lastly, it emphasises on prevention of

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<sup>&</sup>lt;sup>11</sup> Human rights, https://www.who.int/news-room/fact-sheets/detail/human-rights-and-health (last visited Jan 11, 2024).

<sup>&</sup>lt;sup>12</sup> General comment No. 14: The right to the highest attainable standards of health, Para 12(b) and 18, https://www.refworld.org/pdfid/4538838d0.pdf.

<sup>&</sup>lt;sup>13</sup> The UN Convention on the Rights of Persons with Disabilities was adopted on December 13, 2006 and entered into force on May 3, 2008.

CONVENTION ON THE RIGHTS OF PERSONS WITH DISABILITIES | OHCHR,

https://www.ohchr.org/en/instruments-mechanisms/instruments/convention-rights-persons-disabilities (last visited Oct 6, 2023).

<sup>&</sup>lt;sup>14</sup> Art 25, UNCRPD states that the States Parties recognize that persons with disabilities have the right to the enjoyment of the highest attainable standard of health without discrimination on the basis of disability.

discrimination in health care services or other services on the basis of disability. Non-discrimination remains the most important principle in application of the right to persons with disabilities. So, on the above analysis the healthcare aspect of the right that can be identified includes non-discriminatory access to quality, affordable and free healthcare; sexual and reproductive health; access to rehabilitation services; physical access to healthcare services and non-discrimination in health and life insurance.

Therefore, we see that non-discrimination is the central principle when it comes to access to healthcare for persons with disabilities. How must then we understand this idea of non-discrimination. Should it mean merely that the healthcare laws and policies are simply universal in their application and not deny healthcare to people due to their disability or should it mean that the government takes positive measures to ensure that persons with disability have actual access to healthcare? Restricting non-discrimination to mean only the former would not make much of a substantial impact on the actual access to healthcare of persons with disabilities. Therefore, non-discrimination must be understood to mean that laws and policies include sufficient measures to ensure that healthcare facilities are actually available by making them physically accessible, that specific healthcare needs of persons with disabilities are provided and also that such healthcare is not denied to persons with disabilities who are incapable of paying for the same. The utilitarian justification for such a substantial understanding of non-discrimination is that there has to be equal access to healthcare for all as that has the general tendency of increasing overall well-being. In light of the above understanding of equity and non-discrimination in access to healthcare for persons with disability, let us look at some healthcare laws and policies in the context of India to find out whether the same requirements have been fulfilled.

III.

#### Access to Healthcare of Persons with Disability in India

As per 2011 census data, the percentage of persons with disabilities of the total population is 2.21%. <sup>15</sup> Out of this total 20% have disability of movement, 19% have disability of sight, 19% have disability with hearing and 8% have multiple disabilities. <sup>16</sup> The number and percentage of persons with disabilities must have only gone up since then. A healthcare system that doesn't take into consideration how such disabilities would most likely be an exclusionary one that doesn't take into account healthcare access seriously. This is why the State must take the access to healthcare of such a significant segment of the population seriously and remove various barriers to access. Persons with disabilities face various barriers in such

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<sup>&</sup>lt;sup>15</sup> Disability in India | Office of Chief Commissioner for Persons with Disabilities, http://www.ccdisabilities.nic.in/resources/disability-india (last visited Feb 16, 2024). <sup>16</sup> *Id.* 

access that include absence of disability friendly transport, communication barriers, inability to access health facilities, absence of disability friendly medical infrastructure etc.<sup>17</sup> <sup>18</sup> <sup>19</sup> When disability intersects with poverty, access to healthcare becomes even more difficult due to multiple barriers to access including financial barriers which is worsened by higher out of pocket expenditure for persons with disabilities.<sup>20</sup> While persons with disabilities face the barriers in accessing healthcare, this is further worsened by further difficulties in obtaining health insurance.<sup>21</sup> Apart from this such access may become even more inequitable when disability intersects with vulnerabilities like gender identity, caste etc.<sup>22</sup> <sup>23</sup> <sup>24</sup> Therefore, healthcare laws and policies must address each of the possible causes behind inequitable and discriminatory access to healthcare. Let us then look at some of the laws and policies that concern healthcare access of persons with disabilities.

# Healthcare Access in Rights of Persons with Disabilities Act, 2016

One of the more recent and very important Acts is the Rights of Persons with Disabilities Act, 2016<sup>25</sup> which was enacted to give effect to India's international law obligations under United Nations Convention on Rights of Persons with

<sup>&</sup>lt;sup>17</sup> Rajeswaran Thiagesan, Vijayaprasad Gopichandran & Hilaria Soundari, *Ethical Framework to Address Barriers to Healthcare for People with Disabilities in India*, 15 Asian Bioeth. Rev. 307 (2023), https://doi.org/10.1007/s41649-023-00239-4 (last visited Feb 16, 2024).

<sup>&</sup>lt;sup>18</sup> Karina Aparecida Padilha Clemente et al., *Barriers to the Access of People with Disabilities to Health Services: A Scoping Review*, 56 Rev. Saude Publica 64 (2022). <sup>19</sup> CDC, *Disability and Health Disability Barriers / CDC*, Centers for Disease Control and Prevention (2019), https://www.cdc.gov/ncbddd/disabilityandhealth/disability-barriers.html (last visited Feb 16, 2024).

<sup>&</sup>lt;sup>20</sup> Thiagesan, Gopichandran, and Soundari, *supra* note 16.

<sup>&</sup>lt;sup>21</sup> For Disabled People in India, Securing Health Insurance Is Still a Difficult Task, The Wire, https://thewire.in/rights/disabled-people-india-securing-health-insurance-difficult-task (last visited Feb 16, 2024).

<sup>&</sup>lt;sup>22</sup> Muriel Mac-Seing et al., *The Intersectional Jeopardy of Disability, Gender and Sexual and Reproductive Health: Experiences and Recommendations of Women and Men with Disabilities in Northern Uganda*, 28 Sex. Reprod. Health Matters 269 (2020), https://www.jstor.org/stable/48617685 (last visited Feb 16, 2024).

<sup>&</sup>lt;sup>23</sup> Willi Horner-Johnson, *Disability, Intersectionality, and Inequity: Life at the Margins, in* Public Health Perspectives on Disability: Science, Social Justice, Ethics, and Beyond 91 (Donald J. Lollar, Willi Horner-Johnson, & Katherine Froehlich-Grobe eds., 2021), https://doi.org/10.1007/978-1-0716-0888-3\_4 (last visited Feb 16, 2024).

<sup>&</sup>lt;sup>24</sup> Hridaya Raj Devkota et al., *Disability, Caste, and Intersectionality: Does Co-Existence of Disability and Caste Compound Marginalization for Women Seeking Maternal Healthcare in Southern Nepal?*, 1 Disabilities 218 (2021), https://www.mdpi.com/2673-7272/1/3/17 (last visited Feb 16, 2024).

<sup>&</sup>lt;sup>25</sup> Rights of Persons with Disabilities Act, 2016., (2016), http://indiacode.nic.in/handle/123456789/2155 (last visited Dec 28, 2023).

Disabilities<sup>26</sup> and the principles contained therein. The Act lays down various rights and entitlements that include, among others, equality and nondiscrimination, especially of women and children with disabilities; community life; reproductive rights etc. It further lays down duties of educational institutions, empowerment programmes and various other social security, rehabilitation and recreation measures. The Act in Section 25 refers and recognises various healthcare rights of persons with disabilities. It requires the appropriate government or local authorities to provide free healthcare in the vicinity and particularly in rural areas subject to family incomes.<sup>27</sup> It further requires providing barrier free access in government and private hospitals, healthcare institutions and centres.<sup>28</sup> One important aspect of this right is that the Act requires priority in attendance and treatment provided to persons with disability.<sup>29</sup> The Act also requires the government and local authorities to take specific measures and schemes to promote healthcare of persons with disabilities that includes essential medical facilities for life saving emergency treatments and procedures<sup>30</sup> and sexual and reproductive healthcare<sup>31</sup> for women with disabilities. Section 26 of the Act requires the government to provide insurance for employees with disabilities. Moreover, under Section 27, governments and local authorities are also required to, within their economic capacities, to provide rehabilitation services and programmes, among others, in health.

Therefore, the Act itself is quite comprehensive in its coverage of concerns for equitable and non-discriminatory access to healthcare of persons with disabilities. However, while the rights with respect to healthcare are created, such rights will not be effective if specific remedies are not provided within the Act for violation of healthcare rights. In other words the law needs to make the concerned governments or local authorities obligated to provide such access to care. The Act must, in the light of the more recent developments like the Sustainable Development Goals (Goal 3.8)<sup>32</sup> that requires providing universal health coverage make it legally binding for the government to provide free access to healthcare to

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<sup>&</sup>lt;sup>26</sup> Convention on the Rights of Persons with Disabilities – Articles | United Nations Enable, https://www.un.org/development/desa/disabilities/convention-on-the-rights-of-persons-with-disabilities/convention-on-the-rights-of-persons-with-disabilities-2.html (last visited Nov 18, 2023).

<sup>&</sup>lt;sup>27</sup> Rights of Persons with Disabilities Act, 2016., *supra* note 24 at Sec 25 (1)(a).

<sup>&</sup>lt;sup>28</sup> *Id.* at Sec 25 (1)(b).

<sup>&</sup>lt;sup>29</sup> *Id.* at Sec 25 (1)(c).

 $<sup>^{30}</sup>$  *Id.* at Sec 25 (2)(j).

 $<sup>^{31}</sup>$  *Id.* at Sec 25 (2)(k).

<sup>&</sup>lt;sup>32</sup> SDG Target 3.8 | Achieve universal health coverage, including financial risk protection, access to quality essential health-care services and access to safe, effective, quality and affordable essential medicines and vaccines for all,

https://www.who.int/data/gho/data/themes/topics/indicator-groups/indicator-group-details/GHO/sdg-target-3.8-achieve-universal-health-coverage-(uhc)-including-financial-risk-protection (last visited Dec 31, 2023).

persons with disabilities who are incapable of paying costs of care. Only such legally guaranteed access to care would ensure that persons with disabilities have equitable and non-discriminatory access to healthcare. Furthermore, the Act talks about insurance only in the context of employees of the government. The Act, therefore, fails to ensure that all persons with disabilities have access to health insurance without discrimination due to disability. Furthermore, the Act should also make rehabilitation services a matter of enforceable right imposing binding obligation on the government to maximally realise the right within the resources available. Apart from the above, the element of equality and non-discrimination should also be given substantial interpretation to provide equitable access to healthcare to all persons with disabilities.

#### Healthcare Access in the Mental Healthcare Act, 2017

The next important recent law that also deal with healthcare access is the Mental Healthcare Act, 2017<sup>33</sup> that has been enacted to protect the rights of persons with mental illness. Section 18 (1) makes it a right of every person to have access to mental healthcare and treatment from mental health services that are run or funded by appropriate government. Thus, the Section imposes a clear duty on the government to provide mental healthcare to all. Furthermore, Section 18(2) of the said Act makes good quality, affordable mental healthcare services available in sufficient quantity accessible to persons with mental illness without any discrimination based on grounds mentioned therein and that also disability. Moreover, such care has to be acceptable to persons with mental illness and their family or caregivers. This provision has both non-discrimination and autonomy principles as is required under international law. Similarly, the Act also provides for advanced directive to be made by a person as to how the person wishes to be treated or not treated and allows appointment of nominated representative(s) for the purpose. It further imposes various duties on governments and mandates creation of Health Authorities. The Act has been a good development in the recognition of rights of persons with mental illness. The specific mention of persons with disabilities is important as mental illness can and does create an additional level of vulnerability and therefore a barrier in access to care. Therefore, it seems that the Act inculcates both principles of non-discrimination and equity in access to mental healthcare for persons with disabilities.

However, none of the above would really be effective unless the actual healthcare schemes and policies also sufficiently address the concerns relating healthcare access of persons with disabilities. One major healthcare scheme is the Ayushman Bharat Pradhan Mantri Jan Arogya Yojana (AB-PMJAY) to achieve Universal Health Coverage (UHC) in order to also meet the sustainable development goal

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<sup>&</sup>lt;sup>33</sup> Mental Healthcare Act, 2017, (2017), http://indiacode.nic.in/handle/123456789/2249 (last visited Dec 28, 2023).

that has the commitment to "leave no one behind".<sup>34</sup> The scheme intends to provide health cover of rupees five lakh per family per year to twelve crore poor and vulnerable families for secondary and tertiary care.<sup>35</sup> While the scheme can be analysed for various reasons, for our current purpose we shall look at beneficiary coverage to see whether it sufficiently covers persons with disabilities under the scheme.

# Beneficiary Coverage under PMJAY vis-a-vis Persons with Disability

The beneficiaries under PM-JAY are broadly categorised into rural and urban beneficiaries. Let us then look at who the beneficiaries are under both categories.Rural Beneficiaries under PM-JAY fall under six out of the seven deprivation criterias under the SECC 2011 for the rural areas and also those who fall under automatic inclusion criteria including destitute/living on alms, manual scavenger households, primitive tribal groups and legally released bonded labour.<sup>36</sup> <sup>37</sup> PM-JAY intends to cover families that fall under at least one of the six deprivation criteria as mentioned above.<sup>38</sup> <sup>39</sup>

## Urban Beneficiaries

Unlike the rural beneficiaries, for the urban areas the beneficiaries are included based on eleven occupational categories of workers. These are: Ragpicker, Beggar, Domestic worker, Street vendor/ Cobbler/ Hawker/ other service provider working on streets, Construction worker/ Plumber/ Mason/ Labour/ Painter/ Welder/ Security guard/ Coolie and other head-load worker, Sweeper/ Sanitation worker/ Mali, Home-based worker/ Artisan/ Handicrafts worker/ Tailor, Transport worker/ Driver/ Conductor/ Helper to drivers and conductors/ Cart puller/ Rickshaw puller, Shop worker/ Assistant/ Peon in small establishment/ Helper/Delivery assistant / Attendant/ Waiter, Electrician/ Mechanic/ Assembler/ Repair worker and Washer-man/ Chowkidar.40

#### The Exclusions

<sup>&</sup>lt;sup>34</sup> About PM-JAY - National Health Authority | GOI, https://nha.gov.in/PM-JAY#skip (last visited Dec 31, 2023).

<sup>35</sup> Id.

<sup>&</sup>lt;sup>36</sup> About PM-JAY - National Health Authority | GOI, Rural Beneficiaries, https://nha.gov.in/PM-JAY (last visited Dec 2, 2023).

<sup>&</sup>lt;sup>37</sup> SECC-2011-FAQs.pdf, https://pmil.in/wp-content/uploads/2019/06/SECC-2011-FAQs.pdf (last visited Jan 12, 2024).

<sup>&</sup>lt;sup>38</sup> About PM-JAY - National Health Authority | GOI, *supra* note 35 at Rural Beneficiaries.

<sup>&</sup>lt;sup>39</sup> SECC-2011-FAQs.pdf, *supra* note 36 at How will the households be ranked in rural areas?

<sup>&</sup>lt;sup>40</sup> About PM-JAY - National Health Authority | GOI, *supra* note 35 at Urban Beneficiaries.

While the SECC 2011 identifies the socio-economically vulnerable in the rural and urban settings in the terms of the criterias as mentioned above, it is nevertheless important from a right to health perspective to include, among others, specifically and explicitly all poor, vulnerable women, children and older persons with disability. As discussed above, the right to health principles of non-discrimination and the equity principle of prioritising the poor and the vulnerable should provide valuable guidelines in this regard. Under the principle of non-discrimination India has the obligation not to exclude from the purview of the PMJAY scheme anyone based, among others, on the grounds of their "physical or mental disability, health status (including HIV/AIDS)" etc..<sup>41</sup> This of course intersects other grounds of vulnerability like poverty, caste, gender, sexual orientation, race, religion etc. Therefore, as is required under both the Rights of Persons With Disabilities Act, 2016 and the Mental Healthcare Act, 2017, persons with disabilities must be provided access to healthcare on a non-discriminatory and equitable basis, which is not explicitly provided under the the PMJAY scheme.

#### Niramaya Health Insurance Scheme

This is an affordable health insurance scheme specifically for persons with disabilities that has been launched by the Department of Empowerment of Persons with Disabilities.<sup>42</sup> Under this scheme a coverage of up to one lakh rupees is provided to persons with disabilities for OPD treatment, regular medical checkup for non-ailing disabled, preventive dentistry, surgery to prevent aggravation of disability, non-surgical hospitalisation, corrective surgery for existing disability, therapies to reduce disability etc.<sup>43</sup> The include also includes transportation costs and requires no pre insurance medical tests.44 All persons with a valid certificate of disability under the National trust Act shall be eligible under the scheme. 45 While the scheme seems to be a commendable targeted insurance scheme only for persons with disabilities, the coverage of only one lakh rupees is not nearly sufficient. Furthermore, the principle of non-discrimination and equitable access to healthcare also requires persons with disabilities have non-discriminatory access to all health insurance programs and not merely the ones that are targeted towards them. The idea of universal health coverage also requires that persons with disabilities have access to healthcare of the same kind and quality as is available to others. Moreover, healthcare insurance schemes meant only for persons with disabilities may not be of adequate quality. Furthermore, universal health coverage along with the principles of non-discrimination and equity

<sup>&</sup>lt;sup>41</sup> General comment No. 14: The right to the highest attainable standards of health, *supra* note 11 at paras, 12 and 18.

<sup>&</sup>lt;sup>42</sup> NIRAMAYA | Ministry of Social Justice and Empowerment (MSJE), https://thenationaltrust.gov.in/content/scheme/niramaya.php (last visited Feb 16, 2024).
<sup>43</sup> Id

<sup>&</sup>lt;sup>44</sup> *Id*.

<sup>&</sup>lt;sup>45</sup> *Id*.

requires providing access to the same healthcare goods, services and facilities and health insurance schemes as are available to others.

IV.

#### Conclusion

To conclude, it can be said that non-discriminatory and equitable access to healthcare is a matter of human rights. Equity requires that we must provide access to healthcare to those who suffer greater deprivation due to their vulnerability and therefore would benefit more from such access. Persons with disabilities are one such vulnerable group that face various barriers in accessing healthcare. Hence, laws and policies relating to healthcare must be framed and tailored to meet and fulfil the needs of persons with disabilities who are at a greater risk of being deprived from such access to healthcare of adequate quality. While India has various laws that are based on the principles of equity and nondiscrimination in access to healthcare laying down various rights, such laws must also provide adequate remedies for violation of binding obligation of the State to provide such healthcare. Moreover, healthcare policies like AB-PMJAY that intend to achieve universal health coverage and leave no one behind must also specifically include persons with disabilities as beneficiaries who need to be prioritised. Only then can we be certain about meeting the healthcare needs of persons with disabilities.