THE REALISATION OF THE RIGHT TO HEALTH OF PERSONS WITH DISABILITIES IN THE COVID-19 ERA: EVALUATING SOUTH AFRICA'S (NON)INCLUSIVE RESPONSE

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Summary

Several international and regional human rights instruments guarantee the right to health of individuals including persons with disabilities and marginalised groups. Emerging reports from international organisations and the Committee on the Rights of Persons with Disabilities reiterate the obligations of state parties to ensure the enjoyment of healthcare services for persons with disabilities. The outbreak of the Covid-19 pandemic in South Africa and the subsequent national lockdown has led to the questioning of the national responses in the context of the right to the health of persons with disabilities. In this regard, this contribution uses a desktop-research based approach to engage three questions. First, the extent of government's inclusion or participation of organisations that (especially) represent the interests of persons with disabilities in the response plans. Secondly, the accessibility of information for persons with disabilities, and thirdly, the accessibility to healthcare and other essential services. A conclusion and recommendations follow.

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1 Introduction

Global statistics indicate that over 1 billion people or 15 per cent of the World's population have some form of disability.¹Approximately 80 per cent of these people are in developing countries.² In South Africa, there are approximately 2.8 million persons with disabilities (PWDs), accounting for about 7.4 per cent of the entire population.³ This excludes PWDs who are institutionalised and children with disabilities under 5 years of age.⁴ According to the Community Survey 2016, PWDs suffer social inequalities whereby 36 per cent are of low socio-economic status.⁵ In terms of race desegregation, the PWDs in the white or Indian/Asian population are within the upper wealth quintile (86.8 per cent and 71.9 per cent respectively). The Black African PWDs represent 44.7 per cent in the lower quintile in comparison to the less than 5 per cent among the coloured, Indian/Asian and white population groups. There is a need to establish the desegregation during the Covid-19 pandemic to establish the numbers of PWDS based on age, race and gender. At the time of preparing this contribution, the authors were not aware of any detailed desegregation following the 2016 study.

From the outset, 'disability' has often been understood as a physical notion, coupled with a modesty that extends to mental contexts.⁶ For the purposes of this presentation, disability should be looked at in a wider perspective that covers physical, intellectual or sensory impairment, medical conditions or mental illness, which may be permanent or transitory.⁷ While it is recognised that the Convention on the Rights of Persons with Disabilities (CRPD) avoids a definition of disability or PWDs, this paper adopts the position of the Protocol to the Africa Charter on the Rights of Persons with Disabilities, which describes a person with disabilities to include

- World Bank 'Disability inclusion overview' https://bit.ly/3l9Qw3v (accessed 8 November 2020); N Kostanjsek et al 'Counting disability: Global and national estimation' (2013) 35 *Disability and Rehabilitation* 1065 at 1069. 1
- UN Department of Economic and Kenaonitation 1005 at 1009. UN Department of Economic and Social Affairs Disability 'Factsheet on persons with disabilities' https://bit.ly/2I7VTCl (accessed & November 2020); S Grech 'Disability and development: Critical connections, gaps and contradictions' in D Hendrych (ed) *Disability in the Global South* (2016) 3-19. Republic of South Africa, Department of Women, Youth & Persons with Disabilities 2
- 3 'Disability statistics' www.womer Statistics.pdf (accessed 7 November 2020). www.women.gov.za/images/FACT-SHEET---Disability-
- 4 As above.
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- As above. As above. V Larocca, J Fraser-Thomas & R Bassett-Gunter "Even if someone has a physical disability, they can still participate" Youth with physical disabilities' motivational physical activity message preferences' (2020) 13 *Disability and Health Journal* 100845. See the definition in the UN General Assembly, Standard Rules on the Equalisation of Opportunities for Persons with Disabilities (1993) UN Doc A/RES/48/96 dated 20 December 1993, Introduction at para 17. See also CESCR General Comment 5: Persons with Disabilities (1994) UN Doc E/1995/22 dated 9 December 1994, para 3. 7

those who have physical, mental, psycho-social, intellectual, neurological, developmental or other sensory impairments which in interaction with environmental, attitudinal or other barriers hinder their full and effective participation in society on an equal basis with others.⁸

This definition is broad enough to cover various aspects that go beyond the usual and narrow concepts of physical and mental disabilities. In this vein, several international and regional human rights instruments guarantee the right to health of individuals. Various international human rights instruments have thematically dealt with the issues of disabilities. These include the Convention on the Rights of the Child,⁹ the African Charter on Human and Peoples' Rights,¹⁰ the African Charter on the Rights and Welfare of the Child,¹¹ the Additional Protocol to the American Convention on Human Rights in the Area of Economic, Social and Cultural Rights,¹² the Protocol to the African Charter on Human and Peoples' Rights on the Rights of Persons with Disabilities in Africa,¹³ and the CRPD.¹⁴ This has greatly informed the informed the widely accepted belief that the rights of PWDs must be protected and promoted through general, as well as specially designed, laws, policies and programmes. South Africa is a party to most of these instruments and as such is bound to engage its obligations to the letter.¹⁶

This contribution argues that the outbreak of the COVID-19 pandemic in South Africa and the subsequent national lockdown has led to the questioning of the national responses in the context of the right to the health of PWDs. Following the statement of the problem and the setting of the scene regarding the rights of PWDs, the contribution discusses the extent of the government's inclusion or participation of organisations that (especially) represent the interests of PWDs in the response plans. This is followed by a discussion of the accessibility of information for PWDs, and accessibility to healthcare and other essential services. A conclusion and recommendations follow.

13 Available at https://bit.ly/3lfRISY (accessed 25 May 2021).

15 Para 6 of General Comment 5 (n 7).

⁸ AU, Protocol to the Africa Charter on Human and Peoples' Rights on the Rights of Persons with Disabilities in Africa (2018) (African Disability Protocol), art 1 https://bit.ly/3liLvGb (accessed 10 November 2020).

UN General Assembly, Convention on the Rights of the Child (1989) United Nations, Treaty Series, vol 1577 3, (20 November1989), art 23.

¹⁰ African Charter on Human and Peoples' Rights, 27 June 1981, CAB/LEG/67/3 rev. 5, art 18(4).

¹¹ Organisation of African Unity (OAU), The African Charter on the Rights and Welfare of the Child, 11 July 1990, CAB/LEG/24.9/49 (1990), art 13.

¹² Additional Protocol to the American Convention on Human Rights in the Area of Economic, Social and Cultural Rights, Document A-52, art 18.

¹⁴ Art 25.

For a list of instruments to which South Africa is a party, see 'General measures of implementation – Chapter 3' https://bit.ly/3g0RAWn (accessed 26 May 2021).

Statement of the problem 2

Despite the high figures of PWDs in South Africa, there is a missing link in the desegregation of the persons affected by COVID-19. The disconnect is that the COVID-19 statistics in South Africa are silent on desegregation on account of race, age, sex and forms of disabilities of infected PWDs. This missing link has affected the responses by the government to PWDs. With an emphasis on the right to healthcare, this disconnect identifies the need to question the responses by the government to ensure the enjoyment of the right to health of PWDs during the pandemic. It offers a chance to question the practical aspects of the regulations in relation to the health of PWDs.

It should be noted that the Committee on the Rights of Persons with Disabilities (the Committee) has expressed concerns about the 2018 report of South Africa. In this regard, the Committee highlighted the absence of meaningful consultation and effective participation mechanisms to ensure that the views, opinions and concerns of PWDs are engaged in policy formulation, including decision-making processes, by public authorities both at the national and local levels.¹⁷ As indicated earlier, a holistic description of PWDs (that includes persons with physical, mental, psychosocial, intellectual, neurological, developmental or other sensory impairments which in interaction with environmental, attitudinal or other barriers hinder their full and effective participation in society on an equal basis with others) has to be used.

Setting the scene: The right to health of PWDs 3

The realisation of the right to health is informed by the extent to which the requisite services are available, accessible, acceptable and of good quality.¹⁸ Without prejudice to these four elements that inform the right to health generally, the context of PWDs is informed by eight major principles underlying the Convention on the Rights of Persons with Disabilities (CRPD) and implementation of obligations within a state.¹⁹ These include the respect for inherent dignity; the principle of nondiscrimination; participation and inclusion in society; respect for difference; and acceptance of PWDs.²⁰ Other principles include equality of opportunity; accessibility; equality between men and women; and the

Para 6 of South Africa's Initial Report to the CRPD Committee (2018).

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UN CESCR, General Comment 14: The right to the highest attainable standard of health (Art 12) (2000) UN Doc E/C.12/2000/4 dated 11 August 2000, para 12(a)-(d). UN General Assembly, Convention on the Rights of Persons with Disabilities, resolution/adopted by the General Assembly (2007) UN Doc A/RES/61/106 dated 24 19 January 2007, art 3.

²⁰ Art 3(a)-(d) of the CRPD (n 19).

respect for the evolving capacities of children with disabilities and their right to the preservation of their identities.²¹

This contribution by design examines three principles, namely: accessibility; equality and non-discrimination; and participation of PWDs in matters that concern them. While the selected principles inform the holistic enjoyment of the right to health of PWDs,²² it is reiterated that this is by no means an exhaustive list but rather furtherance of the discussion herein.

3.1 Normative content of the right to health of PWDs

The International Covenant on Economic, Social and Cultural Rights (ICECSR) provides for the right to health.²³ Article 12 of the ICESCR calls on states to establish an expansive public health system which embraces the fulfilment of the socio-economic rights based on the provision of civil and political rights.²⁴ Further insights are evident in General Comment 14 of the ICESCR that elucidates on the expansive interpretation of the right to health.²⁵ This General Comment solidifies the public health underpinnings of the right to health to include the need to ensure that both the public and private providers of health services and facilities uphold the principle of non-discrimination in relation to persons with disabilities.²⁶ The protection of the right to health has to be in the bounds of the highest attainable standard of health conducive to living a life in dignity.²⁷ The Committee of Economic, Social and Cultural Rights further observes that the enjoyment of the right to health is dependent on other rights such as privacy, dignity, life and non-discrimination.²⁸ It also reasons that states are obligated to ensure access to healthcare services for all on a nondiscriminatory basis, with regard to the needs of vulnerable and marginalised groups in society.²⁹ States have to realise available, accessible, acceptable and quality healthcare services for everyone.³⁰ The obligations extend to respect, protection and fulfilment of the enjoyment of the right to health. A state will be in breach of its duty to respect the right to health if it fails to adopt a legislative framework on the right to health.

- Art 3(e)-(h) of the CRPD (n 19). 21
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- Art 3 of the CRPD (n 19). Art 3 of the CRPD (n 19). UN General Assembly, International Covenant on Economic, Social and Cultural Rights, 16 December 1966, United Nations, Treaty Series, vol 993, 3, art 12. See art 12(2)(d) of the ICESCR (n 23 above). It provides that: 'The steps to be taken by the States Parties to the present Covenant to achieve the full realization of this right 24 shall include those necessary for ... (d) The creation of conditions which would assure to all medical service and medical attention in the event of sickness.'
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- General Comment 14 (n 18). Para 26 of General Comment 14 (n 18). See also para 34 of ICESCR General 26 Comment 5 (n 15).
- 27 Para 1 of General Comment 14 (n 18).
- 28 Para 12 of General Comment 14 (n 18).
- 29 As above.
- 30 As above.

The CRPD offers various definitions that underscore the protection of PWDs. The requisite article provides that discrimination refers to

distinction, exclusion or restriction on the basis of disability which has the purpose or effect of impairing or nullifying the recognition, enjoyment or exercise, on an equal basis with others, of all human rights and fundamental freedoms in the political, economic, social, cultural, civil or any other field.³¹

To this end, there is a need to apply the principle of non-discrimination in a manner that does not affect the holistic enjoyment of rights generally by PWDs. Further discussion on the CRPD is provided below. The Convention on the Elimination of all forms of Discrimination against Women adds its voice to discrimination and provides for nondiscrimination against women in areas of healthcare,³² discrimination on the basis of sex,³³ and participation of women in matters that concern them ³⁴

There are regional human instruments in Africa that speak to the protection of the rights of PWDs. First, the African Charter on Human and Peoples' Rights provides for the right to freedom from discrimination,³⁵ duty on persons to respect others without discrimination,³⁶ participation in government,³⁷ right to equal access to public property and services in the country,³⁸ and the right to health.³⁹ The Protocol to the African Charter on Human and Peoples' Rights on the Rights of Women in Africa (Maputo Protocol) extenuates this right to health and reproductive rights for women and children,⁴⁰ accessible health services,⁴¹ participation in political and decision-making processes,⁴² and protection of women with disabilities.⁴³ Furthermore, the Protocol to the African Charter on Human and Peoples' Rights on the Rights of Persons with Disabilities (African Disability Protocol) calls for the need for accessibility of the services to PWDs,⁴⁴ and lays down various principles on the protection of PWDs.

- Art 2 of the CRPD (n 19). 31
- 32 Art 12 of the CRPD (n 19).
- 33 Art 1 of the CRPD (n 19). 34 Art 11 of the CRPD (n 19).
- 35 Art 2 of the ACPHR (n 10).
- 36 37 Art 28 of the ACPHR (n 10). Art 13 of the ACPHR (n 10).
- 38 Art 13 of the ACPHR (n 10).
- 39
- Art 16 of the ACPHR (n 10). AU, Protocol to the ACPHPR on the Rights of Women in Africa (Maputo Protocol) dated 11 July 2003, art 14 https://au.int/en/treaties/protocol-african-charter-human-40 and peoples-rights-rights-women-africa (accessed 10 November 2021). Art 14(2)(a) of the Maputo Protocol (n 40). Art 9 of the Maputo Protocol (n 40). Art 23 of the Maputo Protocol (n 40).
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- Art 15 of the African Disability Protocol (n 8). 44

These include the best interests of the child, reasonable accommodation,⁴⁵ the right to health,⁴⁶ and non-discrimination.⁴⁷

South Africa's obligations under the aforesaid international and regional instruments require it to take all appropriate measures to promote the physical, cognitive and psychological recovery, rehabilitation and social reintegration of PWDs.⁴⁸ These persons may become victims of exploitation or violence (or abuse) that results from the provision of protection services.⁴⁹ One may argue that the enjoyment of the rights of PWDs in times of public health emergencies is not provided for by the CRPD, based on the wording that

States Parties shall take, in accordance with their obligations under international law, including international humanitarian law and international human rights law, all necessary measures to ensure the protection and safety of persons with disabilities in situations of risk, including situations of armed conflict, humanitarian emergencies and the occurrence of natural disasters.⁵⁰

This is partly because public health emergencies may be manmade.⁵¹ This potentially dangerous predicament is solved by the requirement in article 25 that calls on states parties to

take all appropriate measures to ensure access for persons with disabilities to services that are gender-sensitive, including health-related health rehabilitation. In particular, States Parties shall:

(a) Provide persons with disabilities with the same range, quality and standard of free or affordable health care and programmes as provided to other persons, including in the area of sexual and reproductive health and population-based public health programmes.⁵²

The provision of these public health programmes, it is argued, may be public health interventions employed at a time of public health emergencies. To this end, rules governing derogations and limitations from rights would come to the fore. The International Covenant on Civil and Political Rights allows a state to derogate from its obligations as informed by the exigencies of the situation.⁵³ Furthermore, the measures need not be inconsistent with other international law obligations like the

- Art 3 of the African Disability Protocol (n 8). 45
- 46 Art 17 of the African Disability Protocol (n 8).
- 47 As above.
- 48 For a list of instruments to which South Africa is a party, see 'General measures of implementation' (n 16).
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- 50
- Art 11 of the CRPD (n 19). Art 11 of the CRPD (n 19) (our emphasis). J Leaning & D Guha-Sapir 'Natural disasters, armed conflict, and public health' (2013) 51 369 New England Journal of Medicine 1836.
- 52
- Art 25 of the CRPD (n 19) (our emphasis). Art 4(1) of the ICCPR. See CCPR, General Comment 29: Article 4: Derogations 53 during a state of emergency (2001) UN Doc CCPR/C/21/Rev.1/Add.11 dated 31 August 2001, paras 4-6.

prohibition of torture,⁵⁴ and the right against discrimination.⁵⁵ Concerning Public health emergencies, the Siracusa Principles on the Limitation and Derogation Provisions in the International Covenant on Civil and Political Rights guide states on engaging restrictions to dealing with human rights in instances of public health emergencies.⁵⁶

Before taking leave of this matter, it should be noted that the Constitution of the Republic of South Africa, 1996 provides for specific rights that underscore the promotion and protection of other rights such as equality before the law,⁵⁷ human dignity,⁵⁸ life,⁵⁹ privacy,⁶⁰ and healthcare.⁶¹ On this basis, this paper now considers the three important issues of accessibility, equality and participation.

3.2 Accessibility

Accessibility is a condition precedent for PWDs to live independently and participate fully and equally in society.⁶² This is because PWDs need access to the physical environment, transportation, information and communication and other facilities and services open or provided to the public. PWDs are effectively denied opportunities to participate in their communities when accessibility is denied.⁶³ Accessibility further includes adequate access to buildings for PWDs.⁶⁴ Critical to ensuring inherent dignity is the provision of access to services,⁶⁵ that leads to the subsequent recognition of the right to the inherent dignity of a person based on his or her worth as a human being.⁶⁶ In the context of the right to health, the essential elements of health like accessibility, and others that include availability, acceptability and the quality of healthcare speak to inherent

- UN General Assembly, Convention Against Torture and Other Cruel, Inhuman or Degrading Treatment or Punishment, 10 December 1984, United Nations, Treaty 54 Series, vol 1465, 85, art 2. See Art 4(1) of the ICCPR (n 32). See paras 8 and 13 generally of CCPR General
- 55 Comment 29 (n 53).
- UN Commission on Human Rights, The Siracusa Principles on the Limitation and 56 Derogation Provisions in the International Covenant on Civil and Political Rights (1984) UN Doc E/CN.4/1985/4, dated 28 September 1984.
- Sec 9 of the Constitution of the Republic of South Africa, 1996. 57
- 58 Sec 10.
- 59 Sec 11.
- 60 Sec 14.
- Sec 27. 61

- on article 9: Accessibility, (2014) UN Doc CRPD/C/GC/2 dated 22 May 2014, para 1. Para 1 of General Comment 2 of 2014 (n 62). The right to accessibility is underscored in art 25(c) of the International Covenant on Civil and Political Rights that accords the 63 right to access to public services.
- Para 12(b) of General Comment 14 (n 18). 64
- 65 Arts 3(f) and 9 of the See CRPD.
- Art 3 of the UN General Assembly, Universal Declaration of Human Rights, 10 December 1948, 217 A (III); preambular paras 1 and 2 and arts 12, 13 of the ICESCR (n 23); paras 1, 3 and 25 of General Comment 14 (n 18); art 25(d) of the 66 CRPD (n 19); preambular para 2 and art 5 of the ACHPR (n 10); and arts 11(5), 13(1), 17(1), 20(1)(c) and 21(1) of the ACRWC (n 11).

See art 9 of the CRPD (n 19). See also CRPD Committee, General Comment 2 (2014) 62

dignity.⁶⁷ Physical acceptability engrains inherent dignity in the provision of health facilities for all sections of the population including the vulnerable or marginalised groups like persons with disabilities.68 Anything to the contrary would most likely amount to discrimination against persons with disabilities.

Accessibility also speaks to the nature and proximity of health services. Regarding nature, the enjoyment should be informed by: access to basic preventive, curative, rehabilitative health services and health education; regular screening programmes; and appropriate treatment.⁶⁹ Concerning proximity, these services have to be readily available for PWDs - in the context of this contribution – at the community levels.⁷⁰ As such, it is expected that the rehabilitation services provided to PWDs would enable them to reach and sustain their optimum level of independence and functioning.⁷¹ The right to accessibility obliges states to apply universal design to goods, facilities, services, products and technologies to allow all persons, including PWDs, easy access.⁷² According to the Committee on the CRPD, the duty of states parties to implement accessibility is unconditional, and states parties may not excuse themselves from meeting their obligations by claiming that it is financially burdensome to do so.⁷³ This is even more imperative during the COVID-19 era.

3.3 Equality and non-discrimination

The CRPD observes that some domestic laws and policies do not acknowledge PWDs as full subjects of rights and rights holders.⁷⁴ It is observed that attitudinal barriers remain the greatest obstacle to the enjoyment of the right to health of PWDs. This often leads to limited access to healthcare in contexts including physical and mental conditions that inhibit the enjoyment of the right to health.⁷⁵ In the wider scheme of things, discrimination based on disability refers to any distinction, exclusion or restriction based on a disability that impairs or nullifies the 'recognition, enjoyment or exercise, on an equal basis with others, of all human rights and fundamental freedoms in the political, economic, social, cultural, civil or any other field'.⁷⁶

- Para 12(a)-(e) and 13 of General Comment 14 (n 18 above). 67
- Para 12(b) of General Comment 14 (n 18). Para 17 of General Comment 14 (n 18). 68
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- 70 As above.
- 71 Para 34 of General Comment 5 (n 15).
- 72 Para 15 of the CRPD.
- 73 Para 25 of the CRPD.
- Para 2 of UN Committee on the Rights of Persons with Disabilities, General Comment 6 on equality and non-discrimination (2018) UN Doc CRPD/C/GC/6 dated 26 April 74 2018.
- See arts 2(2) and 3 of the ICESCR (n 23); Para 18 of General Comment 14 (n 18). 75
- 76 See art 2 of the CRPD.

As such, the yardstick is to what extent access to healthcare is informed by other reasons on account of the status of the person and whether this can be justified.⁷⁷ The protection from discrimination extends to all persons including infants and children with disabilities through the call to states to accord them the opportunity to enjoy a fulfilling and decent life and to participate within their community.^{78°} The protection also calls on states to refrain from any action that discriminates against PWDs.⁷⁹

The CRPD adopts the concept of reasonable accommodation in addressing discriminatory practices against PWDs in all endeavours of life. Reasonable accommodation means transforming or refashioning the world in such a manner that recognises that persons with disabilities have the same rights as everyone. It means dismantling those social barriers erected for persons with disabilities. Discrimination is any attitude or practice that maintains these barriers. Failure to provide reasonable accommodation is one way of maintaining such barriers and is therefore discrimination. The Committee has held in one of its decisions that failure on the part of a state to investigate and punish acts of violence perpetrated against persons with albinism amounted to discrimination in contravention of the CRPD.⁸⁰

In the context of regulations handed down to mitigate the spread of the COVID-19 pandemic, it is expected that they [do not] exacerbate or lead to the violation of the rights of PWDs. With regard to the right to health, jurisprudence from the Committee on CRPD urges States to

prohibit and prevent discriminatory denial of health services to persons with disabilities and to provide gender-sensitive health services, including sexual and reproductive health rights. States parties must also address forms of discrimination that violate the right of persons with disabilities that impede their right to health through violations of the right to receive health care on the basis of free and informed consent, or that make facilities or information inaccessible.81

A case that best highlights discriminatory practices against PWDs in the healthcare setting is the *Eldridge* case.⁸² In that case, the court held that failure to provide facilities for sign language interpretation that would

UN Committee on Economic, Social and Cultural Rights (CESCR), General Comment 6: The Economic, Social and Cultural Rights of Older Persons, 8 December 77 1995, E/1996/22, para 21. Para 22 of General Comment 14 (n 18). See also para 34 of General Comment 5 (n 15).

⁷⁸ Rule 2, para 3 of the Standard Rules on the Equalization of Opportunities for Persons with Disabilities (n 7). See preambular paras (d) & (h) and art 25(f) of the CRPD (n 19). Para 30 of General Comment 6 (n 77).

Y v Republic United of Tanzania Communication 023/2014 (Views adopted on 31 August 80 2018)

Para 66 of General Comment 6 (n 77). See also Committee on the Rights of Persons with Disabilities General Comment1: Article 12: Equal recognition before the law (2014) UN Doc CRPD/C/GC/1 dated 19 May 2014, para 41.
 Eldridge v British Columbia (Attorney-General) (1977) 151 DLR (4th) 577.

assist hearing-impaired patients to communicate with health service providers in the same way as unimpaired patients constituted discrimination in violation of the Canadian Charter on Rights and Freedoms. According to the Court, the adverse effects of discrimination are relevant in the context of PWDs. This case is illustrative of how a substantive equality approach can mitigate the negative effects of discriminatory practices against PWDs in the realisation of access to healthcare services, especially during COVID-19. It would seem that the position in Eldridge case has now been codified in article 17(f) of the African Disability Protocol, which enjoins states to take measures to facilitate access to healthcare services for PWDs by: 'Ensuring that healthservices are provided using accessible formats and that care communication between service providers and persons with disabilities is effective' 83

It suffices to note that the requirement to steer clear of nondiscrimination is not a duty of only the government but private health providers as well.⁸⁴ This is in line with the requirement that the persons providing the service must maintain full respect for the rights and dignity of PWDs.⁸⁵

3.4 Participation

The CRPD provides for the participation of PWDs in matters that concern them.⁸⁶ It is expected that the active and informed participation of everyone in decisions that affect their lives and rights informs the human rights-based approach to public decision-making processes, and ensures good governance and social accountability.87 This is against the background that the extent of participation of PWDs in matters that concern them illustrates the extent of their inclusion by states.⁸⁸ As such, states are called on to guarantee and support the participation of PWDs through organisations of PWDs.⁸⁹ The participation of PWDs in matters affecting their lives, particularly in the context of healthcare is crucial to upholding their rights to dignity and equality.

⁸³ As above.

In para 26 of General Comment 14 (n 18), the Committee stresses that both the public 84 health sector and the private providers of health services must comply with the principle

<sup>of non-discrimination in relation to persons with disabilities.
Para 34 of General Comment 5 (n 15). See preambular para (h) of the CRPD (n 19).
Art 3(c) of the CRPD (n 19), provides for the principle of the full and effective participation and inclusion of PWDs in society.
Committee on the Rights of Persons with Disabilities, General Comment 7 on the</sup>

participation of persons with disabilities, including children with disabilities, through their representative organisations, in the implementation and monitoring of the Convention (2018) UN Doc CRPD/C/GC/7 dated 9 November 2018, para 2. Para 3 of General Comment 7 (n 87). 88

Para 94(g) of General Comment 7 (n 87).

In light of the foregoing principles and guidance from international law, it should be recalled that the Constitution of the Republic of South Africa recognises the peculiar position of PWDs. It provides that everyone is equal before the law and has the right to equal protection and benefit of the law.⁹⁰ Besides, the state has to refrain from unfair discrimination against anyone on various grounds including disability.⁹¹ On this basis, the right to healthcare is underscored to be available to everyone.⁹²

4 Contextualising the COVID-19 pandemic

The origins and chronology of the outbreak of the COVID-19 pandemic are well-documented and need not be repeated here.⁹³ Since then, this virus has spread to 219 countries, affected over 167 million people and resulted in over 3.4 million deaths.⁹⁴ At the time of writing, the United States had reported close to 33 million cases and over 587 000 deaths, while India reported 27 million infections and over 300 000 fatalities.95 South Africa had 1.6 million positively confirmed cases and over 55 000 deaths.⁹⁶ The greatest fear is in the steps that have to be taken to engage the third wave. It should be noted that the desegregation of these figures does not show the extent to which PWDs are affected. This anomaly is extended to data that is not desegregated based on age, sex or race. While the authors are alive to the critical positioning of these elements, it is argued that the best way to plan for the effected persons is to soar above these elements and seek to engage with how to best help the affected individuals.

In consonance with other countries, South Africa imposed lockdowns to ensure social distancing. Its lockdown restrictions have been gradually eased through a five-level tier system under the regulations promulgated under the Disaster Management Act.⁹⁷ It is not in doubt that various rights like the right to movement and accessibility of services like health and education have been greatly affected. The right to life in the context of ensuring livelihood, human dignity, health and education has also been curtailed.⁹⁸ The state remains obliged to promote and protect the rights of

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- Secs 27(1)(a), 28(1)(c) and (f)(ii) of the Constitution. C Huang et al 'Clinical features of patients infected with 2019 novel coronavirus in Wuhan, China' (2020) 395 *The Lancet* 497. 93

Sec 9(1) of the Constitution. 90

⁹¹ Sec 9(3) of the Constitution.

WHO 'Coronavirus Disease (COVID-19) Dashboard' https://covid19.who.int (accessed 25 May 2021). 94 95

As above.

WHO 'South Africa' https://bit.ly/38t8YAP (accessed 25 May 2021). See also Department of Health 'Covid-19: Online resource & news portal' https://bit.ly/ 96 2YsURX1 (accessed 25 May 2021).

⁹⁷ Disaster Management Act 57 of 2002

⁹⁸ This has led to untold hardships on all PWDs.

people within its territories to ensure the continued enjoyment of their rights like health, education, housing, and food and nutrition.

In a joint statement, the UN Committee on the Rights of Persons with Disabilities advised states on how to protect the rights of PWDs.¹⁰⁰ It called on states parties to take all possible measures to ensure the protection and safety of PWDs in the national response to situations of risk and humanitarian emergencies.¹⁰¹ The measures have to speak to the protection of their access to the highest attainable standard of health without discrimination, general wellbeing and prevention of infectious diseases, and to protect against negative attitudes, isolation, and stigmatisation that may arise during the crisis.¹⁰² Furthermore, the Committee advised on the use of the SDG 2030 Agenda to safeguard the rights and well-being of persons with disabilities.¹⁰³ States are called on further to accelerate measures of deinstitutionalisation of PWDs from all types of institutions¹⁰⁴ and to adopt measures to appropriately respond to the COVID-19 pandemic, through inclusion and the effective participation of PWDs.¹⁰⁵ These measures are also corroborated by a report by the International Commission for Jurists, which states that while persons with disabilities encounter different challenges relating to the enjoyment of the right to health, the situation is compounded by the outbreak of COVID 19 pandemic.¹⁰⁶ The UN Special Rapporteur on the Rights of Persons with Disabilities has noted that:

Owing to high levels of poverty, discrimination, violence and social exclusion, as well as significant barriers in access to health-care services, persons with disabilities, are at higher risk of developing ill-health than the general population and, therefore, more likely to require and use health-care services.¹⁰⁷

- See Committee on Economic, Social and Cultural Rights 'Statement on the coronavirus disease (Covid-19) pandemic and economic, social and cultural rights' E/C.12/2020/1 (6 May 2020). See also African Charter on Human and Peoples' 99 Rights 'Press statement on human rights based effective response to the novel COVID-
- 19 virus in Africa' https://bit.ly/3n4FLA6 (accessed 2 October 2020).
 100 UN Office of the High Commissioner 'Joint Statement: Persons with Disabilities and COVID-19 by the Chair of the United Nations Committee on the Rights of Persons with Disabilities, on behalf of the Committee on the Rights of Persons with Disabilities and the Special Envoy of the United Nations Secretary-General on Disability and Accessibility' https://bit.ly/2Ik0n8E (accessed 2 November 2020).
- 101 Para 2 of the Joint Statement (n 100).
- 102 As above.103 Para 4 of the Joint Statement (n 100).
- 104 Para 5 of the Joint Statement (n 100).
- 105 As above.
- 106 International Commission of Jurists (ICJ) 'Living like people who die slowly: The need for right to health compliant COVID-19 responses' (2020) https://bit.ly/38lNMws
- (accessed 2 November 2020).
 107 UN General Assembly 'Rights of persons with disabilities: Note by the Secretary-General to the General Assembly on the report of the Special Rapporteur on the rights of persons with disabilities' Catalina Devandas-Aguilar, submitted in accordance with Human Rights Council resolution 35/6 https://bit.ly/32FId8H (accessed 2 May 2021).

The Committee on CRPD has affirmed the obligations of states to ensure the right to equality and non-discrimination in the enjoyment of healthcare services for PWDs.¹⁰⁸ The Committee on Economic, Social and Cultural Rights has noted that PWDs must be provided the same level of medical care within the same system as other members of society.¹⁰⁹

To this end, the question to which the paper now turns is to what extent the national responses speak to the protection of PWDs. In a bid to evaluate their access to the highest attainable standard of health, and to protect against negative attitudes, isolation, and stigmatisation, the three principles of accessibility, equality and non-discrimination and participation will be engaged.

5 The extent of the government's inclusion or participation of organisations

The concept of inclusion is birthed out of the Sustainable Development Goals that are informed by the aphorism 'leaving no one behind'.¹¹⁰ Various specific developments have taken place since then. For instance, the United Nations proposed that all the preparedness and responses of states have to be inclusive of and accessible to all persons including women with disabilities and include accessibility for all persons, including women with disabilities.¹¹¹

Following the adoption of the COVID-19 Regulations under the Disaster Management Act, the Department of Social Development adopted measures to cushion the effects of COVID-19 on vulnerable persons. Regarding PWDs, measures were introduced to support them by allowing caregivers to continue assisting them to do their shopping and to access their social grants.¹¹² It should be noted that this relief was evident in regulations and the authors are not aware of any other specific or thematic regulations that have been made under the Disaster Management Act to deal with specific aspects of PWDs. This is the identification of the lack of inclusion that follows the lack of participation of the PWDs or their organisations in the enactment of the regulations concerning the COVID-19 era. Involving marginalised and disadvantaged groups in decision-

¹⁰⁸ General Comment 6 (n 74).

¹⁰⁹ Para 34 of General Comment 5 (n 7).

¹¹⁰ UN Department of Economic and Social Affairs 'Sustainable Development Goals' https://sdgs.un.org/goals/ (accessed 8 November 2020).

¹¹¹ As above.

¹¹² SA Government 'Disability – Coronavirus COVID-19' https://www.gov.za/covid-19/ individuals-and-households/disability-coronavirus-covid-19 (accessed 8 November 2020).

making in matters that affect their lives is not only empowering but also upholds their dignity.¹¹³

Participation has been a contested issue that has continually come up in courts of law. In the Doctors for Life International, the Constitutional Court held that concerning participation in the enactment of legislation, Parliament and the National Council of Provinces have to ensure that provincial interests are taken into consideration in the national lawmaking process through the facilitation of public involvement as long as it is reasonable to do so.¹¹⁴ It was indeed unreasonable to conduct in-depth facilitation during the lockdown.¹¹⁵ The Court added that the participation by the public continuously provides vitality to the functioning of representative democracy through the encouragement of citizen in the country to be actively involved in public affairs.¹¹⁶ It should be recalled, however, that the government was able to put in place a team to advise the presidency on the COVID-19 pandemic, after the declaration of the state of disaster and the adoption of the various regulations. Surely, it did not need much effort to add organisations representing PWDs. The establishment of the National Command Council to influence decisions on the regulations adopted to mitigate the spread of COVID-19 should have engaged organisations of PWDs to ensure a certain iota of participation.117

The extent of consultation or public participation by the Minister of Cooperatives and Traditional Affairs before handing down the regulations under the Disaster Management Act under the DMA was greatly limited. In *De Beer*, the Court noted that the making of regulations and the issuing of directives by the Minister in terms of the DMA are subject to a specific limitation-enactment after consultation with 'the responsible Cabinet member', responsible for each specific functional area of jurisdiction.¹¹⁸ The making of the regulations are informed by the need to take necessary measures to assist and protect the public, provide relief to the public, and protect property.¹¹⁹ There was no participation of the masses let alone PWDs or institutions that support this cause.¹²⁰ The only logical aspect of the regulations that speaks to the plight of persons with disabilities

- 115 This was reiterated in Reyno Da Wid De Beer v the Minister of Cooperative Governance and Traditional Affairs Gauteng High Court Constitutional Application 21542 of 2020, para 5.3.
- 116 Doctors For Life (n 114) para 115.
- 117 For a detailed engagement of the National Command Council, see JA Singh 'How South Africa's Ministerial Advisory Committee on COVID-19 can be optimised' (2020) 110 South African Medical Journal 439.
- 118 De Beer (n 115) para 6.1. See also sec 27(2) of the Disaster Management Act.
- 119 Sec 27(2) of the Disaster Management Act.
- 120 As above.

¹¹³ See 'Report of the UN Special Rapporteur on extreme poverty and human rights (Magdalena Carmona) on the right to participation of persons living in poverty' HRC/ 23/6 (11 March 2013).

¹¹⁴ Doctors for Life International v Speaker of the National Assembly 2006 (6) SA 416 (CC) para 29.

indicates that the major and outstanding reference to them related to the provision of the social and disability grant which would continually be paid.¹²¹ Other than this aspect (which was not informed by participation), there are no direct thematic regulations that are adopted to particularly deal with the challenges of persons with disabilities. The danger in this lack of engagement continues to prevent the country from obtaining logical answers to pressing problems like gender-based violence involving PWDs and CWDs. In this regard, the UN Special Rapporteur on extreme poverty and human rights has noted:

[T]he main aim of human rights is transforming power dynamics between individuals in society, in order to challenge oppression, subvert the subordination and marginalization of certain groups and individuals, and promote individual agency, autonomy and respect of the inherent dignity of every human being.122

The lack of a counter-intuitive approach was evident in the nonrecognition of the evolving capacities of children who would have communicated their views on how to be helped in the era of COVID-19. One may also argue that it was a missed opportunity at obtaining clarity for PWDs from specific organisations.

As noted earlier, accessibility to the physical environment, transportation, information and communication and to other facilities and services aids PWDs to live independently and participate fully and equally in society.¹²³ It is not in doubt that most public health centres and hospitals provide for access for PWDs. Global results by the COVID-19 Disability Rights Monitors states that this accessibility is greatly limited to urban hospitals. It is stated that accessible transport is limited especially from rural areas to hospitals and clinics.¹²⁴ In areas where there is accessibility success, it is devoid of access concerning the provision of quality services for persons with emotional disabilities.¹²⁵ Furthermore, earlier research that was carried out before the lockdown indicates that access to healthcare in rural areas starts as a barrier to persons without disabilities, before the narrative of their effect on PWDs.¹²⁶

- 121 These Regulations, initially referred to as the Directions published in Government Gazette 43258, Government Notice R480 of 29 April 2020 as amended by Government Notices R.608 of 28 May 2020, R.714 of 25 June 2020, R.763 of 12 July 2020, R.846 of 31 July 2020, R.891 of 17 August 2020, R. 999 of 18 September 2020, R.1011 of 20 September 2020, R.1053 of 1 October 2020 and R.1104 of 21 October 2020, have reiterated that the temporary disability grant will continue to be paid until 31 December 2020.
- 122 Para 15 of the Report of UN Special Rapporteur on extreme poverty and human rights (n 113).
- (n 113).
 123 Art 9 of the CRPD (n 19); see also para 1 of General Comment 2 (n 62).
 124 'COVID-19 disability rights monitor' https://www.covid-drm.org/country/ZA (accessed 8 November 2020).
 125 'South Africa's Voluntary National Review (VNR) Report' (2019) 43.
 126 J Trani et al 'Stigma of persons with disabilities in South Africa: Uncovering pathways from discrimination to depression and low self esteem' (2000) 265 Social Science &
- from discrimination to depression and low self-esteem' (2020) 265 Social Science & Medicine 113449.

In the context of the right to health, South Africa has recognised in its Voluntary National Review Report that the main challenges are the lack of access to healthcare, especially in rural areas.¹²⁷ With specific reference to the right to health, there is a limitation in terms of enjoying healthcare from care providers.

Accessibility of information for PWDs 6

As indicated earlier, there is no desegregated data on the numbers of PWDs who have been affected by COVID-19 in South Africa. This makes it a problem as far as one does not know the magnitude of the support that is required by this vulnerable group. As a result, the greatest challenge lies in the lack of information that can be disseminated. It should be noted that access to information constitutes an integral part of the right to health. Without proper information, people in general and PWDs in particular may not be able to protect themselves. Access to information is greatly tilted to persons with specific disabilities. It is argued that a person who can read sign language is among the few PWDs who may benefit from information from the state. This has been a crucial aspect of the dissemination of information. However, the United Nations state that only 28 per cent of PWDs globally have access to benefits.¹²⁸ To this end, a study in South Africa shows that rehabilitation services, like physiotherapy, occupational therapy, speech therapy and hearing therapy were only available to 28 per cent of the PWDs.¹²⁹ Desegregation of the forms of disability in South Africa includes sight, hearing, communication, physical and mental disability as well as difficulty in self-care.¹³⁰ As such attempts to deal with disabilities have to speak to all these categories. In this regard, the African Disability Protocol urges states to ensure access to information for PWDs by: 'Ensuring that persons with visual impairments or with other print disabilities have effective access to published works including by using information and communication technologies'.¹³¹ As illustrated by the *Eldridge* case, the state is obligated to ensure access to health-related information to PWDs to enable them to enjoy their right to health.

131 Art 24(d) of the African Disability Protocol (n 8).

¹²⁷ South Africa''s Voluntary National Review (n 125).
128 UN Department of Economic and Social Affairs 'Disability and Development Report: Realizing the Sustainable Development Goals by, for and with persons with disabilities' (2018) https://bit.ly/36fGZSh (accessed 25 May 2021).
129 Disability and Development Report (n 128) 52.
130 Statistics SA 'Census 2011: Profile of persons with disabilities in South Africa' https:// bit.ly/218xTip (accessed 8 November 2020).
131 Art 24(d) of the African Disability Protocol (n 8)

Accessibility of healthcare and other essential 7 services

Statistics show 6 per cent of PWDs in South Africa lack access to healthcare facilities;¹³² 30 per cent of students with disabilities report that schools are not accessible; and 17 per cent of women with disabilities have experienced violence because of their disabilities.¹³³ The closest that the government has come concerning the provision of support has been through the adoption of particular COVID-19 policy responses to guide healthcare workers. The policy documents of accessibility to healthcare do not engage the position of PWDs, and secondly, they take on a medial rather than a human-rights based approach.¹³⁴ While the former focuses on treatment following a medical condition, the human rights-based approach uses human rights standards to realise the rights of an individual.¹³⁵ It is premised on the notion that every individual must be treated with respect.¹³⁶ This approach emphasises the safeguard of the interests of marginalised and disadvantaged groups in society through respect for dignity, non-discrimination and equality, participation, accountability, access to information and transparency.¹³⁷

To this end, under the National Infection Prevention and Control Strategic Framework,¹³⁸ health workers are guided on how to ensure patient safety through the use of the built-in environments, water, sanitation, environmental cleaning and healthcare waste management.¹³⁹ While this is commendable, it only speaks to help the patients who are in the healthcare setting, there is no regard to those who are in other settings like in their home or in institutions where the persons who care for them are expected to provide the same or higher level of support.

Furthermore, there is a lack of emphasis on the extent of support that is deliberately channelled to PWDs. If anything, the document mentions PWDs once - namely, the need to have at least one toilet for PWDs.¹⁴⁰ As such, while this information albeit insufficient is available for the healthcare workers, it is not provided for PWDs to place them in a position

¹³² Disability and Development Report (n 128) 57.

¹³³ Disability and Development Report (n 128) 114.
134 While the medical approach may speak to the provision of support, a human rights-based approach calls on the use of preventive measures as means to protect and

promote the right to health of PWDs.
 135 UNICEF 'Human rights-based approach to programming' (2020) https://uni.cf/ 39HKAdb (accessed 8 November 2020).

¹³⁶ As above.
137 As above.
138 Department of Health 'National infection prevention and control strategic framework'
138 Department of Health 'National infection prevention and control strategic framework' (March 2020) https://www.nicd.ac.za/wp-content/uploads/2020/04/National-Infection-Prevention-and-Control-Strategic-Framework-March-2020-1.pdf (accessed 25 May 2021).

¹³⁹ National infection prevention and control strategic framework (n 138) 31.

¹⁴⁰ National infection prevention and control strategic framework (n 138) 33.

to know their rights and be able to enforce them. It is argued that this omission rather exacerbates an institutionalised model of discrimination that is seen in the silence of the national response mechanism on the guidance to health workers and the reiteration of the rights of PWDs.

Another critical response mechanism is the Allocation of Scarce Critical Care Resources during the COVID-19 Public Health Emergency in South Africa.¹⁴¹ This resource provides for the guide the triage of critically ill patients if a public health emergency creates demand for critical care resources like ventilators and critical care beds.¹⁴² This is a welcome development and critical to the provision of healthcare to the critically ill, including PWDs. As mentioned earlier, this is informed by the perspective that a person has to be critically ill to benefit from scarce critical care resources. The rhetorical questions that come to the fore are: what about the use of preventive measures that culminate in a possible avoidance of this problem? What about the deliberate use of the scarce resources for the provision of support to the PWDs in their various settings, and above all, to what extent is this information available to them? The heightened danger in the application of this response mechanism lies in the health decisions that are based on discrimination informed by aspects such as age and the value of life. To this end, the use of the clinical Frailty Scale to determine who gets support may effectively limit support to PWDs.¹⁴³ None of these documents speaks directly to disability. Accessibility speaks to the availability of collected data and how its dissemination presents barriers that affect PWDs. The unpacking of accessibility to health services is informed by the extent to which PWDs have received treatment.

8 Conclusion

The paper has highlighted some of the challenges facing PWDs in the realisation of their right to health during the COVID-19 pandemic. First, the preparation of the Declaration and the Regulations under the Disaster Management Act are limited to specific ministerial powers. This is because the intent is to control the emergency for a limited period. This position greatly influenced the extent to which any form of participation would be engaged. There has been no inclusion of participation of organisations of

¹⁴¹ Critical Care Society of South Africa 'Allocation of scarce critical care resources during the COVID-19 public health emergency in South Africa' (2 April 2020) https://bit.ly/ 3lcVvAC (accessed 25 May 2021).

 ¹⁴² Critical Care Society of South Africa (n 141). For a detailed discussion on triaging persons with disabilities in a time of Covid-19 in South Africa, see EL McKinney, V McKinney & L Swartz 'COVID-19, disability and the context of healthcare triage in South Africa: Notes in a time of pandemic' (2020) 9 *African Journal of Disability* 766.

^{South Africa: Notes in a time of pandemic' (2020) 9} *African Journal of Disability* 766.
143 Critical Care Society of South Africa (n 141) 5-9. Other instructive policy documents that may be looked at include the National Health Laboratory Service 'Coronavirus disease 2019 (COVID-19): Quick reference for clinical health care workers' (25 May 2020).

PWDs in the adoption of measures. In instances where there has been inclusion and participation, it is not readily available. The available measures to provide information and services reveal the use of a rather medical-oriented approach that engages in treatment rather than a human rights-based approach that takes on preventive, promotional and protective measures.

The accessibility of information for PWDs, and subsequent access to healthcare and other essential services is limited to specific calibres of PWDS. While some of the support provided like the social and the temporary disability grants is crucial, a deliberate participatory approach needs to be adopted. Matters of discrimination based on decisions that follow who should receive treatment continue to trickle in, exacerbating the already vulnerable position of the PWDs. The failure to engage the PWDs or the institutions that support their cause shows a lack of inclusive engagement, a lack of participation. This greatly affects the accessibility of information and services.

It is highly probable that the data on the COVID-19 infections has details on the age, sex, race and forms of disability, though the nondisclosure of the same is informed by other reasons. Nevertheless, it is imperative that this information is given to offer a clear picture of the effect on COVID-19 on the PWDs. The interventions by government have to be in tandem with the figures on the desegregation of PWDs so as to ensure participation and the desired accessibility of information and services. It is proposed that a multi-disciplinary empirical study that tests this conceptual framework against human-rights based theories be done to test the argument and sub-claims in a qualitative or quantitative study.

A re-evaluation of the process of adopting regulations for periods of emergencies should be revisited to inculcate a human rights-based approach as the mode of protecting the rights of PWDs. Concerning shadow or alternate reports by NGOs to the Committee of the RPD, this should be submitted to evaluate the extent to which SA as a state party has engaged the protection of PWDs in the COVID-19 pandemic.