Opinion Article

The challenge of including people with disabilities in the strategy to address the COVID-19 pandemic in Brazil

doi: 10.1590/S1679-49742020000500023

Veronika Reichenberger[1] - orcid.org/0000-0001-6778-2682
Maria do Socorro Veloso de Alburquerque[2] - orcid.org/0000-0002-1520-700X
Renata Bernardes David[3] - orcid.org/0000-0003-1956-6672
Vinícius Delgado Ramos[4] - orcid.org/0000-0002-4566-6637
Tereza Maciel Lyra[5] - orcid.org/0000-0002-3600-7250
Christina May Moran de Brito[4] - orcid.org/0000-0003-3775-6533
Luciana Sepúlveda Köptcke[3] - orcid.org/0000-0001-7079-6575
Hannah Kuper[1] - orcid.org/0000-0002-8952-0023

[1]London School of Hygiene and Tropical Medicine, London, United Kingdom
[2]Universidade Federal de Pernambuco, Centro de Ciências Médicas, Recife, PE, Brazil
[3]Fundação Instituto Oswaldo Cruz, Brasília, DF, Brazil
[4]Universidade de São Paulo, Faculdade de Medicina, São Paulo, SP, Brazil
[5]Fundação Instituto Oswaldo Cruz, Instituto Aggeu Magalhães, Recife, PE, Brazil

The pandemic caused by the novel coronavirus (SARS-CoV-2) has posed a huge challenge, given that so far there are no vaccines or treatment proven to be effective against the infection of the virus.[1] As such, social distancing and self-isolation have been the main guidelines for preventing the spread of COVID-19. People with disabilities face specific situations of vulnerability, especially in the context of Brazil's current health, social and political crises, as well as potentially facing even bigger challenges in view of the measures to contain the pandemic.

The Convention on the Rights of Persons with Disabilities, created in 2006 by the United Nations,[2] provides the following definition of people with disabilities:

> those who have long-term physical, mental, intellectual or sensory impairments which in interaction with various barriers may hinder their full and effective participation in society on an equal basis with others.[2]

Despite there being no consensus on their greater vulnerability to the virus, simply because they have a disability, a considerable part of disabled people are recognized as being at risk of developing the most severe form of COVID-19, whether it be because of comorbidities, or because of specific needs in their daily routines, such as relying on a carer, and the impact of the disease on other support systems - family, friends and services that usually provide the support that they need.[3] Moreover, on average people with disabilities are in older age groups and are therefore more prone to developing underlying health conditions, such as cardiovascular, respiratory, kidney and metabolic diseases; these being determinant factors for them to be considered a high-risk group.[4]

*The study received financial support from the São Paulo Research Foundation (FAPESP), reference 2017/50358-0. Fundação de Apoio à Pesquisa do Distrito Federal (FAP-DF), reference 19300000355/2018-80; Fundação de Amparo à Ciência e Tecnologia do Estado de Pernambuco (FACEPE), reference APQ-0925-4.06/17; e Medical Research Council (MRC), reference MR/R022755/1.

Correspondence:
Veronika Reichenberger – London School of Hygiene & Tropical Medicine, Keppel Street, London. WC1E 7HT
E-mail: veronika.reichenberger@lshtm.ac.uk

Measures such as social distancing and self-isolation are not always possible for just over 6% of the Brazilian population who face considerable functional limitations and need support to carry out their daily activities, such as eating, getting dressed or having a bath.[5,6] For these individuals, it is the State's responsibility to adopt additional social protection measures and maintain their support structures in a secure manner, offer necessary services and promote social inclusion, as well as access to relevant information and services.[7,8]

In the midst of Brazil's complex epidemiological, political and socioeconomic context, as well as the budget restrictions imposed by the Constitutional Amendment of 95[9] and political and scientific tensions in society on how to address the pandemic,[3,10] it has fallen to the diverse leaders of the Brazilian national health system, Sistema Único de Saúde (SUS), to invest and act in the areas of prevention, diagnosis, treatment and rehabilitation.[11]

The government, civil society and social watchdog mechanisms of SUS policy have taken action in the protection of people with disabilities in the context of the pandemic. These actions include accessible information campaigns, initiatives to increase social protection, through social distancing and isolation, and preventive measures in therapeutic and inclusive residences.[8] Civil society organizations have emphasized the importance of including accessible resources in information campaigns. This was emphasized because of challenges that emerged with regard to putting into practice the Brazilian Law on Inclusion of People with Disabilities, provision of accessible formats, and reasonable adaptations of care protocols for people with disabilities.[12,13] In turn, Brazilian government institutions have published information about COVID-19 and specific guidance on preventing infection in accessible formats for people with different kinds of disabilities.[14,15] Recently, the Women, Family and Human Rights Ministry began to register institutions that provide assistance to people with disabilities, to support them during the pandemic.[16]

The National Health Council has recommended that the Federal Administration provide protection measures for people with disabilities in therapeutic and inclusive residences.[17] However, guidelines like those issued on preventing and controlling SARS-CoV-2 infection in long-stay institutions for the elderly and in shelter institutions have overlooked key aspects such as accessibility of these facilities, as well as hygiene and communication protocols about the disease.[18]

Previous experiences show that in a context of a crisis, situations of vulnerability and inequality are not only revealed, but also increased in society. The Zika virus epidemic, for instance, exposed the bottleneck in SUS specialized care and gave visibility to the lack of care services provided to other children and adults with disabilities in Brazil. The Zika virus epidemic also reaffirmed the problems faced by families to ensure continuity of care.[19]

An additional challenge in the care of people with disabilities is the scarce availability of specialized care and hospital structure to treat more complex COVID-19 cases, such as unequal distribution of health resources, with less availability in the North and Northeast regions.[20,21] This adds to already existing difficulties faced by people with disabilities in accessing SUS facilities, such as lack of health worker preparation to include them in services, as seen in the congenital Zika virus syndrome epidemic.[19]

Exponential growth of COVID-19 cases and discrepancy in the availability of human resources and hospital equipment between the country's states and regions have revealed unequal capacities in addressing the pandemic.[22] In some Brazilian states, health systems came to the verge of collapse, due to their limitations, and were obliged to chose which people should or should not receive intensive care. [22]

In the case of the COVID-19 pandemic, this situation can lead to justified lack of care, with ethical implications. In response to the need to stratify risk, the Regional Councils of Medicine of the states of Rio de Janeiro, São Paulo and Pernambuco went as far as to suggest the adoption of the Unified Prioritization Score, based on the existence and pre-existence of certain conditions and dysfunctions, as well as the Clinical Frailty Scale.[23] In general, there is no evidence that Brazil is assuring the inclusion of people with disabilities as a priority group, as is advised by the National Health Council.[17] Technological resources capable of guaranteeing people with disabilities the same quality of services as is provided to other people need to be available,[17] and, in a pandemic such as the current one, they need to be prioritized in accordance with the legal provisions of the Statute of

People with Disabilities.[24] The Brazilian Federation of Down Syndrome Associations has reiterated the need to ensure non-discrimination of people with Down syndrome, with regard to treatment protocols and access, in situations in which resources are scarce.[25] It is also important to reaffirm that the Right to Health is enshrined in the Brazilian Constitution and failure to ensure it is a human rights violation.[4]

Lack of care also manifests itself through reduction in the availability of necessary services. People with disabilities and those who depend on rehabilitation therapies may present functional decline, which is why routine support of their care must be maintained, according to the different health conditions presented, ensuring comprehensive care for their needs, with reasonable adjustments being made.[26]

In Brazil, official data on confirmed COVID-19 cases or deaths are classified by age range, race/skin color, geographical location and risk factors. There is no disaggregated information about COVID-19 among people with disabilities.[27] It is therefore essential to collect data about disability and include them within the COVID-19 response, making it possible to measure the vulnerability of people with disabilities to infection and compare them to people without disabilities.

It is hoped that the Brazilian social protection and assistance programs will be scaled up during and after the pandemic. These measures will contribute to dealing with economic consequences, especially for more vulnerable populations, including people with disabilities. Special attention should be given to initiatives that promote inclusion and maintenance of disabled people in the formal labor market, albeit working remotely, with the aim of ensuring their access to income through emergency actions.

This challenge also represents an opportunity to explore the use of telemedicine in providing care and support to people with disabilities during the pandemic, in the hope that this mechanism will be effectively made available and contribute to improving health care accessibility. International experiences in the use of telemedicine have shown to be beneficial to diverse populations.[28]

Adoption of measures to promote equity, guaranteed accessible communication and social protection, are fundamental measures of an inclusive response to the pandemic. People with disabilities should have the role of protagonists in the COVID-19 response, as service defenders and users, not victims. It is of paramount importance to consult people with disabilities about their experiences, additional needs and suggestions, so that the responses to COVID-19 are more comprehensive, fairer and more effective.

It is essential that the Brazilian State: (i) implements a response strategy capable of ensuring the participation of people with disabilities in the process of planning and carrying out strategies in response to the emergency; (ii) takes into consideration the accessibility of measures intended for individuals with different kinds of disabilities; and (iii) that it undertakes comprehensive and representative data collection, in order to have knowledge about the impact of the pandemic and the actions adopted for people with disabilities. Brazil's capacity to respond to the pandemic should be monitored closely, as it will reveal to what extent political choices, anchored in disputed values and interests, may lead to underinvestment in healthcare and protection of vulnerable populations. It is highly important that society and its representative bodies act to contribute to the improvement of this scenario.

References

1. Sanders JM, Monogue ML, Jodlowski TZ, Cutrell JB. Pharmacologic treatments for coronavirus disease 2019 (COVID-19): a review. JAMA [Internet]. 2020 May [cited 2020 Oct 21];323(18):1824-36. Available from: https://doi.org/10.1001/jama.2020.6019
2. United Nations - UN. Convention on the rights of persons with disabilities (CRPD) [Internet]. New York: United Nations; 201- [cited 2020 Oct 07]. Available from: https://www.un.org/development/desa/disabilities/convention-on-the-rights-of-persons-with-disabilities.html
3. World Health Organization - WHO. Guidance note on disability and emergency risk management for health [Internet]. Geneva: World Health Organization; 2013 [cited 2020 Oct 06]. Available from: https://apps.who.int/iris/bitstream/handle/10665/90369/9789241506243_eng.pdf;jsessionid=7CDDABBCD82BEA84BE53058DCF153ED0?sequence=1
4. Hashemi G, Wickenden M, Kuper H. SDGs, Inclusive health and the path to universal health coverage. DGS [Internet]. 2017 [cited 2020 Oct 21];4(1):1088-111.

Available from: https://disabilityglobalsouth.files.wordpress.com/2012/06/dgs-04-01-03.pdf

5. Instituto Brasileiro de Geografia e Estatística – IBGE. Censo demográfico 2010 [Internet]. Rio de Janeiro: Instituto Brasileiro de Geografia e Estatística; 2012 [citado 2020 jun 10]. Disponível em: https://biblioteca.ibge.gov.br/visualizacao/periodicos/94/cd_2010_religiao_deficiencia.pdf

6. Devandas C. COVID-19: ¿Quién protege a las personas con discapacidad?, alerta experta de la ONU [Internet]. Ginebra: ONU Derechos Humanos; 2020 [citado 2020 abr 15]. Disponible en: https://www.ohchr.org/SP/NewsEvents/Pages/DisplayNews.aspx?NewsID=25725&LangID=S

7. Amorim EG, Liberali, G, Medeiros Neta OM. Avanços e desafios na atenção à saúde de pessoas com deficiência na atenção primária no Brasil: uma revisão integrativa. Holos [Internet]. 2018 [citado 2020 out 21];(1):224-36. Disponível em: https://doi.org/10.15628/holos.2018.5775

8. Brasil. Presidência da República. Lei nº 13.982, de 2 de abril de 2020. Altera a Lei nº 8.742, de 7 de dezembro de 1993, para dispor sobre parâmetros adicionais de caracterização da situação de vulnerabilidade social para fins de elegibilidade ao benefício de prestação continuada (BPC), e estabelece medidas excepcionais de proteção social a serem adotadas durante o período de enfrentamento da emergência de saúde pública de importância internacional decorrente do coronavírus (Covid-19) responsável pelo surto de 2019, a que se refere a Lei nº 13.979, de 6 de fevereiro de 2020 [Internet]. Diário Oficial da União, Brasília (DF), 2020 abr 2 [citado 2020 maio 03]. Disponível em: http://www.planalto.gov.br/ccivil_03/_ato2019-2022/2020/lei/l13982.htm

9. Brasil. Presidência da República. Emenda Constitucional nº 95, de 15 de dezembro de 2016. Altera o Ato das Disposições Constitucionais Transitórias, para instituir o Novo Regime Fiscal, e dá outras providências [Internet]. Diário Oficial da União, Brasília (DF), 2016 dez 15 [citado 2020 maio 03]. Disponível em: http://www.planalto.gov.br/ccivil_03/constituicao/emendas/emc/emc95.htm

10. The Lancet. COVID-19 in Brazil: "So what?". Lancet [Internet]. 2020 May [cited 2020 May 3];395 (10235):1461. Available from: https://doi.org/10.1016/S0140-6736(20)31095-3

11. Croda J, Oliveira WK, Frutuoso RL, Mandetta LH, Baia-da-Silva DC, Brito-Sousa JD, et al. COVID-19 in Brazil: advantages of a socialized unified health system and preparation to contain cases. Rev Soc Bras Med Trop [Internet]. 2020 Apr [cited 2020 Out 11];53:e20200167. Available from: http://dx.doi.org/10.1590/0037-8682-0167-2020

12. Organização Nacional dos Cegos do Brasil - ONCB. Manifesto da Organização Nacional de Cegos do Brasil – ONCB, sobre o Covid-19 e as implicações da pandemia no cotidiano e nos custos de vida das pessoas com deficiência beneficiárias do Benefício de Prestação Continuada – BPC [Internet]. Brasília: Organização Nacional dos Cegos do Brasil; 2020 [citado 2020 abr 17]. Disponível em: https://www.camarainclusao.com.br/noticias/coronavirus-oncb-divulga-manifesto-sobre-impacto-na-vida-de-pessoas-com-deficiencia/

13. Federação Brasileira das Associações de Síndrome de Down - FBASD. Todas as pessoas importam – Nota às autoridades públicas sobre o risco de exclusão no atendimento a pessoas com deficiência, na pandemia de Covid-19 [Internet]. Brasília: FBASD; 2020 [citado 2020 abr 23]. Disponível em: https://federacaodown.org.br/index.php/2020/04/23/todas-as-pessoas-importam-nota-as-autoridades-publicas-sobre-o-risco-de-exclusao-no-atendimento-a-pessoas-com-deficiencia-na-pandemia-de-covid-19/

14. Governo Federal (BR). Ministério da Mulher, da Família e dos Direitos Humanos (BR). Cartilhas: covid-19 [Internet]. Brasília: Governo Federal; 2020 [citado 2020 maio 03]. Disponível em: https://www.gov.br/mdh/pt-br/assuntos/covid-19/cartilhas

15. Governo do Estado de São Paulo. Secretaria dos Direitos da Pessoa com Deficiência produz conteúdos de forma acessível e dá orientações de prevenção para esse público, cuidadores e familiares [Internet]. São Paulo: Governo do Estado de SP; 2020 [citado 2020 maio 03]. Disponível em: https://www.saopaulo.sp.gov.br/coronavirus/pessoacomdeficiencia

16. Ministério da Mulher, da Família e dos Direitos Humanos (BR). Ministério vai mapear e auxiliar instituições que prestam auxílio às pessoas com deficiência [Internet]. Brasília: Ministério da Mulher, da Família e dos Direitos Humanos; 2020 [citado 2020 maio 06]. Disponível em: https://www.gov.br/mdh/pt-br/assuntos/noticias/2020-2/abril/ministerio-vai-mapear-e-auxiliar-instituicoes-que-prestam-auxilio-as-pessoas-com-deficiencia

17. Conselho Nacional de Saúde - CNS (BR). Recomendação nº 019, de 6 de abril de 2020.

Recomenda medidas que visam a garantia dos direitos e da proteção social das pessoas com deficiência e de seus familiares [Internet]. Brasília: CNS; 2020 [citado 2020 abr 17]. Disponível em: http://conselho.saude.gov.br/recomendacoes-cns/1095-recomendacao-n-019-de-06- de-abril-de-2020

18. Agência Nacional de Vigilância Sanitária – Anvisa (BR). Orientações para a prevenção de o controle de infecções pelo novo coronavírus (SARS-CoV-2) em instituições de longa permanência para idosos (ILPI). Nota Técnica GVIMS/GGTES/ANVISA nº 05/2020 (atualizada em 24/06/2020) [Internet]. Brasília: Anvisa; 2020 [citado 2020 abr 17]. Disponível em: https://www20.anvisa.gov.br/segurancadopaciente/index.php/alertas/item/nota-tecnica-gvims-ggtes-anvisa-n-05-2020-atualizada-em-24-06-20?category_id=244

19. Albuquerque MSV, Lyra TM, Melo APL, Valongueiro SA, Araujo TVB, Pimentel C, et al. Access to healthcare for children with Congenital Zika Syndrome in Brazil: perspectives of mothers and health professionals. Health Policy Plan [Internet]. 2019 Sep [cited 2020 Oct 21];34(7):499-507. Available from: https://doi.org/10.1093/heapol/czz059

20. Castro M, Carvalho L, Chin T, Kahn R, Franca G, Macario EM, et al. Demand for hospitalization services for COVID-19 patients in Brazil. MedRxiv [Internet]. 2020 Apr [cited 2020 Oct 21]. Available from: https://doi.org/10.1101/2020.03.30.20047662

21. Costa NR, Lagos MJ. A disponibilidade de leitos em unidade de tratamento intensivo no SUS e nos planos de saúde diante da epidemia da covid-19 no Brasil. Nota Técnica [Internet]. Rio de Janeiro: Fiocruz; 2020 [citado 2020 out 21]. Disponível em: http://observatoriohospitalar.fiocruz.br/biblioteca/disponibilidade-de-leitos-em-unidade-de-tratamento-intensivo-no-sus-e-nos-planos-de

22. Castro CS, Holzgrefe Jr JV, Reis RB, Andrade BB, Quintanilha LF. COVID-19 pandemic: scenario of the Brazilian health system for coping with the crisis. Res, Soc Devel [Internet]. 2020 [cited 2020 Oct 21];9(7):1-8;e516974383. Available from: https://www.arca.fiocruz.br/handle/icict/41585

23. Imprensa Nacional (BR). Recomendação nº 5, de 27 de abril de 2020. Recomenda a utilização do Escore Unificado para Priorização (EUP-UTI) de acesso a leitos de terapia intensiva, assistência ventilatória e paliação, como meio de hierarquização da gravidade dos pacientes, na ausência absoluta de leitos suficientes para atender a demanda terapêutica [Internet]. Diário Oficial da União, Brasília (DF), 2020 abr 28 [citado 2020 maio 03];Seção I:107. Disponível em: https://www.in.gov.br/en/web/dou/-/recomendacao-n-5-de-27-de-abril-de-2020-254212950

24. Brasil. Presidência da República. Lei nº 13.146, de 6 de julho de 2015. Institui a Lei Brasileira de Inclusão da Pessoa com Deficiência (Estatuto da Pessoa com Deficiência) [Internet]. Diário Oficial da União, Brasília (DF), 2015 jul 7 [citado 2020 maio 05]. Disponível em: http://www.planalto.gov.br/ccivil_03/_ato2015-2018/2015/lei/l13146.htm

25. Federação Brasileira das Associações de Síndrome de Down - FBASD. Nota em defesa da vida durante a pandemia de Covid-19 no Brasil 2020 [Internet]. Brasília: FBASD; 2020 [citado 2020 maio 03]. Disponível em: http://federacaodown.org.br/index.php/2020/04/03/nota-em-defesa-da-vida-durante-a-pandemia-de-covid-19-no-brasil/

26. Prvu Bettger J, Thoumi A, Marquevich V, De Groote W, Battistella LR, Imamura M, et al. COVID-19: maintaining essential rehabilitation services across the care continuum. BMJ Global Health [Internet]. 2020 [cited 2020 Oct 21];5(5);e002670. Available from: http://dx.doi.org/10.1136/bmjgh-2020-002670

27. Ministério da Saúde (BR). Open Datasus. Banco de dados de síndrome respiratória aguda grave – SRAG 2020 – incluindo dados da COVID-19 [Internet]. Brasília: Ministério da Saúde; 2020 [citado 2020 out 06]. Disponível em: https://opendatasus.saude.gov.br/dataset/bd-srag-2020

28. Galea MD. Telemedicine in rehabilitation. Phys Med Rehabil Clin N Am [Internet]. 2019 May [cited 2020 Oct 21];30(2):473-83. Available from: https://doi.org/10.1016/j.pmr.2018.12.002

Associate Editor: Taís Freire Galvão - orcid.org/0000-0003-2072-4834