

United Kingdom Research and Innovation awards grant for a national DATAFREE survey on persons with disabilities in South Africa to understand the effects of COVID-19

<https://www.thisability.co.za/2020/12/11/united-kingdom-research-and-innovation-awards-grant-for-a-national-datafree-survey-on-persons-with-disabilities-in-south-africa-to-understand-the-effects-of-covid-19/>

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by Tim Hart and Nthabiseng Molongoana

COVID-19 disability experience and human rights study

In the wake of National Disability Rights Awareness Month in South Africa, we are pleased to announce that an international consortium of researchers and disability service providers is embarking on a national online DATAFREE survey to understand the socio-economic, wellbeing and human rights related experiences of people with disabilities in COVID-19 times in South Africa. This project is funded by **UK Research and Innovation** through the **UK Government's Global Challenges Research Fund (GCRF)** and the **Newton Fund**.

At least 12% and possibly as high as 20% of South Africa's population are persons with disabilities. While the statistics are not clear we know that the number is higher than generally presented by Statistics South Africa, a fact they acknowledge in the WPRD. People with impairments that can become disabling covers a spectrum from complete or partial immobility, restricted communication, sensory deprivation, and psychosocial and neurological complications. Some people may have more than one challenge, increasing their inability to function optimally in society. This is compounded by the unfriendly and unaccommodating sociocultural and physical environment. This situation is despite the numerous laws and policies to the contrary and the lack

of will to enforce the rights of persons with disabilities and to listen to their voices. The COVID-19 pandemic and subsequent national disaster lockdown measures has worsened this situation as more and more people lose jobs, close-down their businesses and subsequently become poorer. During the first couple of months, disability support organisations noted a high increase in demand for services and support due to the loss of income, removal of temporary disability grants and the inability to access much needed disability support services from the public and private sector.

In its Wave 2 COVID-19 Agile Response awards, the UKRI awarded funds to investigate the socio-economic, wellbeing and human rights related experiences and perceptions of people with disabilities during COVID-19, to a consortium of researchers and persons with disabilities, comprised of the Institute of Development Studies (IDS) in the UK, the Developmental, Capable and Ethical State research division of the Human Sciences Research Council (DCES-HSRC) in South Africa and the National Council of and for Persons with Disabilities (NCPD) in South Africa.

The research proposal review panel stated that were in agreement “that this was a strong proposal that covered an important topic and knowledge gap. The PI and team were deemed to have the necessary expertise to deliver the project, with strong policy partnerships and stakeholder engagement. The methodology was clear and well defined”.

The partnership

The consortium is led by IDS’s Dr Mary Wickenden Mary is an internationally recognised scholar and has worked on disability experiences, rights and policy in South, Southern, Eastern and West Africa and Asia and the UK. Dr Tim Hart of DCES-HSRC and Ms Nthabiseng Molongoana (NCPD) will coordinate the study in South Africa along. Both Tim and Nthabi have years of research experience and are persons with disabilities. The research team members comprise of several persons with disability of all races and genders, ensuring that the research is inclusive. Furthermore, two persons with disabilities have been employed to specifically work on the project. The consortium is established to ensure rigorous and robust research that recognises and reports on the voices of all persons with disabilities who volunteer to participate in the study. The partnership is itself novel as it includes an independent UK research organisation, a South African national disability support organisation and a science council.

The first research team inception meeting was held on the 27th of October 2020. Since then, the partners have had two main meetings and have met with some disability stakeholders in South Africa. An online survey instrument has been developed and approved by the HSRC Research Ethics Committee.

This study is independently funded, and we will be providing feedback at different stages to all stakeholders. Thus, we encourage all national, provincial and local disability support organisations, alliances, private organisations, employers and the state to assist us and encourage persons with disabilities whom they know to participate in this crucial study. We are reaching out to all persons with disabilities in order to understand the effect COVID-19 has had on their lives. We are aiming at a national sample of 4000 voluntary respondents from a cross-section of persons with disabilities so that we get comprehensive feedback on their experiences and ideas for the future.

Importance of the study

The COVID-19 pandemic has placed its toll on global and South African citizens during 2020. The resulting change in people’s lives has been profound. Within South Africa, as elsewhere, a lot of information has been gathered about how South Africans are experiencing and adapting to the COVID-19 outbreak and the subsequent lockdown since 27 March this year. Unfortunately, little of this information portrays the circumstances of persons with disabilities from a personal experiential perspective. However, it is important to understand the impacts of the Coronavirus pandemic and particularly the lockdown on persons with disabilities and their experiences and perceptions about this pandemic.

These experiences and perceptions may well differ from persons who do not have disabilities. Therefore, these must be captured and reported directly to various stakeholders (government,

private sector and disability civil society support organisations) and in the press as well as through other popular, social and scientific media. Furthermore, there is a need to ensure that persons with disabilities are not overlooked generally in South African society and particularly in future occurrences of national disasters and mitigation legislation. Part of the study will determine the effects of the disaster management framework on persons with disabilities in the country.

While there has been some research going on about people with specific disabilities, the majority of persons with disabilities fall outside these research activities, either due to the focus of the studies or the research methods used. To ensure that people in a variety of situations are not overlooked during this time of uncertainty we will do a national research online study to investigate and understand the experiences and perceptions of a wide range of persons with diverse disabilities in South Africa. We encourage as many persons with disabilities to participate in the research. Anybody unable to complete the questionnaire themselves can be assisted by a family member or carer. Similarly, a parent/guardian/carers can respond on behalf of a child under 18 or anybody else who may be unable to respond themselves.

DATA FREE

The team has developed a national online DATA FREE survey to cover the various impairments. This is designed to ask about the specific challenges and experiences persons with disabilities may have had during the pandemic and the lockdown and ideas about the future. The research team will use ICTs such as feature phones, smartphones, tablets and computers to engage with persons with disabilities to complete the online survey, to avoid the risk of contact during the coronavirus period and to adhere to lockdown regulations. The process is voluntary and confidential, and respondents will not be identified. Importantly the process is DATA FREE so that those voluntary respondents who use mobile data or mobile phones to log onto the internet will not bear the cost of connecting and completing the survey. A link to the questionnaire will be circulated in mid-January 2020. We will keep you posted on how to access this link.

Broad Feedback of the results

We will be sharing the findings in different ways, including having at least two webinars during this 9-month study to share our findings with different audiences. Online facilities will be provided to accommodate persons with disabilities, including captioning and SA sign language interpreters. Regular web posting, blogs and social media interaction will be conducted to keep South Africans informed of the process.

Further information will be made available through disability support organisations using social media, partner websites and the press. More information about the UKRI support can be obtained from the [UKRI news website](#).

For further information and updates, Tim Hart can be contacted at thart@hsrc.ac.za, Nthabiseng Molongoanaat nthabiseng@ncpd.org.za and Mary Wickenden at m.wickenden@ids.ac.uk

Related web and social media sites about the research that will be regularly updated include the following:

Facebook: <https://www.facebook.com/disabilities.sa/>; <https://www.facebook.com/idsuk>; <https://www.facebook.com/HSRC-DCES-272413589802629/>; <https://www.facebook.com/HumanSciencesResearchCouncil>; <https://www.facebook.com/disabilities.sa/>

LinkedIn: <https://www.linkedin.com/in/developmental-capable-and-ethical-state-0624001a4/>; <https://www.linkedin.com/school/institute-of-development-studies/>

Instagram: https://www.instagram.com/disabilities_sa/; https://www.instagram.com/ids_uk/

Websites: <http://www.hsrc.ac.za/en/departments/dces>; <http://www.hsrc.ac.za>; <https://ncpd.org.za/>; <https://www.ids.ac.uk/>

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