

# **Extending the findings of the "Socioeconomic wellbeing and human rights-related experiences of people with disabilities in COVID-19 times in South Africa" to Government and stakeholders to create awareness and build an inclusive society**

## **PROJECT TUASAA FINAL REPORT (Supplementary PG funding) 31 May 2022**

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|                           |  |
|---------------------------|--|
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## **INTRODUCTION**

Persons with disabilities are among the most significant minorities in society yet often very marginalised. In South Africa, between 12% and 20% of the population aged over five are estimated to have activity limiting impairments. Between October 2021 and January 2022, the HSRC DCES division ran a project funded by the United Kingdom Research and Innovation (UKRI) in conjunction with the Institute of Development Studies (UK) (IDS) and the National Council of and for Persons with Disabilities (SA) (NCPD). The project officially ended on 26 October 2021, but the UKRI granted a No Cost Extension (NCE). However, due to delays outside the project team's control, some work was not completed by 26 October 2021. Also, following delegates' comments during the survey data presentation on 13 October 2021, the HSRC DCES wanted to do further work on the project. A proposal was submitted to the HSRC-DCEO Research for funding to complete this work. This proposal was approved, and ethics clearance was extended for another year. This report covers the activities done as part of this project. Some activities were not completed and have been delayed either due to the shortage of time or due to advice from partners on the UKRI project and following inputs from government and civil society stakeholders during this project. The proposed actions are tabled below, and the remainder of the report outlines the progress and achievements made regarding each proposed action. The report concludes with a summary of achievements and what must still be done.

## **PROPOSED ACTIONS**

In the submitted proposal, the following actions were proposed:

- Develop a government and disability organisation engagement strategy.
- Consolidate the reports
- Do the final cleaning and curation of the data
- Produce three evidence/policy briefs.
- Write two journal articles for this financial year and next, depending on the publication turnaround time.
- Have three engagements with government departments – webinar or round table as the COVID-19 situation allows – regarding the findings and design the way forward.
- Have discussions with NCPD and other DSOs to see how we can collaborate to put a case forward to improve the existing disaster framework for persons with disabilities.
- Work on recommendations to be included in the disaster framework to ensure it is disability-inclusive and develop a report with this information acquired from evidence, especially from the dialogues with the Government and other stakeholders.
- Try to secure future research from government departments to take recommendations forward over the medium-term to assist COGTA, MWYPD and DSD in the design of a disability-inclusive framework

- Dr Hart will travel to the UK in March 2022 to make presentations at IDS with partners and present lectures to students and other disability fora.

### **Develop a government and disability organisation engagement strategy.**

During an initial consultation with project team members, it was noted that many of the team had some long-standing commitments and would not be able to avail themselves to all activities but would assist where they could in meeting the project objectives/actions. The decision was taken that Dr Hart would engage directly with government departments and disability organisations – Disability Service Organisations (DSO) and Disabled People's Organisations (DPO).

The timing of the project (November 2021 – March 2022) proved difficult to get commitments from various stakeholders in the private and non-profit sectors working with persons with disabilities. While the PI had several telephonic and email consultations with different stakeholders, the general feeling from stakeholders was that November, December and January were too busy a period for most organisations and that people would be taking leave over December and January. February 2022 also proved a difficult time to get people to commit to meetings to develop a strategy to take the fundamental findings forward. In late February 2022, Dr Hart went to the UK to disseminate the results and engaged with different UK disability research organisations. He was thus unavailable to follow up on initial conversations and take the strategy development component further while in the UK. On a much more positive note, he made several new contacts within the sector, and he has started engaging with several of these organisations and individuals.

### **Have engagements with government departments – webinar or round table as the COVID-19 situation allows – regarding the findings and design the way forward**

Three engagements with government departments were proposed for this project to discuss the findings and design a way forward, so that disaster responses include persons with disabilities during the COVID-19 pandemic and future pandemics or states of disaster, such as the recent floods in KwaZulu Natal. Given the time constraints and the challenges of different stakeholders to commit to suitable times, these activities did not occur. Still, we hope this will materialise in the future – from May 2022.

### **Consolidate the reports**

The following two project reports were finalised and made available through the Institute of Development Studies open docs platform and the HSRC RMS.

- Hart, T., Davids, Y.D., Wickenden, M., Majikijela, Y., Ngungu, M., Thompson, S., Pienaar, G., Rubaba, T., Molongoana, N., Bohler-Muller, N., Du Toit, T., Kalis, A., Boya, L. & Mofokeng, M. (2022). Socioeconomic wellbeing and human rights-related experiences of people with disabilities in Covid-19 times in South Africa: final report. (Commissioned by the Institute of Development Studies (IDS), January). DOI: 10.19088/IDS.2022.013  
<https://opendocs.ids.ac.uk/opendocs/handle/20.500.12413/17239>
- Wickenden, M., Hart, T., Thompson, S., Pienaar, G., Rubaba, T. & Bohler-Muller, N. (2022) Literature review to support a survey to understand the socioeconomic, wellbeing and human rights-related experiences of people with disabilities during Covid-19 Lockdown in South Africa. (Commissioned by the Institute of Development Studies (IDS), February). DOI: 10.19088/IDS.2022.012, <https://opendocs.ids.ac.uk/opendocs/handle/20.500.12413/17206>

An online final report was submitted to the UKRI on the ResearchFisch platform in March 2022. However, we are still awaiting final clarification from the UKRI about the requirements for their final report (different to that of the ResearchFisch platform), which has more to do with partnerships, experiences and collaborative public outputs rather than the detail and content of the findings discussed in the two reports above. The PI and CO-PI submitted an interim report in early November 2022, but this will likely need to be updated. The time frame for this UKRI final report is sometime in May 2022.

### **Final cleaning and curation of the data**

At a meeting in January with the PI, Dr Mary Wickenden, she suggested that we aim to have the data curated towards the end of October 2022. This period would enable the team to produce more journal articles before the dataset was publicly available on the HSRC website. According to the funder, UKRI, they also want the data made available on other websites: UKRI-funded data services such as the EMBL-EBI at <https://www.covid19dataportal.org/submit-data>, the UK Essex Data Archive at <https://www.ukdataservice.ac.uk/deposit-data/howto.aspx>, the Health Data Research Innovation Gateway at <https://healthdatagateway.org/> (for health and care data and which includes annotation tools to generate rich metadata, and support for data access management) or the dedicated Coronavirus repository at OpenAIRE hosted at <https://zenodo.org/communities/covid-19?page=1&size=20>. Other repositories can be found on registries such as <https://fairsharing.org/collection/COVID19Resources> or the <https://www.re3data.org/>. Once the HSRC curation is completed, we will discuss with Dr Wickenden, and the UKRI which repositories mentioned above are most suitable.

The quantitative data analysis team finalised the data management and quality control in March 2022. The process included data cleaning by checking and editing for logical consistency, for permitted range checks, for reliability on derived variables and for filter instructions. Data with wrong codes or out of range codes was cleaned. Basic univariate and bi-variate descriptive statistical analyses using SPSS software packages were conducted as a first step towards developing insights on quality of data collected. The data analysis team consisted of three HSRC staff members that were mostly responsible for the data management and analysis. However, one senior expert from the HSRC and two experts from IDS also reviewed the quality of the data as well as provided statistically analysis assistance.

Curation of the primary quantitative dataset is currently on-going. 1) The dataset has been cleaned and anonymised to ensure that individual respondents cannot be identified. For example, the team deleted variables with personal information, categorised / recoded variables to express the content in more general terms, removed relationships between variables or summarising / aggregating variables 2) The metadata / codebook has been produced 3) The survey questionnaire is now available as a pdf file 4) the dataset is now available in Excel and SPSS versions.

The next steps involve 1) assigning copyright and conditions of access 2) Data documentation and filling in the curation documents and 3) keeping all codes coded and command files used in data management.

### **Produce three policy briefs.**

- One policy Brief was submitted to HSRC Press and printed.  
Tim GB Hart, Mary Wickenden, Stephen Thompson, Yul Derek Davids, Yamkela Majikijela, Mercy Ngungu, Tinashe Rubaba, Nthabiseng Molongoana (2022). Experiences of people with disabilities during Covid-19 in South Africa: The exacerbation of disadvantage. HSRC Policy Brief, March 2022.
- A second policy brief has been externally reviewed. The authors are addressing the reviewers' comments.  
Perceptions of access to COVID-19 Vaccine demand amongst South Africans with disabilities. Tim GB Hart, Mary Wickenden, Stephen Thompson, Yul Derek Davids, Yamkela Majikijela, Mercy Ngungu, Tinashe Rubaba, Nthabiseng Molongoana, Therina Wentzel-du Toit and Lebogang Boya.

- A third policy brief is in the conceptual phase and will be sent for external review per the funder's request and then to the HSRC Press. It will emphasise economic challenges and food insecurity among people with disabilities during the pandemic.

**Write two journal articles.**

- The first journal article was submitted to the South African Health Systems Trust and published in December 2021.  
Tim GB Hart, Yul Derek Davids, Mary Wickenden, Yamkela Majikijela, Mercy Ngungu and Stephen Thompson. (2021). Perceptions of persons with disabilities on the COVID-19 vaccine roll-out in South Africa. South African Health Review 2021. Durban: Health Systems Trust. Pp 287-295.
- A second journal article is being submitted to the African Journal of Disability. Understanding the socioeconomic, wellbeing and human rights-related experiences of people with disabilities during Covid-19 lockdown in South Africa: results and policy implications of an online survey by Mary Wickenden, Tim GB Hart, Yul Derek Davids, Stephen Thompson, Mercy Ngungu and Yamkela Majikijela.

**Have discussions with NCPD and other DSOs to see how we can collaborate to put a case forward to improve the existing disaster framework for persons with disabilities.**

Dr Hart had several separate discussions with the different directorates within the Department of Women, Youth and Persons with Disabilities (DWYPD) from October 2021 to late March 2022 and with the Social Protection Directorate of the Department of Social Development (DSD).

In October 2021, the Ministry of Women, Youth and Persons with Disabilities (DWYPD) requested Dr Hart review and assess an Inception Report undertaken by a service provider to the DWYPD and the United Nations Development Programme (UNDP) on disability research conducted in South Africa. This joint UNDP and DWYPD study focused on the "Study on the Elements and Economic Costs of Disability for Children with Disabilities and Persons with Physical Disabilities in South Africa, Part 2". The report outlined the progress of the study, which builds on a pilot study commissioned by the Department of Social Development (DSD), the UN Partnership to Promote the Rights of Persons with Disabilities (PPRPD) and the Department of Women, Children and Persons with Disabilities (DWYPD) in 2014. The previous report focused on the elements of the financial and economic costs of disability to households in South Africa. Dr Hart was asked to assess the current inception report that focused on children and people with physical disabilities. The DWYPD accepted his recommendations. In late November 2021, Dr Hart was asked by the DWYPD to review the draft final report. He did this between 25 and 28 November 2021. The DWYPD accepted his findings and recommendation on 29 November 2021.

In November 2021, DWYPD nominated Dr Tim Hart to serve on the Disability Advisory Group (DAG) of Statistics South Africa. In February 2022, the Statistician-General appointed him to serve on the DAG from April 2022. The HSRC is becoming recognised as a critical player and valued contributor in the disability policy arena. Furthermore, in February 2022, the National Council of and for Persons with Disabilities nominated Dr Hart for the HSRC and USAF Medal for Social Sciences and Humanities awards for Engaged Scholarship, considering how he inclusively engaged with and incorporated DSOs/DPOs and Research Institutes into the UKRI project. They also emphasised his general contributions to the disability sector during the previous ten years.

**Work on recommendations to be included in the framework to ensure it is disability-inclusive and develop a report with this information acquired from evidence, especially from the dialogues with the Government and other stakeholders.**

Due to the inability to get the stakeholders to attend at least one webinar/roundtable during this time frame, the desired information could not be obtained, and no report was produced. The team suggests that this work continues in the coming financial year to continue networking with the Government and the DSO/DPO sector. It is imperative that the study findings get better buy-in from all departments and an inclusive contribution to the framework is compiled and tabled. This intention is in line with a statement made by Dr Praveena Sukhraj-ely, Chief Director: Governance and Compliance, DWYPD at the MRC Seminar on 30 March 2022, where she made it clear that the mandate of the department was to facilitate Disability Rights across departments and society. However, the department experienced ongoing challenges, despite the high-level indicators in the Implementation Matrix of 2016.

**Securing future research from government departments to take recommendations forward over the medium-term**

In November 2021, the South African National Council for the Blind (SANCB) contacted Dr Hart requesting a proposal to do a qualitative study on "The social and economic impact of COVID-19 on the lives of blind and partially sighted adults in Gauteng". Dr Hart had several emails and telephonic conversations to clarify the terms of reference for such a project. When this was not readily forthcoming, a short proposal was submitted in an email indicating the likely costs and the ballpark figures for different options depending on the sample size. Follow-up was done in January, but no response was received. Despite the discussions with SANCB, which noted that there was no limit for the funding, it is assumed that the proposed figures of R600 000 and R800 000 are unaffordable for non-profit disability organisations, and this could be the reason why they did not pursue their request.



Dr Hart was made aware of an RFP from the Department of Women, Youth and Persons with Disabilities - "Harmonisation of Disability Rights Reporting Instruments and development of results-based reporting template" in mid-February 2022. Because of the nature of the RFP and notably the proportion of disability researchers required to comprise the project research team, Dr Hart contacted NCPD and other networks to see if anybody was interested in partnering on this call. However, no researchers were available, and as Dr Hart was going to be overseas during the planned inception period, it was decided not to submit a Proposal.

At the Department of Women, Youth and Persons with Disabilities request, the HSRC submitted a proposal in mid-March 2022. This proposal, entitled *Feasibility Study for a Socio-Economic Empowerment Index for the Department of Women, Youth and Persons with Disability Quotation Reference Number: RFP 03-2021/2022*, was submitted and led by two of the project team members, Prof Narnia Bohler-Muller and Prof Joleen Steyn-Kotze with the assistance from Dr Tim Hart and other team members, including other DCES scholars interested in Women, Youth and Disability Studies. The proposal aims to look at the development of local, national and global reporting indicators, and the team's experience in the recent UKRI study will help make valuable contributions to the other skills within DCES. The value of the proposal is ZAR 749 000.00.

### **Dr Hart's meetings and dissemination trip to the United Kingdom in March 2022**

The survey component of the study was conducted online with persons with disabilities and received 1857 responses, making it one of the most extensive surveys on this group of people in South Africa and probably the continent during COVID-19. A literature review helped guide the questions and provide more detail about the plight of persons with disabilities before and during the pandemic. A webinar to present some of the key findings was held on 13 October and attended by 232 registered participants from stakeholders in Government, organisations for persons with disabilities, and persons with disabilities who completed the survey. Several UK network partners felt that these findings were highly relevant, especially given the sample size, deemed one of the most extensive in-country surveys during COVID-19. Several invitations were made to present these findings.

Travel restrictions eased in January 2022, and Tim Hart travelled to the UK in March, where he presented work at the Institute for Development Studies Seminar The impact of COVID-19 on people with disabilities in six countries: Three studies – same story! (the link: [https://www.youtube.com/watch?v=rYCRgkU\\_CDU&t=154s](https://www.youtube.com/watch?v=rYCRgkU_CDU&t=154s) ) on 1 March 2022 (attended by about 50 delegates), the Disability under siege group was coordinated by Birmingham University on 2 March 2022 (attended by over 100 representatives) and was joined online by NCPD and IDS colleagues. The links to this conference are below:

Introduction: <https://www.youtube.com/watch?v=-Lb13VGKgVM>

1A Partnering with DPOs: <https://www.youtube.com/watch?v=0MeYVXu6rVA>

1B Working with people with disabilities as co-researchers: <https://www.youtube.com/watch?v=3i-JnPDFMF4&t=6s>

2A Research during a pandemic / in multiple crises: <https://www.youtube.com/watch?v=jgv7ltaC74o&t=2518s>

2B: Research with children with disabilities: <https://www.youtube.com/watch?v=h9AjGfDjq-l&t=625s>

Keynote - Dr Ola Abu Alghaib (UNPRPD): <https://www.youtube.com/watch?v=4jdsx9JYApA>

Dr Hart was then asked to present on behalf of the HSRC, NCPD and IDS teams at the ICED Disability and COVID-19 Conference, organised by the London School of Hygiene and Tropical Medicine, between the 14-17 March 2022. He presented on 15 March. About 150 international delegates attended the Conference. ICED link for Dr Hart's presentation is here <https://lshtm.cloud.panopto.eu/Panopto/Pages/Viewer.aspx?id=1224115c-6368-460d-bee5-ae7400b18983>

Following this event, he was contacted by Prof Jill Hanass Hancock of the SA Medical Research Council to present at the Third Forgotten Agenda Webinar on 30 March 2022 (around 70 people attended). The webinar focused on research conducted in South Africa during the COVID-19 pandemic and aimed to explore the critical question: **How can we improve our response in times of crisis?**

Webinar recording: <https://youtu.be/bye0xt3gSH0>

Prof Jill Hanass Hancock has pushed for developing a policy brief that summarises the essential findings and ways to improve responses to make them more disability-inclusive. This idea will be followed up in the current financial year.

During his trip to the UK, Dr Hart had meetings with Dr Irma Booyens of the University of Strathclyde in Glasgow. It was agreed that given the study's findings, the University of Strathclyde would consider entering a possible MOU with the HSRC and consider looking into collaborating on projects relating to disability, tourism, decent work and gendered employment. Project collaboration was to come before any MOU.

## CONCLUSION

The project has had mixed results. While it enabled the team to complete many outstanding tasks, it was hampered during attempts to bring specific stakeholders together. The main challenges were mainly because of timing and other commitments, including the common choice of many people to take annual leave during December and January. Nevertheless, the project achieved most of its key actions/objectives and established new relationships within and outside the Government. It can be acknowledged that considering nominations to various positions and calls for proposals, the DCES disability group is regarded as a serious player in

disability rights and studies locally and at least in the UK. This acknowledgement is remarkable for an endeavour that started during COVID-19 (July 2020) and has only been going for 20 months. One recommendation is that, if possible, some Parliamentary Grant funds be allocated to ensure that there is some continuity with government and civil society stakeholders. This cash injection would enable those activities not yet completed – notably collaborative interactions with government and DSO/DPO stakeholders to be achieved. R300 000 from the Parliamentary Grant should suffice to complete these necessary actions.

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