



Explorations of the impact of COVID-19 on people with disabilities in by Unknown Author is licensed under

six countries: Three studies – same story!

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(Disability Research Team at IDS)

+ Guest speaker Tim Hart (HSRC – South Africa)

+ video inputs from two of our local researchers Shadrach Chuba-Uzo (Nigeria) and Anita Sigdel (Nepal),

+ video excerpt - young people in Nepal.

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Introduction

We will describe and discuss findings from three studies about the impact of Covid-19 on people with disabilities in six countries in Africa and South Asia , using 3 contrasting methodologies

- 1) Lives turned upside down by Covid-19 (as part of DID and Inclusion Works) – Qualitative study in Nigeria, Uganda, Kenya, Bangladesh and Nepal
- 2) South Africans with disabilities’ experiences of Covid-19 - socio-economic, wellbeing and human rights focus. A large online survey designed to inform government DRR frameworks to be more disability inclusive
- 3) ‘PARDAN’ Nepali teenagers with disabilities’ perspectives on Covid-19 - used innovative inclusive and participatory methodologies to explore the experiences of 12 children living rurally

Followed by reflection (panel Q and A) on the marked similarities in the findings, which suggest that there are some universal aspects of the experience of people with disabilities, where their usual marginalisation and exclusion is exacerbated during crises.

Brief background

As soon as COVID-19 emerged a large number of predictive and advisory documents emerged from various bodies e.g.

- UN - WHO, UNICEF, UNHCR, ILO
- INGOs with an interest in disability e.g. HI, CBM, etc
- Organisations of people with disabilities (OPDs) both nationally and internationally –e.g IDA
- Both single impairment and overarching organisations: deaf, blind, psychosocial impairments, children, women with disabilities, community based rehab workers etc

All

- **warned of the likely exacerbation of disadvantage that was a risk in the pandemic**
- **advised re inclusive approaches – to ensure the support of people with disabilities in the crisis situation**
- **said that a disability inclusive approach to DRR and to pandemic preparedness and responses was needed** (some countries have this in policy but not well implemented)

Other studies on Disability and COVID-19

Quantitative and qualitative studies started to emerge quite fast – from early 2020

- Disability Rights Monitor (DRM) (Brennan et al 2020) – Global online survey - 134 countries
<https://covid-drm.org/assets/documents/Disability-Rights-During-the-Pandemic-report-web.pdf>
- IDA (International Disability Alliance) – looked at OPD's responses
- IDDC (International Disability and Development Consortium) – looked at INGOs responses
- Country specific studies, e.g. ADD Bangladesh & Cambodia
- More in the global north than the south
- Looking at specific sectors / angles – e.g. re: disability rights realisation, access to healthcare, triage for hospitalisation and vaccine, social protection and relief, accessibility of information (eg in the media and meetings), access to usual services etc

Study 1. Stephen Thompson (M Wickenden, J Shaw, B Rohwerder)

Lives turned upside down in COVID-19 times

Aim

- To explore the experiences and perceptions of people with disabilities of the COVID-19 pandemic.
- To gather their recommendations for actions during future pandemics or similar crises.

Focus

Focused on participants who were already involved in Inclusive Futures in Bangladesh, Kenya, Nigeria, Nepal and Uganda.

(Inclusion Works and DID programmes)

Method selected

- Narrative interviews
 - Conducted online
 - 2 interviews with each participant, 2 months apart

Method justification

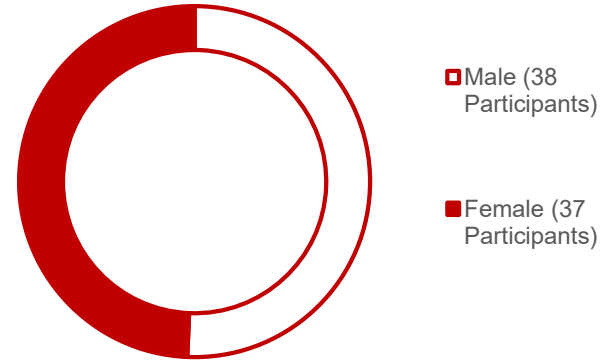
- An inclusive, accessible approach
- Interviewee led – participants could chose to talk about what was important to them
- Provides insights on emotional and contextual aspects
- Accessible regardless of education, language competence or communication mode

Participants

- 75 participants
 - 30 from Bangladesh
 - 15 from Nepal
 - 10 from Kenya
 - 10 from Nigeria
 - 10 from Uganda.

- 10 participants had physical impairments, 7 had visual impairments, 3 had hearing impairments, 16 intellectual impairments, 6 psychosocial impairments, 12 had other impairments, and 21 had multiple impairments.

Gender balance



Working with peer researchers

- In Nigeria, Kenya, Uganda and Bangladesh we worked with four local researchers already working with us on Inclusive Futures (one of the four has disabilities).
- Also recruited 3 new researchers in Nepal and Bangladesh (two with disabilities).
- Early career researchers (including two with disabilities) were paired with more experienced researchers to develop their capacity.
- Extensive training provided and peer support system established.





“It was a big opportunity for me. This job was the first one of my life. As a person with a disability, I have always wanted to do something for people like me. I will say through this work that my wish has been fulfilled, because the people I worked with were people with disabilities like me.”

Rabia from Bangladesh

Videos from Shadrach (Nigeria) and Anita (Nepal)

Main findings

Two main types of impact

- Subjective – emotional impacts
- Concrete/material impacts

Emotional/subjective impact

Uncertainty

Shock

Fear

Loss of opportunities

Loss of freedom

Limited Social relations

- People with disabilities lost work and education opportunities – this had an impact on hopes and future prospects.
- Being stuck inside had an impact on access to social support networks, healthcare and rehabilitation.
- This had an impact on both mental and physical health, as well as independence.

Quotes

“But for them it’s very hard. For them everything is mundane, same room, same kitchen and all. So, they get very irritated when they have to stay in the same place for long time and get aggressive.”

(Parent of child with deaf blindness, Nepal)

“I am totally stuck in my house. My study is totally stopped. I can’t apply for any jobs – there are no new jobs during COVID-19. Everything is totally uncertain right now.....”

(Woman with albinism, Bangladesh.)

Economic impact and associated feelings

People with disabilities experienced major negative economic impacts, falling into poverty and facing food insecurity, which caused immense stress and reducing people's reserves, putting them in debt.



Quotes on economic impact

“I am back to work.... My salary was cut. Half cut.”

(Woman with intellectual impairment, Nigeria)

“there has been lifting of the regulations but getting back to business is still something I see from a far as all the savings were diverted and spent for my daily basic needs.”

(Woman with physical impairment, Uganda)

Exacerbated stigma and discrimination

- Negative attitudes and fear towards people with disabilities
- This was exacerbated for those needing physical support due to visual or physical impairments
- People with deaf-blindness were particularly affected.
- Gendered Impacts
 - Gender based violence
 - Cultural norms and related responsibilities

Changes over time

- **Contrasting fortunes and fear for the future**
- Context dependent – five countries at different stages
- During the second interview some people felt more positive with a resumption of income earning and more food on the table.
- Others worried about the consequences of a second wave due to depleted resources and financial concerns.



Conclusions

(Recommendations later - combined with other studies!)

- People with disabilities were often already often marginalised and financially insecure before COVID-19
- The crisis exacerbated this marginalisation
- The pandemic has resulted in feelings of uncertainty for many people with disabilities in low income contexts.

Study 2. Tim Hart – HSRC Human Sciences Research Centre – SA
(with IDS and NCPD) Funder: UKRI – GCRF

South Africans with disabilities' experiences of Covid-19

An online survey

- The research specifically looked at the socio-economic, wellbeing and human rights related experiences
- Data collected through an online voluntary survey with nearly 2,000 respondents >possibly one of the largest datasets on people with disabilities' Covid-19 experiences in a single country

Initial evidence motivating study

- Between 12%-20% of the SA population over 5yrs have some form of disability
- COVID-19 – What is impact on persons with disabilities in South Africa?
 - Overlooked generally by disaster relief
 - Ignored by pandemic directives
 - Impacted negatively by regulations aimed at virus control
 - Neither DM Act (2002) or the DMF (2005) acknowledge people with disabilities or that they have diverse needs different to other vulnerable groups
 - Section 3.5 of Disaster implementation framework far from complete

Further background

- Desire to explore further evidence but constrained by Covid-19 regulations relating to fieldwork – online self-administered survey with associated weaknesses.
- Strong collaboration between National DSO, national research council and international research institute.
- Research process very collaborative and knowledge exchange encouraged and respected
- Roles of 3 partners: IDS funder liaison, and overall leadership, HSRC local project management, and NCPD access to people with disabilities and DSO networks. NCPD instrumental in survey distribution and high response rate
- 1857 final valid responses

High-level key findings

- Very little government interventions – reliance on DSO sector and other NGOS
- Communication about Coronavirus and monthly meetings inadequate for certain types of disabilities as most rely on Television – captions not existent, SASL interpreters not always visible
 - >Resulted in confusion about services available
- Negative economic impact of regulations 30% unemployed at start of Lockdown
 - > 13% Job losses, 11% reduced pay, 6% compulsory leave, impact on own business
- 31% receiving disability grant but 33% receiving the (paltry) SRD grant. 10% elderly persons grant – implication is that most are poor – less GBP 238 per month

Unusual experiences

- Higher food insecurity generally 40%, 29% during the survey
- 76% difficulty in paying for basic living expenses and increases in disability expenditure
- Care and rehabilitative services – 60% reliant on services and 73% interrupted
- Psychosocial experiences – 60% Stressed, 54% Depressed, 52% Scared/Anxious, 42% lonely – limited social interaction as many live alone
- Most government and other providers considered by 48% to be doing a poor job
- 37% rely on state but greater movement to DSOs 51%

Conclusions

- Disability Disaster Framework far from complete – must be completed urgently
- Overlooked by many interventions – lack of disability-inclusive approach
- Mitigation and control regulations had negative consequences on rehabilitative and other services
- Diversity within sector ignored
- Interventions seem to have reached those on the system – existing grant recipients
- Little interaction/collaboration across departments and with DSOs
- Data driven response but lack of disability data!
- 83% feel that government should monitor circumstances during pandemics – ensure continuity of services and monitor rights protection

Study 3. Brigitte Rohwerder

PARDAN: Participatory Action Research with Disabled Adolescents in Nepal





Rationale

- Adolescents (aged 10-19) with disabilities are uniquely affected by the COVID-19 pandemic and other humanitarian emergencies but their experiences are rarely documented.

Objectives

- To understand adolescents with disabilities experiences of the pandemic
- To develop research methods and tools with adolescents to increase their participation in research about the effect of the pandemic



Participants

12 adolescents with disabilities
11 caregivers

- Age range of 11-17 years old
- 5 girls, 7 boys
- 4 physical impairments
- 2 visual impairments
- 1 speaking impairment
- 2 with hearing impairments
- 3 multiple impairments (2 physical and intellectual, 1 physical and speaking)
- 4 adolescents with disabilities did not usually go to school



Data collection tools

Topics

Your story of COVID times

Going deeper

Family and Friends'

Recommendations

Anything else?





Findings: experiences of COVID-19

Economic hardship

“There is a huge amount of money that needs to be paid to the shop, and I am fearful about how we will pay it back”

Fear of death and illness

“I thought we would all die.”

Stigma

“I felt very bad. They treated me like I had corona. They didn’t let me sit on the bench and in the vehicle.”

School and social life

“I cannot play with my friends because school is closed. I cannot read and write. I feel bored staying here. I long for when I can go to school and feel free.”

PARDAN Conclusions

- Existing inequalities were exacerbated
- Social isolation increased families' vulnerability
- Internet access key to enabling social contact and access to education
- Discrimination exacerbated by COVID-19
- Relied on Organisation of Persons with Disabilities

- Research with adolescents with disabilities is necessary for an inclusive response to the pandemic.
- Our research tools were effective in facilitating research about the experiences of adolescents with disabilities.



Acknowledgements

The research team:

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- Dr Mary Wickenden & Ms Brigitte Rohwerder, IDS

The film:

- Mr Dinesh Deokota Media for Development

Partners:

- Disabled Association Myagdi & Association of the Disabled Women Udaypur
- Kathmandu based advisory committee
- ALL the participants, their family and friends



Mary - Commonalities across the 3 studies

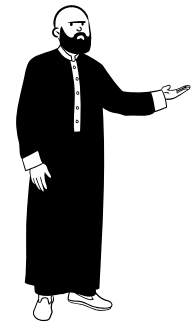
- ❖ **All 3 studies show that there is still a deep seated level of stigma and discrimination experienced by many people with disabilities and their families, their pre-COVID-19 disadvantage was exacerbated by the pandemic**
- ❖ **There is an endemic level of negative stereotyping and structural violence which puts people with disabilities in liminal positions , in communities and in systems**
- ❖ **Despite global treaties such as the UN Convention on the Rights of People with Disabilities (UNCRPD)**
- ❖ **Implications for policy makers and planners for disaster and emergency responses - a disability inclusive approach is needed throughout**
- ❖ **Practitioners, service providers and others need to know how to be more disability aware and inclusive in their activities**

Key messages

- Disaster and emergency planning must be disability inclusive
- Representatives and organisations of people with disabilities must be included in planning
- All services must be provided in accessible and inclusive ways
 - Including health, education, relief etc.
 - Whether provided by the government, the community or non-government organisations.
- Information should be provided in multiple accessible formats
- Recognition of the different impacts on people with different impairments is needed
- Be alert to exacerbation of pre-existing disadvantage/discrimination
- Be aware of emotional/psychological/social/economic impacts as well as health needs and impacts

What needs to happen?

- Governments must ensure that their responses, interventions and their policies in times of crisis are disability inclusive.
- This is essential to address and avoid exacerbating pre-existing disadvantage and discrimination, and to provide equal opportunities for all.



Panel Discussion + Q and A

Tim, Stephen, Brigitte

Questions from the audience? – in the chatbox or raise a hand!

Many thanks to you all for participating

and

Thanks to..

- ❑ all the adults and children with disabilities and their families who joined in these three studies, who gave up their time to help us understand their experiences
- ❑ all the in-country researchers for their commitment and energy
- ❑ all the partner organisations (e.g. INGOs and Organisations of People with Disabilities – OPDs) who assisted with recruitment and logistics, analysis, dissemination
- ❑ the funders of the three studies UK AID (Inclusive Futures), UKRI - GCRF and Agile response for their support

PARDAN Video

<https://www.youtube.com/watch?v=gAZSkg-4R90>

8 minutes!

An in-person reception will also be held after the webinar in IDS for those who would like to meet the speakers and continue the conversation at 3 pm!

Publications so far

Special issue of Disability Studies Quarterly (DSQ) on COVID

Study 1

- Wickenden, Shaw, Thompson, Rohwerder (2021) Lives turned upside down in COVID-19 times: exploring disabled people's experiences in 5 low-and-middle income countries using narrative interviews. Disability Studies Quarterly Vol 41 no3 <https://dsq-sds.org/article/view/8375>
- ‘Because of COVID, Everything is a Mess’ How Have People with Disabilities Experienced the Pandemic in Nepal and Bangladesh? Joint report <https://opendocs.ids.ac.uk/opendocs/handle/20.500.12413/16521> +Easy read versions, Nepali and Bangla summaries
- Policy brief : Taking a Disability-Inclusive Approach to Pandemic Responses <https://opendocs.ids.ac.uk/opendocs/handle/20.500.12413/16515>

Study 2 SA

Coming soon on IDS open docs – Extended literature review, Project report, Policy Briefs

In press- SAHR journal paper on COVID vaccine access for People with Disabilities in SA

Study 3 PARDAN

- Research brief:

[Research brief about the methods we used \(English\)](#); [Research brief about the methods we used \(Nepali\)](#)

[Research brief about our findings \(English\)](#); [Research brief about our findings \(Nepali\)](#)

- Scoping review: [Understanding how children and young people with disabilities experience COVID-19 and humanitarian emergencies in low- and middle-income countries: a scoping review protocol.](#)

Further examples of Study 1 publications

- **IW Bangladesh report:** [“Everything is Totally Uncertain Right Now”: People with Disabilities’ Experiences of the COVID-19 Pandemic in Bangladesh \(ids.ac.uk\)](#)
- **IW Kenya report:** [“This Time of Corona Has Been Hard”: People with Disabilities’ Experiences of the COVID-19 Pandemic in Kenya \(ids.ac.uk\)](#)
- **IW Nigeria report:** [“This Pandemic Brought a Lot of Sadness”: People with Disabilities’ Experiences of the COVID-19 Pandemic in Nigeria \(ids.ac.uk\)](#)
- **IW Uganda report:** [“The Situation has Exposed Persons with Disabilities to Double Edged Pain”: People with Disabilities’ Experiences of the COVID-19 Pandemic in Uganda \(ids.ac.uk\)](#)
- **Methodology blog:** [Conducting disability-inclusive remote research during the pandemic - Institute of Development Studies \(ids.ac.uk\)](#)
- **Findings blog:** [Exploring how people with disabilities have experienced the Covid-19 crisis \(ids.ac.uk\)](#)