Breakout session 2: Adapting research methods

15th March 2022









Breakout session 2: Adapting research methods

Chair: Tom Shakespeare	
Sara Haragonics	Using participatory video to explore stories about the impact of COVID-19 on people with psychosocial disabilities in Ghana and Indonesia
Jörgen Lundälv	Conducting remote participatory research of disability and Covid-19 via disability organisations in Sweden
Vera Kubenz	Methodological reflections on developing an inclusive situational analysis framework
Shailaja Tetali	Data collection entirely using mobile phone, from persons with disability: Research experience and some reactions from participants.

Sara Haragonics

Using participatory video to explore stories about the impact of COVID-19 on people with psychosocial disabilities in Ghana and Indonesia









Using participatory video to explore stories about the impact of COVID-19 on people with psychosocial disabilities in Ghana and Indonesia











Sara Haragonics, University of Theatre and Film Arts, Budapest Erminia Colucci, Middlesex University
Annabella Osei-Tutu, University of Ghana
Diana Setiyawati, Universitas Gadjah Mada
Lily Kpobi, University of Ghana
Roberta Selormey, University of Ghana
Ursula Read, University of Warwick/King's College London
Joseph Bugayire, translator
Salim Mohammed, translator
Alhassan Salifu, translator

RESEARCH BACKGROUND

Aim: To understand the impact of COVID-19 on people with psychosocial disabilities in Ghana and Indonesia and inform guidelines for inclusive recovery

Methods:

- Interviews conducted with people with lived experience of mental illness, caregivers and stakeholders to explore the impact of COVID-19 and sources of support
- Interviews analysed thematically with peer-researchers
- Key themes included: Impact on access to mental health care, impact on livelihoods, family and community life and religious practice
- Participatory video used to explore emerging themes

Participatory video

What is Participatory video (PV)?

- Creative methodology
- Enables people/communities/groups to share their stories through filmmaking
- Handing over control
- Works well also with people who are illiterate

(Lunch and Lunch, 2006)

Location and participants

- Indonesia: Yogyakarta, Java (online)
- Ghana: Tamale, Northern Ghana (face-to-face)

Ghana PV workshop

Participants:

- 10 participants (8 female, 2 male)
 5 were caregivers/mothers and 5 were people with psychosocial disabilities
 All were Muslim and aged 18-60 years

Research team:

- 2 PV facilitators: Erminia Colucci and Sari Haragonics
- 3 researchers and 4 peer researchers with psychosocial disabilities (who were also participants)
- 3 male interpreters/participants



Visiting participants

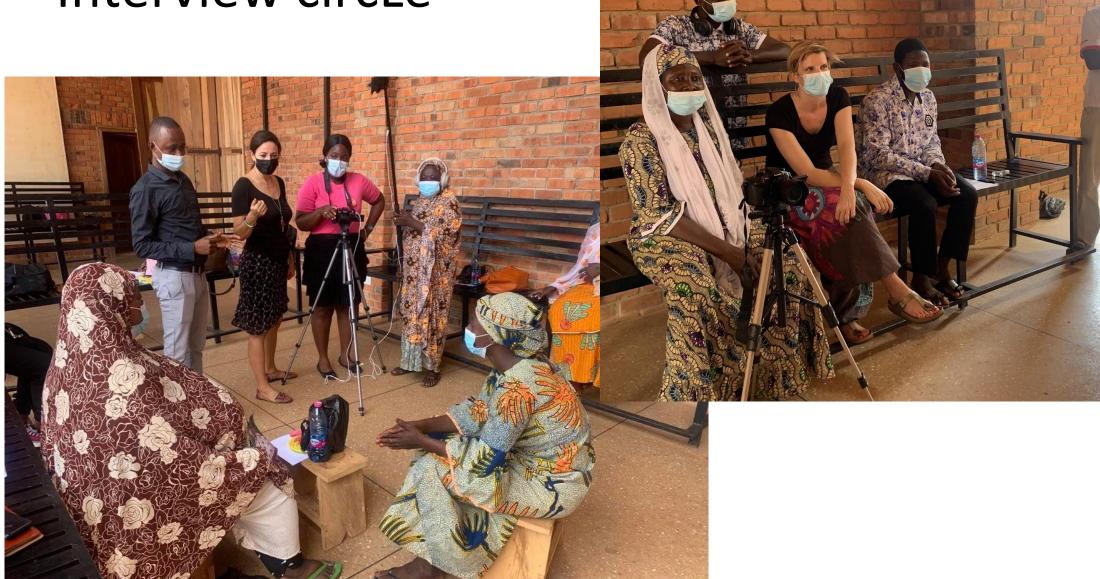


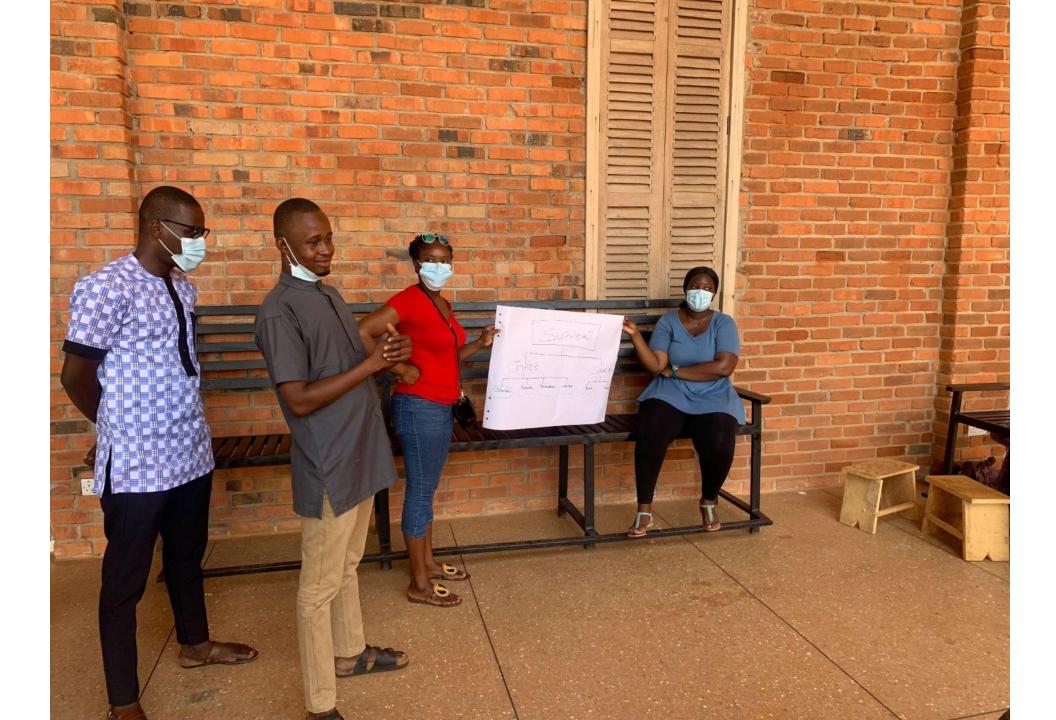


Day 1.

- Opening circle
- Interview in a circle (2 groups): Story of picture/object
- Watching back: Reflection: How was it to see yourself back on film? What did you like/dislike?
 - Technical: How was the image?
- Peer-researchers introducing themes and research findings

Interview circLe





DAY 2.

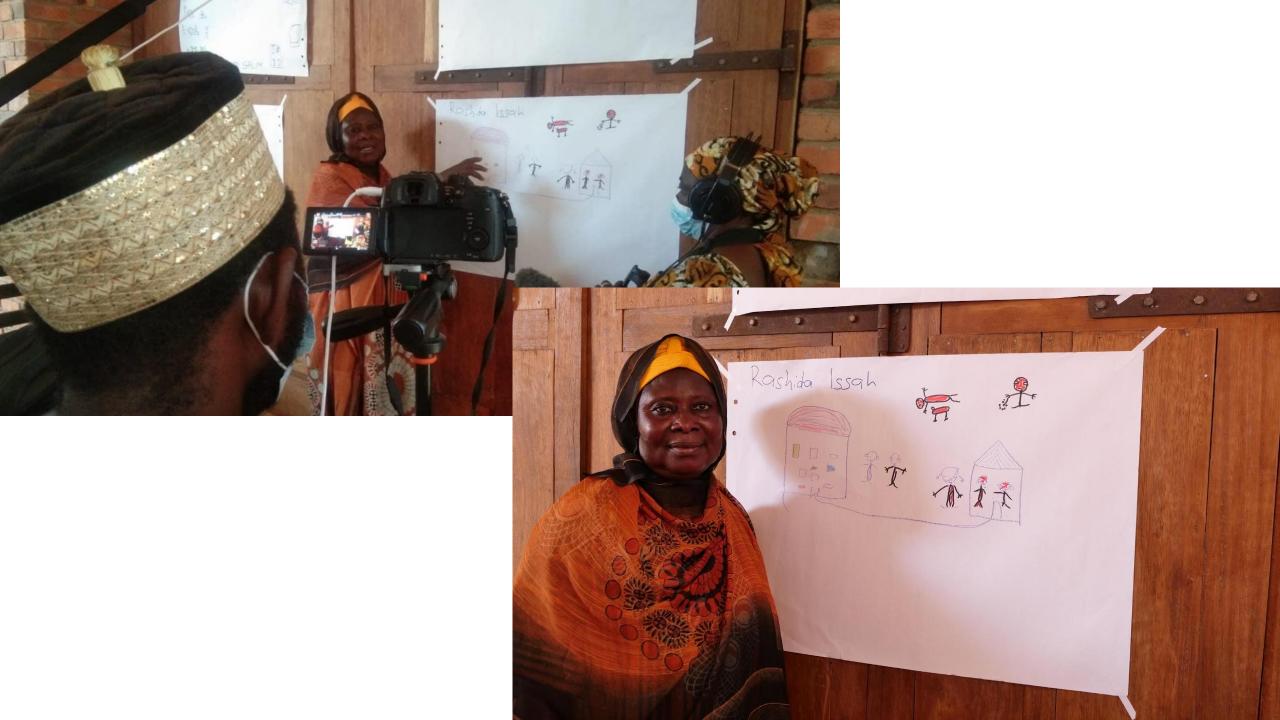
• FILM PLANS:

Developing the storyline collaboratively in small groups: own story, someone else's or totally fiction:

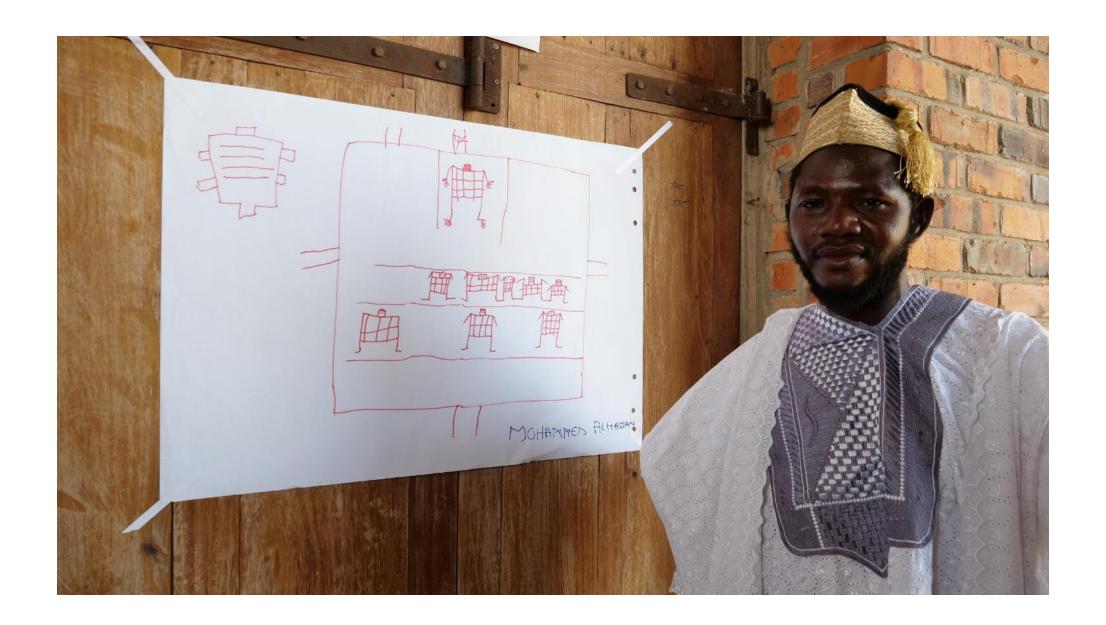
Question: "How was life during COVID for people living with mental illness in your community?"

- Developing the story board as a group and drawing it
- Storytelling: Telling the story to the group in front of the image, recording each other
- Voting: consensus on 2 stories to be developed into films



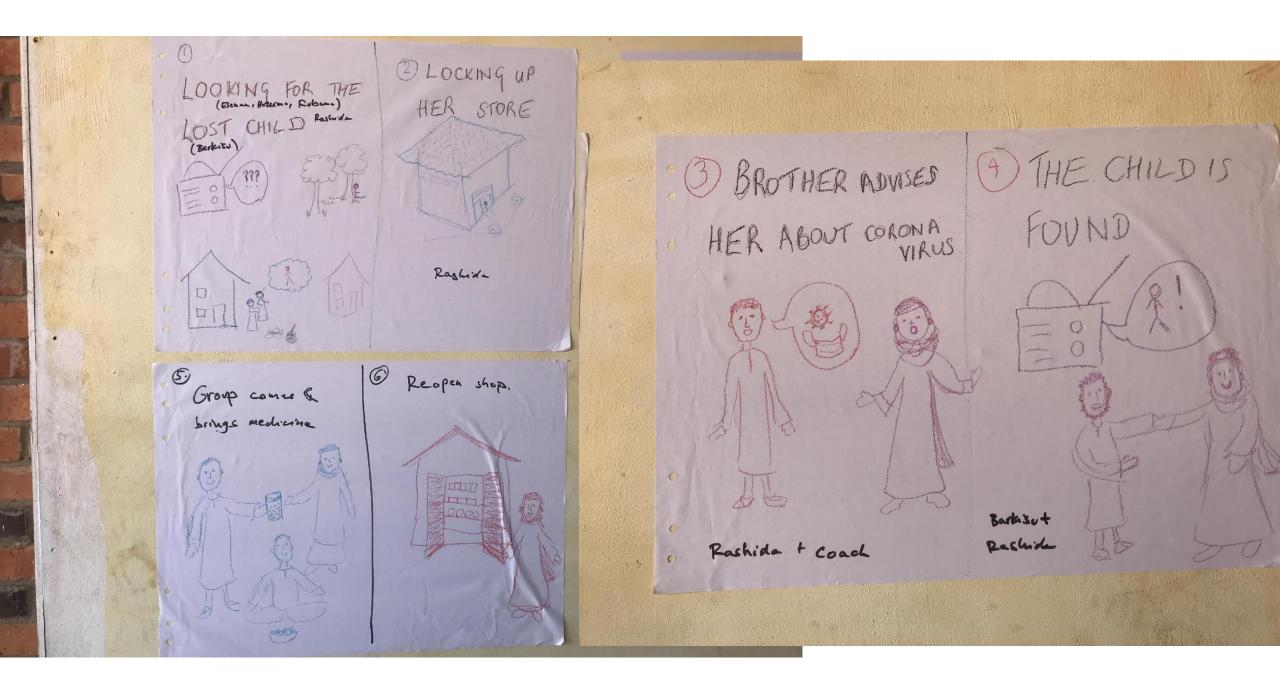






Day 3.

- Filming stories
- Rashida and Alhassan in two groups
- Narrating the story
- 3-5 scenes



Conclusion

- PV enables marginalised and disadvantaged groups, such as people with disabilities and limited literacy, to share their experiences and advocate for change.
- Can be liberating and empowering for participants
- Helps looking at oneself from the outside
- Generates dialogue
- Films will be used as part of engagement and dissemination activities to foster understanding of the impact of the pandemic on people with psychosocial disabilities and priorities for inclusive recovery

For more info and videos:

With grateful thanks to the participants, the peer researchers (Esenam Drah, Lisa Forson, Ofosuware Joseph, Hannan Legend), the interpreters (Alhassan Salifu, Salim Mohammed, Joseph Bugayire), Savannah Centre for Contemporary Art (SCCA), Mental Health Society of Ghana, BasicNeeds Ghana and Stephen Asante.

For more information and other videos: https://movie-ment.org/

Research team contacts:

Erminia Colucci: E.Colucci@mdx.ac.uk

Ursula Read: ursula.read@warwick.ac.uk

Sara Haragonics: sari.haragonics@gmail.com

Annabella Opare-Henaku: aopare-henaku@ug.edu.gh

Diana Setiyawati: diana@ugm.ac.id



Jörgen Lundälv

Conducting remote participatory research of disability and Covid-19 via disability organisations in Sweden

Future working life for people with disabilities

- Learning from experiences gained during the Covid-19 pandemic

Conducting remote participatory research of disability and Covid-19 via disability organisations in Sweden – A valid method?

Jörgen Lundälv, University of Gothenburg
Magnus Eriksson, RISE
Elisabet M. Nilsson, Malmö University
Lars Lindberg, Nordic Welfare Centre in Stockholm









Future working life for people with disabilities - Learning from experiences gained during the Covid-19 pandemic

Research project (2022–2024):

Working life during the Covid-19 pandemic: social participation, learning experiences, design opportunities and future work life for people with disabilities

What have we learned from working, living and acting during the Covid-19 pandemic – when life as we know it changed from one day to another? How can these experiences contribute to improve the conditions for people with various forms of disabilities to participate in and contribute to working life?









Future working life for people with disabilities

- Learning from experiences gained during the Covid-19 pandemic

- The research assumes a participatory approach and is conducted in collaboration with the stakeholders.
- New proposals on how working life for people with disabilities can be organised and facilitated.
- The primary stakeholders of the project are people with various forms of disabilities, including their families.
- The secondary stakeholders are authorities, civil society organisations, and employers who are part of creating conditions for this group to partake in and contribute to working life.
- The project is financed by Forte and run by University of Gothenburg, RISE and Malmö University.
- For more information, see the project web site: https://dworklife.uni.mau.se









Future working life for people with disabilities

- Learning from experiences gained during the Covid-19 pandemic

Conducting remote participatory research of disability and Covid-19 via disability organisations in Sweden

– A valid method?







Future working life for people with disabilities

- Learning from experiences gained during the Covid-19 pandemic

Going via the disability organisations – A valid method?

- Representation
 - To what extent can they represent the experiences of their members
 - Not speak from their own experiences and perspectives, but from a "typical member"
- Research ethics
 - Less risk of sensitive personal circumstances in the research
 - Less demand on participants time outside of their organisational role
 - Not apply for ethical permit
 - Representation on an organisational level
- Online vs physical meetings
 - An including approach
 - What new forms of inclusions and exclusions are potentially created?
 - People can participate from their homes
 - Issues of data security









Future working life for people with disabilities - Learning from experiences gained during the Covid-19 pandemic

Conducting remote participatory research of disability and Covid-19 via disability organisations in Sweden

- A valid method?
- What other alternatives have been used in remote participatory research to learn from?
- Directions for method innovation for remote participatory research?









Future working life for people with disabilities - Learning from experiences gained during the Covid-19 pandemic

Contact Information

Jörgen Lundälv (jorgen.lundalv@socwork.gu.se)
Associate Professor in Social Work, Department of
Social Work, University of Gothenburg
Associate Professor in Traffic Medicine, Department
of Surgical and Perioperative Science, Umeå
university, Sweden
www.gu.se

Elisabet M. Nilsson (elisabet.nilsson@mau.se)
Senior lecturer in Interaction design, PhD in
educational sciences
School of Arts and Communication (K3), Malmö
University, Sweden
www.mau.se

Magnus Eriksson (magnus.eriksson@ri.se) Senior Researcher RISE Research Institutes of Sweden

Lars Lindberg

www.ri.se

(lars.lindberg@nordicwelfare.org)
Senior adviser
Nordic Welfare Centre in Stockholm
www.nordicwelfare.org

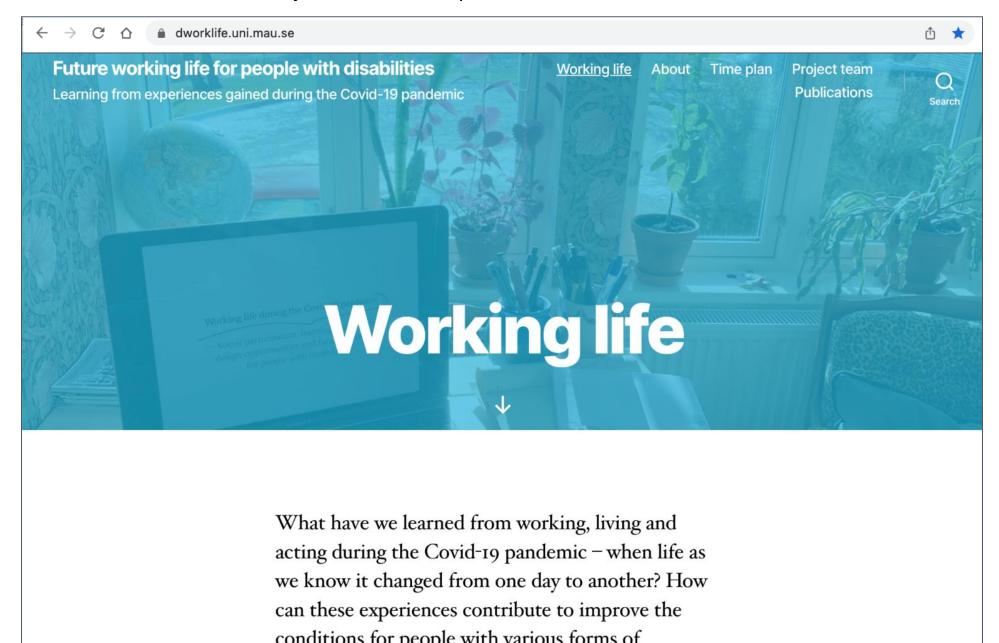








Project web site: https://dworklife.uni.mau.se



Vera Kubenz

Methodological reflections on developing an inclusive situational analysis framework





Methodological reflections on developing an inclusive situational analysis framework





Background



Photo by Jonathan Cooper

About the project

• Funded by AHRC under GCRF from Sep 2020 to April 2022

 Working in collaboration with UN Partnership for the Rights of Persons with Disabilities (UNPRPD)

 Led by Prof Dina Kiwan, University of Birmingham, as part of the wider GCRF Disability Under Siege Network+ programme

Previous disasters and disability

 During previous pandemics, epidemics, and natural disasters, persons with disabilities were frequently neglected

 Little evidence on the effect of previous disasters, or any improvements in provision in the aftermath

 How can we ensure that lessons are learned so we can 'build back better'?

Aims and objectives

 Aim: To develop an analytical framework to promote and support the implementation of a disability-inclusive response and recovery from COVID-19

Objectives:

- To conduct a literature review on the impact of COVID-19 on persons with disabilities in Low- and Middle- Income Countries (LMICs)
- To develop a framework for situational analysis for use in UNPRPD's pilot funded projects, and ensure this is evidence-informed and participatory
- To identify future/emerging research priorities and gaps in research, and inform the priorities for UKRI/UNPRPD research collaboration
- Developing equitable working relationships with the LMICs to foster longterm cross-disciplinary collaborations between LMICs, UK researchers, and UNPRPD

Methods



Literature review methodology

- Semi-systematic review of 113 articles on disability and COVID-19 or other pandemic/disasters in LMICs published up to Dec 2020
- Covering sectors of Health, Education, Economy, Community (with Health most common topic)
- Most literature was 'grey', usually NGO reports and emerged in first four months
- Little evidence emerged from previous emergencies

Development of framework

• Literature review provided overview of issues faced by persons with disabilities, developed into an analysis matrix

 Building on existing quantitative and qualitative research methods that enable a critical and rigorous analysis

 Focussing on broader themes that emerged from the literature review (deprioritisation, lack of consultation, medicalisation) and built these into the analytical framework

Consultation and refinement

- Advisory group of persons with disabilities from LMICs (including activists and academics)
- Two-way communication process with the UKRI/UNPRPD research collaboration through its advisory group
- Facilitation of network of eight case studies, benefiting from learning from their participatory and creative methods
- Review of existing best practice
- Feedback from wider stakeholders and general public through engagement events



Results & Conclusion

Key features of framework

- Analytical: Enabling critical analysis and drawing of conclusions on priorities
- Evidence-based: Building on research methods to a systematic and rigorous approach
- Inclusive: Emphasising involvement and consultation with persons with disabilities, including recommendations on equitable collaboration
- Detailed: Focussing on both quantitative data which represents a major gap, and qualitative/creative methods for understanding lived experience
- Nuanced: Encouraging consideration on exploring complexities and interconnections of systems, rather than 'quick fixes'

Learning points and conclusion

• Highlighting the benefits of collaboration and equitable partnerships, eg between Global North and Global South, research and development

 Developing ways in which research can be both analytical and rigorous, as well as participatory and inclusive

 Learning on creative, inclusive and participatory methods that is relevant to research, policy, and development stakeholders

 Providing actors in UNPRPD partner countries with a tool for evidencebased recommendations based on specific local/national contexts

Shailaja Tetali

Data collection entirely using mobile phone, from persons with disability: Research experience and some reactions from participants.



Data collection using mobile phone: Research experience, and reactions from participants.

Shailaja Tetali, Nandakishore K, GVS Murthy, Shilpa S, Sureshkumar K, Gowri I, Neena J

Public Health Foundation of India

Background

- This is regarding data collection for the PENDA project in India
- Pandemic related lockdowns and associated restrictions
- Data collection almost entirely remotely (mobile phone)
- We describe reactions from some participants during data collection for the study 'impact of COVID 19 on persons with disability'.

Methods

- Two rounds of data collection conducted remotely
- 6 states of India
- Recruitment using NGOs working with persons with disability
- In depth interviews and key informant interviews
- Contacted the same participant in Round 1 and 2
- Round 1 had 62 IDI and 10 KII (Early 2021)
- Round 2 included 41 IDIs and 3 KIIs (Late 2021)

Results- Recruitment and consent

- Was smooth for both rounds
- Data collection for Round1 led to enthusiastic responses
- Round 2 was not easy
- Participants had to be called 3-15 times on phone before the interview.

Results- Participant perspectives

- Some respondents refused to continue the interview.
- Tried to convince them about indirect benefits through policy level changes and future preparedness
- "if you are not providing money, why should we talk to you again"
- "is it the right thing to ask about our issues, when you are not providing any solutions to us"
- Others responded politely, asked us to call back, with the number then not reachable, with no further response.

Interviewer perspectives

- "In R 1, we could choose participants to interview from list. In Round 2, contacting the same participant has been highly challenging"
- Message saying...Call has been forwarded. After few seconds, call ends..
- "Please call in half an hour. When I tried to call again, number was unreachable. No response to Whatsapp messages"

Conclusions

- Remote data collection was convenient given the circumstances of the pandemic
- But there were challenges: variable responses- some participants were forthcoming with their opinions, while others were more hesitant
- Overcoming the challenges
- Larger picture to be kept in mind...



- Acknowledgements: All the participants, interviewers
- Grateful to ICED, LSHTM for funding this project

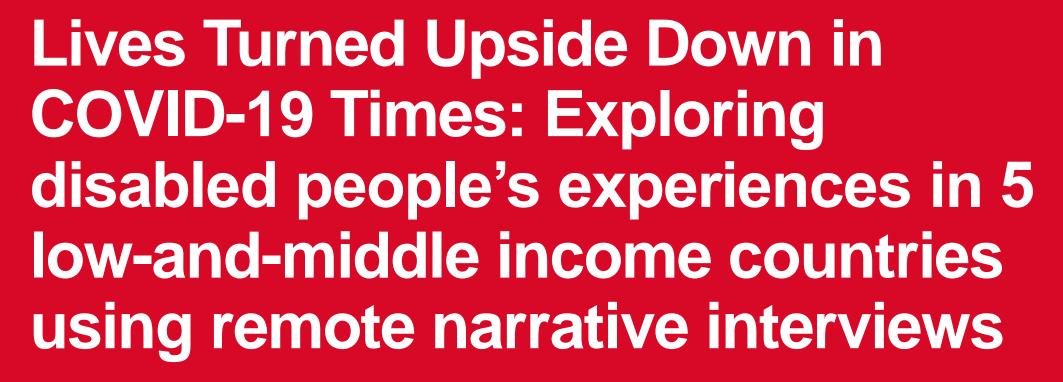
Thank you

Brigitte Rohwerder IDS

Lives Turned Upside Down in COVID-19 Times: Exploring disabled people's experiences in 5 low-and-middle income countries using remote narrative interviews







March 2022

Introduction

Aims of the research

 To explore the experiences and perceptions of people with disabilities of the COVID-19 pandemic.

Focus

- 75 participants who were already involved in Inclusive Futures in Bangladesh, Kenya, Nigeria, Nepal and Uganda. (Inclusion Works and DID programmes)
- 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.

Method selected – putting interviewees in the driving seat

- 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

Working with peer researchers

- In Nigeria, Kenya, Uganda and Bangladesh we worked with four local researchers already working with us on Inclusion Works (one of the four has a disability).
- 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 online training provided and peer support system established.

"From the beginning, I would say that I would never think that I would be involved in research.

Actually 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

Experience of one of the peer researchers: Anita's story

The impact of Covid-19 on people with disabilities in six countries - Anita Sigdel - YouTube

Experiences of doing disability inclusive remote research

- The importance of an initial call to get to know the participant
- Establishing and meeting remote access and communication support needs before the actual interview
- Reimbursing data costs or enabling access to needed technology
- Use of local language
- Allowing enough time and accounting for possible network and connectivity issues

Experiences of participants

"Thank you for the discussion. I never thought I could be an analyser. I have been here wondering if this is me speaking!" (man with physical disability, Kenya)

"Thank you for involving me and recognising that I can have something to share. You have done it differently from others who never see the abilities of persons with disabilities." (man with intellectual disability, Uganda)

"I want to thank the organisers and coordinator of this programme for this wonderful privilege you've given to me to hear my opinion and my voice in this research. To the interviewer, SC, thank you very much for your patience and accommodation." (man with albinism, Nigeria)

"I am happy I am able to give information and help in a way. It helps someone to feel that the challenges others are facing are common. It is very therapeutic." (woman with psychosocial disability, Kenya)

Publications

- Journal article: <u>Lives turned upside down in COVID-19 times</u>: <u>exploring disabled people's experiences in 5 low-and-middle income countries using narrative interviews | Wickenden | Disability Studies Quarterly (dsq-sds.org)</u>
- 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)
- DID Bangladesh and Nepal report: 'Because of COVID, Everything is a Mess' How Have People with Disabilities
 Experienced the Pandemic in Nepal and Bangladesh? (ids.ac.uk)
- Policy brief: <u>Taking a Disability-Inclusive Approach to Pandemic Responses (ids.ac.uk)</u>
- 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)
- Webinar: The impact of Covid-19 on people with disabilities in six countries: Three studies same story! YouTube





Thank you for listening

IDS team: Brigitte Rohwerder, Stephen Thompson, Mary Wickenden, Jackie Shaw, & Caroline Martin

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Thanks to all our participants who told their stories so willingly and openly

and

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