

EXPLORING THE EXPERIENCES OF PEOPLE WITH DISABILITIES DURING COVID-19

INTERVIEWER TRAINING

Dr Morgon Banks & Dr Shaffa Hameed

London School of Hygiene & Tropical Medicine

STUDY OVERVIEW

AIM: To explore the experiences of people with disabilities during the COVID-19 pandemic and identify possible strategies to better promote the inclusion of people with disabilities in response activities.

Part of a global study involving different settings (Ghana, Zambia, Bangladesh, India, Zimbabwe, Syrian refugees in Turkey).

OBJECTIVES (1)

- Explore the experience of people with disabilities during COVID-19:
 - The effects of the COVID-19 pandemic on the health of people with disabilities, including their mental health, and ability to access needed ongoing healthcare (e.g. rehabilitation, psychiatry, chronic illness management).
 - The economic effects of the COVID-19 pandemic (e.g. on livelihoods, food security, income) amongst people with disabilities.
 - Other impacts of the COVID-19 pandemic on the daily lives of people with disabilities (e.g. social life, access to social care and other key services).

OBJECTIVES (2)

- Evaluate the extent to which people with disabilities are included in response activities. For example, we will:
 - Assess knowledge and opinions of COVID-19 and direct response measures (e.g. social distancing, hygiene, access to vaccines) amongst people with disabilities.
 - Identify strategies used by stakeholders (e.g. DPOs, NGOs, relevant government department and global agencies) to include people with disabilities in responses to the COVID-19 pandemic (i.e. prevention, treatment, and interventions to mitigate the health, social and economic impacts) and explore their strengths and weaknesses.

WHY IS THIS RESEARCH IMPORTANT?

- People with disabilities often left behind in emergencies
- Higher risk of severe disease, COVID-19 mortality: e.g. in the UK people with disabilities 2-3x more likely to die from COVID-19
- More likely to face other negative consequences due to the pandemic such as:
 - Loss of work
 - Disruptions to schooling
 - Isolation, poor mental health
 - Lack of access to non-COVID healthcare
- More likely to be excluded from direct (e.g. prevention, care) response and indirect response (e.g. access to income support,

METHODS – QUALITATIVE RESEARCH

- We will conduct in-depth interviews with ~60 people with disabilities
 - Includes people with different types of disabilities (e.g. physical, vision, hearing, intellectual)
- Also interviewing key informants (e.g. government officials, NGOs)

WHAT IS DISABILITY

WHAT IS DISABILITY?

- **Exercise 1:** In groups of 2-3, discuss how would you define disability?

DISABILITY IS COMMON



15% of the world's population has a disability

UNCRPD DEFINITION

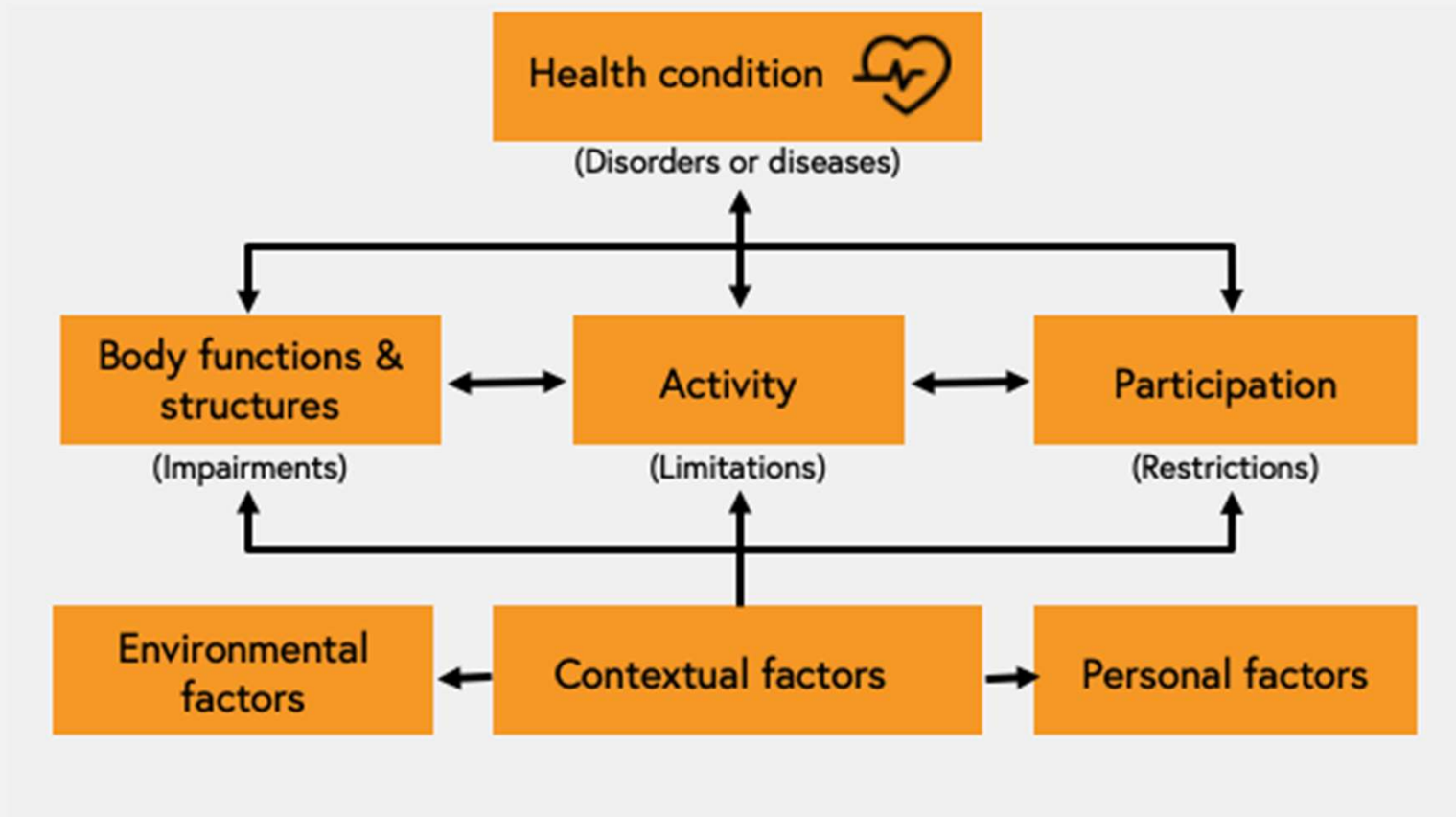
Different types of disability, not short-term difficulties (e.g. broken leg, temporary illness)

e.g. negative attitudes towards disability, buildings without ramps, lack of sign language/Braille

*Persons with disabilities include 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**'*

e.g. go to school, work, participate in community/social events

INTERNATIONAL CLASSIFICATION OF FUNCTIONING, DISABILITY & HEALTH (ICF)



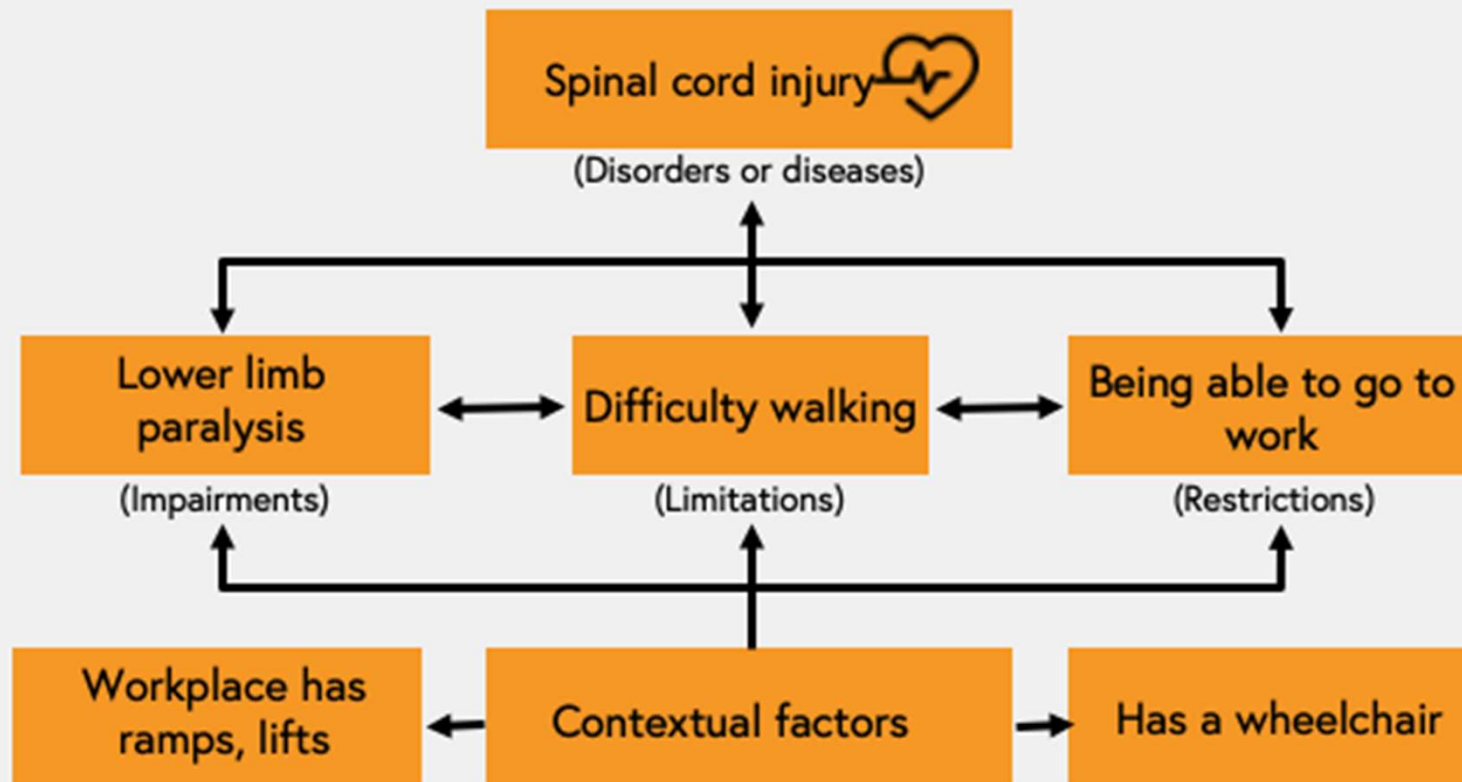
AT RISK OF EXCLUSION

- There is increasing research showing people with disabilities often experience:
 - Greater risk of poverty
 - Poorer physical and mental health
 - Exclusion from work, education and healthcare
 - Stigma and discrimination
 - Inaccessible environments



© Régis Binard / Handicap International

ICF EXAMPLE



DISABILITY & COVID-19

EXERCISE

- ***In groups of 2-3, think about if and how the following may be different for people with disabilities compared to people without disabilities. Think about how it may differ amongst people with disabilities (e.g. different types of disability, men vs women etc)***
 - Access COVID-19 prevention (e.g. access to vaccines, social distancing, hygiene)
 - The effect of COVID-19 on health (e.g. access to needed health services, mental health)
 - Access to services (e.g. education)
 - The economic impact of COVID-19 (e.g. on jobs, income)
 - Access to programmes to target the indirect impact of COVID-19 (e.g. cash transfers, food relief)

ACCESS COVID-19 PREVENTION

- Information not available in accessible formats (e.g. Braille, sign language, screen reader compatible)
- Difficulties social distancing (e.g. needing caregiver support, not understanding why important)
- Difficulties undertaking proper hygiene measures (e.g. washing hands frequently for people with disabilities affecting upper body)
- Vaccine distribution sites not accessible (e.g. bookings, buildings)

HEALTH

- People with disabilities have a higher need for healthcare (e.g. rehabilitation, counselling). Disruptions to these services can worsen health and functioning.
- May face more isolation during pandemic
 - Some may need to self-isolate because a health condition puts them at greater risk of severe disease
 - Others may become more isolated due to disruptions to needed services (e.g. personal assistance, repairs/replacements to assistive devices)

EDUCATION AND OTHER SERVICES

- Schools shifting to remote/at-home instruction may not have the needed supports for students with disabilities
- Loss of specialist supports/services that were previously provided at school
- Personal assistance (from a provider/family) may be disrupted due to the need to social distance; caregivers may not be able to follow preventative guidelines (e.g. using masks)

ECONOMIC IMPACT

- People with disabilities more likely to work in the informal sector or in unsteady jobs– more at risk of losing work when pandemic hits
- Discrimination of disability and lack of accommodations in the workplace makes it harder to find another job
- Some programmes to address the economic impacts of COVID-19 (e.g. cash transfers, food relief) may not be inclusive of people with disabilities
 - Information about them not accessible
 - Registration processes not accessible
- Some reports of disruptions in the delivery of social protection (e.g. Disability Allowance, Old Age Pensions) during COVID-19

ACCESS TO PROGRAMMES

- Do programmes provide information in accessible formats (e.g. Braille, sign language etc)?
- How do people apply/receive benefits?
 - Do they need to travel far?
 - Are buildings/online systems accessible to people with different disabilities?
- Do attitudes about disability prevent people from accessing programmes?

STUDY PROCEDURES



GENERAL FORMAT OF INTERVIEW

- 1) Pre-Interview: Call ahead to arrange interview, find out about communication supports
- 2) Day of: In-person: Clear the room of all but essential people; Phone: make sure you're in an area with good connection/privacy
- 3) Take informed consent
- 4) Start recorder
- 5) Conduct interview

I. PRE-INTERVIEW

- Call the person with a disability. Make sure you're talking to the person with a disability and not another household member, unless the person with a disability has severe difficulty understanding (even then, try to verify for yourself).
- Describe the study and what will be involved if they choose to participate. Offer to read the information sheet or email it to them.
- Ask if they are interested in being interviewed. If they are, ask about any adaptations needed (e.g. sign language interpretation). Determine if a proxy interview with a caregiver is needed.

WHO DO YOU INTERVIEW?

- The best option is ALWAYS to interview the person with a disability directly
- There are accommodations we can provide to support the participation of the person with a disability, such as having a sign language interpreter over a video call
- You should ask when setting up the interview what supports the person requires

WHO DO YOU INTERVIEW? TALKING TO CAREGIVERS

- There are two situations where we might talk to a caregiver instead of the person with a disability
 - 1) **Children (below age of consent):** you may want to ask all or some of the questions to their caregiver.
 - Children <10 years: interview the caregiver only.
 - Children 10+ years: try asking questions first to the child and then talk to caregiver if you need additional information
 - 2) **Adult with severe difficulty understanding or communicating**
- In these instances, you should ask who knows the most about the person with a disability's daily life and/or who assists them with daily activities

SCENARIO I

- You want to interview John, 19 years, who has a cognitive disability. His mother says he won't be able to talk with you.
- *What do you do in this instance?*

SCENARIO I (ANSWERS)

- You should try to check for yourself John's communication abilities.
 - For example, ask to talk to John and ask him some basic questions (e.g. what is your name? How are you today?)
 - Ask the mother how she communicates with John. Can we use this strategy (best case)? If not, can she help us talk to John? Even limited information is better than no information.
- If you still can't find a way to communicate with John, you should ask who would be best to interview instead (i.e. who knows the most about John's daily life)

SCENARIO 2

- You call to arrange interview Mary (35 years), who is deaf.
- *What do you do in this instance?*

SCENARIO 2 (ANSWERS)

- Ask a family member how best to communicate with Mary. For example, can she read if we send written instructions/questions? Does she know sign language?
- Arrange to have these supports available at the time of the interview.

SCENARIO 3

- You talk to Jane (42 years), who has an intellectual disability. She can communicate a bit, but you're not sure if she'll understand all your questions.
- *What do you do in this instance?*

SCENARIO 3 (ANSWERS)

- Conduct as much of the interview with Jane as possible. You may need to simplify some of your questions.
- If you think you still need more information, you can also conduct a separate interview with Jane's caregiver.

SCENARIO 4

- The person with a disability is Scott (12 years), who has a physical disability.
- *What do you do in this instance?*

SCENARIO 4 (ANSWERS)

- Conduct as much of the interview with Scott as possible. You may need to skip some questions that aren't relevant for children (e.g. questions about work, accessing services).
- After talking to Scott, interview his caregiver. Ask him/her questions that either Scott wasn't able to answer or where you think more detail would be helpful.

2. WHERE SHOULD YOU CONDUCT THE INTERVIEW?

- We may be conducting phone and/or in-person interviews, depending on the participants preference and COVID-19 guidance.
- For phone interviews: Pick somewhere quiet, with good reception and privacy. Ask the participant to do the same.
- For in-person interviews: Pick somewhere quiet, away from other people, where the participant feels comfortable. Make sure the location is accessible.

Both: Make sure you have all needed supports for the interview (e.g. sign language, simplified information/interview sheets)

SCENARIO 5

- You are doing an in-person interview with Sarah, who has a physical disability. Her husband is also in the interview room.
- *Is this a good set-up? Why/why not? What if anything, could be improved?*

SCENARIO 5 (ANSWERS)

- We ideally want to interview the participant alone.
- You can explain the study in the presence of Sarah's husband, but you should explain that under study protocols, you must speak to Sarah alone.
- Do not ask Sarah if she wants her husband present. However, if she specifically asks for him to stay (without any prompting from anyone), this is ok.

SCENARIO 6

- Claire is deaf but can communicate through sign language. You can't meet in person because of COVID-19 guidance.
- *What do you do?*

SCENARIO 6 (ANSWERS)

- Arrange for an interview over a video conferencing app (e.g. Skype, Zoom, WhatsApp) with a sign language interpreter present.
 - If she doesn't have a computer/Smartphone, ask if she can use a friend's/family member's
- If video conferencing isn't possible, send Claire the interview questions for her to provide written responses.

3. INFORMED CONSENT

- BEFORE starting any interview, you need to take informed consent
- Consent is needed from everyone who is answering your questions
- If you do not get consent you CANNOT CONTINUE. There are no exceptions to this

KEY POINTS OF INFORMED CONSENT

- Participation is completely voluntary
 - Decision on whether or not participate will not affect their receipt of benefits, services
 - We are unable to offer compensation or any other direct benefits
- Interviewee is free to stop the interview at any time or refuse to answer any question
- We will be recording the discussion
- Any information disclosed will be kept confidential. We will not share with government or anyone else

INFORMED CONSENT STEPS

- Read out the information sheet
- Check if the participant has any questions
- If they are happy to proceed, go through the consent sheet
- You will need caregiver consent for all children (below age of consent) and for adults with severe difficulties understanding/communicating

INFORMED CONSENT: PHONE INTERVIEWS

- Read out the information sheet
- Check if the participant has any questions
- Explain that you must record their consent to continue
- Turn the recorder ON
- Read the 5 bullet points on the Informed Consent form
- Say out loud: “Today is [DATE]. If you agree to participate please state your full name”
- Once they say their name, STOP the recording
- Save recording with their ID number

INFORMED CONSENT: IN-PERSON INTERVIEWS

- Read out the information sheet or give to participant to read
- Check if the participant has any questions
- Ask them to sign and date the Informed Consent form
- For people who are blind or illiterate, you can either:
 - Do a recorded verbal consent (like for phone interviews)
 - Ask them to thumbprint. Have a witness (e.g. other family member) sign as well.

WHO DO WE SEEK CONSENT FROM? (ADULTS)

Category	Who do we need consent from?	Who do we interview?
Adult with a disability, no or mild difficulty understanding or communicating		
Adult with a disability, moderate understanding or communicating but can still answer some questions		
Adult with a disability, very severe difficulty understanding or communicating, cannot answer any interview questions		

WHO DO WE SEEK CONSENT FROM? (ADULTS – ANSWERS)

Category	Who do we need consent from?	Who do we interview?
Adult with a disability, no or mild difficulty understanding or communicating	Person with a disability only	Person with a disability alone
Adult with a disability, moderate understanding or communicating but can still answer some questions	Person with a disability AND caregiver	Person with a disability and caregiver
Adult with a disability, very severe difficulty understanding or communicating, cannot answer any interview questions	Caregiver	Caregiver alone

WHO DO WE SEEK CONSENT FROM? (CHILDREN)

Category	Who do we need consent from?	Who do we interview?
Child (<10 years)		
Child (10+ years)		

WHO DO WE SEEK CONSENT FROM? (CHILDREN - ANSWERS)

Category	Who do we need consent from?	Who do we interview?
Child (<10 years)	Caregiver	Caregiver
Child (10+ years)	Caregiver + child (if child answering questions)	Child and, if needed, caregiver (separately)

SCENARIO 7

- Emily (age 60) is deaf. How do we get her consent for the interview?
- *What do you do?*

SCENARIO 7 (ANSWERS)

- If she uses sign language, you can video record consent.
- You can also get written consent by sending her the information and consent sheets ahead of time and asking her to sign and return to you (before the interview begins)

SCENARIO 8

- Tom (age 10) has a visual impairment. Who do we get consent from and who do we interview?
- *What do you do?*

SCENARIO 8 (ANSWERS)

- You must get consent from Tom's caregiver
- If Tom will be answering your questions, you need his consent too

SCENARIO 9

- Meera (age 40) has a learning disability.
- *Who do you need consent from? Who do you interview?*

SCENARIO 9 (ANSWERS)

- If you think Meera has not fully understand the study and study protocols, you should get caregiver consent.
- If Meera is able to understand/communicate enough to answer at least some of the questions though you should still interview her. If you interview her, you must get her consent too.

CONFIDENTIALITY

- One of your biggest responsibilities is keeping the information shared with you PRIVATE
- Do not share or discuss information about any participant with anyone outside the research team
- Keep your audio recorder, notes and consent forms secure and do not show them to others. Do not leave them unattended.
 - Return all materials to CRP at the end of data collection

TIPS FOR GOOD INTERVIEWING

- **Ask follow-up questions (probes)**
 - It is very important to explore issues – the topic guides are just a starting-point
- **Don't talk about your own experience/opinions**
 - It can be tempting to try to relate to the participant by sharing your own experiences but you should not do this during the interview.
- **Be engaging but neutral**
 - Make sure you are not overly positive or negative in your responses
 - Watch your body language – avoid excessive nodding/shaking your head, frowning etc

QUESTIONING STYLES: DOS AND DON'TS

DON'Ts

Leading questions

- *What problems with bullying have you had at school?*
- *Don't you have problems at school?*

Closed or 'yes/no' questions

- *Did you feel sad at that point?*
- *Did you think the treatment was good?*

Questions with several parts/ideas

- *What do you know about COVID-19, like how do you get it, how do you prevent it, how is it treated?*

DOs

Neutral questions

- *What is your relationship like with your fellow students? Your teachers?*

Open questions

- *How did you feel at that point?*
- *What did you think about the treatment?*

Short, simple questions

What do you know about COVID-19?

What do you know about ways to prevent getting COVID-19?

ARE THESE APPROPRIATE INTERVIEWER INPUT? IF NOT, HOW CAN THEY BE IMPROVED?

- “I really agree with what you just said, the same thing happened to me once”
- “You said before [CONTRADICTIONARY INFORMATION]. So what you just said now can’t be right. I think you mean XXX”
- “You’re not making any sense.”
- “Thanks for sharing.”
- “I’m sorry, but a few minutes ago I thought you said [CONTRADICTIONARY INFORMATION]. Could you clarify this for me?”
- “I’m not quite sure I understand what you mean by that. Could you tell me a little more?”

SCENARIO 10

You want to know how about a participant's experience accessing COVID-19 vaccinations. This is part of your dialogue:

Interviewer: "Can you tell me about your experience getting the coronavirus vaccine?"

Participant: "Yes I got the vaccine last month. I'm very happy I have it now."

Is this enough information? What are some follow-up questions you can ask?

SCENARIO 10 (ANSWERS)

Example follow-up questions:

- Talk me through the steps of how you got the vaccine
 - How did you find out about the programme?
 - How did you make an appointment?
 - Where did you go and how did you get there?
 - How was the appointment itself?
 - What, if anything, did you find helpful or challenging during each of these steps?

CONSIDERATIONS FOR INTERVIEWING PEOPLE WITH DISABILITIES

HEARING IMPAIRMENT

- Ask about preferred communication strategies when setting up the interview. This might include: sign language, lip-reading, written communication or speaking in a quiet space/at a louder volume

Other considerations:

- Face the person at all times when speaking.
- Get the person's attention before you start speaking, using visual cues.
- Speak slowly and clearly, at a steady rhythm.
- Shouting does not help.
- If you think you have not been understood, rephrase your sentence.
- If an interpreter is present, still speak directly to the deaf person.

VISUAL IMPAIRMENT

- When you approach a blind person remember to identify yourself clearly, and indicate anyone else who is present
- Give verbal rather than written messages (e.g. read the information sheet)
- Do not leave someone talking to an empty space. Say when you wish to end the interview or move away.

PHYSICAL IMPAIRMENTS

- If you are talking to someone in a wheelchair try to put your head at the same level
- Do not push a wheelchair without asking the person first.
- People who use sticks or crutches may find it difficult to use their hands while standing so do not expect this
- Never address the escort or personal assistant, instead of the person with a disability, always talk to the person.

COMMUNICATION DIFFICULTIES

- Be encouraging and patient. Do not correct or speak for the person. Wait until the person finishes and resist the temptation to finish sentences.
- Where possible, ask questions that require short answers or just a nod or shake of the head.
- If you do not understand, do not pretend. Repeat as much as you do understand and use the person's reactions to guide you. Ask them to tell you again, if necessary

INTELLECTUAL IMPAIRMENTS

- Be prepared to explain more than once, if the person does not understand the first time.
- If necessary, suggest that the person may want to have a friend or relative present during the interview.
- Make sure true consent is given. Involve a carer if you are unsure.

REVIEWING THE INTERVIEW GUIDE

NOTES SECTION

Description	Notes
Code (ID)	
Interview date and time	
Interviewer	
Interviewee	
Impairment type(s)	
Disability degree	
Gender	
Age	
Work status	
Highest level of education	
Observations Including but not limited to: <ul style="list-style-type: none">• Challenges during the interview• About the disability (e.g. difficulties with activities, presence of assistive devices)	

EXERCISES

- 1) In groups, review the text of the topic guide (in English and translated language). Consider:
 - Are any questions unclear?
 - Are all questions relevant for the study setting? If not, how can they be adapted?
 - What might be some probing questions that you would use to gain further information?
 - Compare the English and [translated language] – are there differences between the two?

- 2) In pairs, practice interviewing each other
 - **Interviewee:** answer questions in a way that will test the interviewer's interviewing skills (e.g. giving short/incomplete responses, going off-topic, providing contradictory information, answering questions out of order to the topic guide)
 - **Interviewer:** remember to asking follow-up/probing questions!

REFERENCING

This training was developed by the International Centre for Evidence in Disability. Any usage should cite:

Banks, L.M. & Hameed, S. (2021) “Exploring the experiences of people with disabilities during COVID-19.” International Centre for Evidence in Disability, London School of Hygiene and Tropical Medicine: London, UK