



Inclusive Research Handbook

Conducting Research With and For People With Disabilities

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A field-tested guide for disability-inclusive study design, ethics, and data collection

Covers six disability categories: physical, visual, hearing, speech, psychosocial, and intellectual

Aligned with the CRPD and South Africa's Promotion of Equality and Prevention of Unfair Discrimination Act

Zonge Research International

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Glossary

Term	Meaning
Acquiescence bias	The tendency to agree with statements regardless of content. More common in interviews where the participant wants to please the researcher.
AAC	Augmentative and Alternative Communication. Devices, apps, or boards that support communication for people who cannot speak or write.
CRPD	United Nations Convention on the Rights of Persons with Disabilities (2006).
Deaf (capital D)	Used by members of the Deaf community who identify with Deaf culture and use sign language. Many do not identify as disabled.
Disaggregation	Breaking down data into sub-groups — for example, by disability type, sex, or age — to reveal differences within a population.
Easy-read	A format for written information that uses short sentences, common words, and images to support comprehension.
OPD	Organisations of Persons with Disabilities — a civil society group run by and for people with disabilities.
PDA (2024)	Persons with Disabilities Act, 2024 (Malawi, Act No. 4 of 2024). Replaces the Disability Act of 2012. The Act prohibits discrimination against persons with disabilities, guarantees reasonable accommodation, strengthens employment protections, enhances inclusion in social protection programmes, and further consolidates the Disability Trust Fund. It mandates MACODA to ensure people with disabilities are incorporated into national programmes.
PEPUDA	Promotion of Equality and Prevention of Unfair Discrimination Act (South Africa, Act 4 of 2000).
POPIA	Protection of Personal Information Act (South Africa) — governs how personal data, including health and disability data, must be stored and used.
Proxy respondent	A person who answers survey questions on behalf of someone else. Use with caution — proxy data may not reflect the participant's own views.
Social model of disability	The view that disability results from barriers in the environment and society, not from the individual's impairment.
Washington Group Short Set (WG-SS)	A set of six survey questions developed to identify disability for data disaggregation purposes.

Introduction

People with disabilities are among the most under-researched groups in Southern Africa. When they do appear in research, they are often treated as subjects rather than participants. This handbook changes that.

Disability-inclusive research is not a separate discipline. It is a standard of quality. Any study that excludes or misrepresents people with disabilities produces incomplete findings and reinforces inequality.

This handbook gives practical, field-tested guidance for researchers working across Southern Africa. It covers study design, ethics, data collection methods, and specific guidance for six disability categories. It is grounded in the United Nations Convention on the Rights of Persons with Disabilities (CRPD) and aligned with South Africa's Promotion of Equality and Prevention of Unfair Discrimination Act (Act 4 of 2000).

Core principles underpinning this handbook

- **Nothing about us without us** — involve people with disabilities at every stage.
- **Respect over charity** — approach participants as rights holders, not recipients.
- **Access is a right, not a favour** — make participation possible by removing barriers.
- **Diversity within disability** — disability is not one experience; it varies widely.
- **Informed consent is non-negotiable** — obtain it in a format the person can understand.

The CRPD and Your Research Obligations

The CRPD (2006) requires that people with disabilities participate fully and equally in public life. Article 31 specifically calls for disaggregated data collection on disability. As a researcher, you are part of that obligation.

CRPD Article	What it means for your research
Article 3 — General Principles	Base your study on respect for dignity, autonomy, and non-discrimination.
Article 9 — Accessibility	Remove physical, communication, and information barriers to participation.
Article 22 — Privacy	Protect disability-related data with the same care as any sensitive information.
Article 31 — Statistics and Data	Collect and disaggregate data by disability type, sex, and age.

Understanding Disability: The Social Model

This handbook uses the social model of disability. Under this model, disability is not a personal problem. It is the result of barriers in the environment and in social structures. A researcher's job is to remove those barriers.

Medical model (avoid this framing)	Social model (use this framing)
A person cannot walk and cannot participate.	Inaccessible venues prevent participation.
A person is deaf and cannot answer questions.	The interview lacks a sign language interpreter.
A person has an intellectual disability and does not understand the questionnaire.	The questionnaire uses language that is too complex.
The participant is a burden to the process.	The process has not been designed for the participant.

Part One: Designing an Inclusive Study

1.1 Deciding Whether and How to Include Disability

Before you begin, ask three questions:

1. Is disability relevant to my research question?
2. Will my sample include or intentionally exclude people with disabilities?
3. What barriers might prevent people with disabilities from participating?

If disability is relevant to your question, plan for it explicitly. If your study is not specifically about disability, you still need to ensure that people with disabilities can participate if they are part of your target population.

Key definition: The Washington Group Short Set of Questions on Disability (WG-SS) is the most widely used tool for identifying disability in surveys. It asks about six domains: seeing, hearing, walking, cognition, self-care, and communication. Use it to disaggregate data.

1.2 Sampling

Most standard sampling methods under-represent people with disabilities. Correct for this intentionally.



Strategies to improve representation

- Partner with Organisations of Persons with Disabilities (OPDs) for participant referrals.

- Use community-based sampling rather than facility-based sampling, which may exclude those who cannot access services.
- Set a disability quota only if it is justified by your research objectives.
- Record refusals and inaccessibility reasons — this data reveals systemic barriers.
- Do not assume household members with disabilities are unavailable.

1.3 Involving People with Disabilities in Research Design

Meaningful involvement goes beyond consultation. At minimum, share your draft tools with at least one person with a disability before piloting. Where possible, engage OPDs in the design phase.

Stage	How to involve people with disabilities
Problem framing	Check that the research question reflects priorities people with disabilities identify.
Tool design	Test draft tools with people from each disability category you plan to include.
Fieldwork	Train researchers with lived experience of disability alongside other field staff.
Analysis	Share preliminary findings with participants or community representatives.
Dissemination	Ensure accessible formats (plain language, audio, large print) for outputs.

1.4 Ethics and Consent

Standard research ethics protocols must be adapted for disability-inclusive research. The core requirements remain the same — voluntary participation, informed consent, confidentiality, and the right to withdraw — but the way you fulfil them must account for different communication needs.



Providing information accessibly

- Use plain language — aim for a reading level that does not require more than six years of schooling.
- Offer the information sheet in multiple formats: print, audio recording, and large print.
- For participants with visual impairments, read the full consent form aloud.
- For participants who are Deaf, provide a signed version or a sign language interpreter.
- For participants with intellectual disabilities, use easy-read formats with images.

Confirming understanding

Asking "Do you understand?" is not sufficient. Use teach-back: ask the participant to explain in their own words what will happen, how their information will be used, and that they can stop at any time.

Documenting consent

- Written signature is not always possible. Accept thumb prints, audio-recorded verbal consent, or witness confirmation as alternatives.
- Where a participant has a legal guardian, obtain consent from both the guardian and, where possible, the participant.
- Keep consent records separate from data files.

Ethics alert: Do not assume incapacity. Most people with disabilities can consent to participate in research. Legal guardianship does not mean a person cannot express preferences or provide assent. Always seek the participant's own agreement first.

1.5 Questionnaire and Tool Design

A well-designed tool reduces participant burden and produces better data. The following principles apply to all tools, but are especially important when participants may have cognitive, literacy, or communication differences.

Design principle	Practical application
Short questions	Keep each question to one idea. Avoid compound questions (e.g. "Did you eat and sleep well?").
Plain language	Use words that are common in everyday speech. Avoid technical or legal terms unless you define them.
Positive framing	Avoid questions that assume limitation (e.g. "Because of your disability, are you unable to...").
Response scale clarity	Explain scales verbally and visually. Show the scale in large print if needed.
Skip logic	Map skip logic carefully so enumerators do not inadvertently skip relevant questions for participants with disabilities.
Time allowance	Allow more time per interview. Do not rush. Build extra time into your fieldwork schedule.

Sample WG-SS question: Do you have difficulty seeing, even when wearing glasses? [No difficulty / Some difficulty / A lot of difficulty / Cannot do at all]

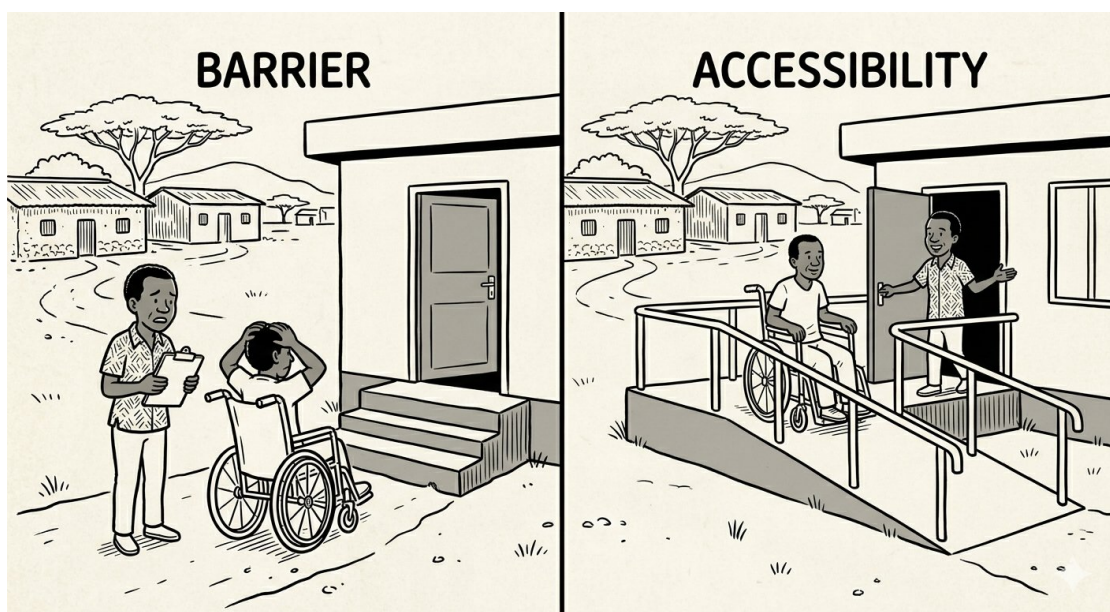
Administer the WG-SS at the start of the interview so you can adapt your method if needed.

Part Two: Fieldwork Guidance by Disability Category

The six categories below are broad groupings. Within each category, experience varies widely. Ask each participant how they prefer to communicate and what support, if any, they need. Do not assume.

2.1 Physical Disabilities

Physical disabilities affect mobility, coordination, and physical functioning. This category includes spinal cord injuries, limb differences, cerebral palsy affecting movement, chronic pain conditions, and other musculoskeletal conditions.



Venue and access

- Confirm wheelchair access before booking any venue: ramps or level entry, accessible toilet, enough space to manoeuvre between seats.
- Check that the surface is firm and level. Gravel, uneven ground, and steep slopes are barriers.
- Home visits may be preferable for participants with severe mobility limitations. Confirm with the participant in advance.
- Do not move a participant's wheelchair, crutches, or other mobility aids without permission.

Interview and data collection

- Ensure seating is at a level where the participant and researcher can make eye contact comfortably.
- Allow more time — fatigue and pain are common among participants with physical disabilities.
- If a participant uses a communication device or types responses, allow adequate time and do not complete sentences for them.

- For self-administered questionnaires, offer a physical support or clipboard if the participant cannot hold the form.

Fieldworker reminder: Ask before helping. Offering help is respectful; assuming it is needed is not. Say: "Is there anything that would make this easier for you?"

2.2 Visual Impairments

Visual impairments range from partial sight to total blindness. Do not assume that glasses correct the issue fully. Confirm at the start of the interview what the participant can and cannot see.



Preparation

- Prepare a large-print version of your consent form and questionnaire (minimum 18-point font).
- Prepare an audio version of key documents where possible.
- Train field staff to read all text clearly and without paraphrasing.

Interview and data collection

- Introduce yourself by name at the start of every interaction: "Hello, I'm [name], a researcher from Zonge Research International."
- Describe the environment briefly at the start: "We are sitting in a quiet room. There is one other person present, a note-taker."
- Do not use visual prompts without a verbal equivalent.
- Read every question and all response options aloud, clearly and at a measured pace.
- Never leave a participant alone without saying so: "I'm stepping away briefly to get some water."
- For focus groups, use verbal turn-taking cues rather than pointing.

Consent note: For participants who cannot read, read the full consent information sheet aloud before beginning. Confirm understanding using the teach-back method. Record verbal consent with witness confirmation.

2.3 Deaf and Hard of Hearing Participants

Deafness and hearing loss exist on a spectrum. Many members of the Deaf community use sign language as their first language and do not identify as disabled — be respectful of this identity.



Preparing for the interview

- Engage a qualified sign language interpreter where the participant uses sign language as their primary communication method.
- Brief the interpreter before the session: explain the research topic, key terms, and the importance of accuracy over paraphrase.
- Ensure the interpreter is positioned so the participant can see both the researcher and the interpreter without turning.
- Prepare written versions of key questions and consent information as a backup.

During the interview

- Speak to the participant, not the interpreter. Maintain eye contact with the participant.
- Allow extra time — signed communication takes longer to render in a second language.
- Sit in good light so the participant can see lip movements and facial expressions.
- Do not cover your mouth when speaking.
- Repeat or rephrase — do not just speak louder — if a participant does not understand.
- For focus groups, seat participants in a semicircle so everyone can see each other.

Interpreter ethics: The interpreter must not add opinions, summarise, or explain. Instruct them to translate everything said — including side comments. Provide them with a copy of the data protection agreement to sign.

2.4 Speech and Communication Impairments

Speech impairments include stuttering, aphasia (often following stroke or brain injury), dysarthria, and selective mutism. Some participants use AAC devices, communication boards, or speech-generating apps.

Before the interview

- Ask the participant or a support person in advance how the participant prefers to communicate.
- If the participant uses an AAC device, ask if the device has the vocabulary needed for your research topic.
- Allow significantly more time than a standard interview.

During the interview

- Do not complete sentences or words for the participant, even if you think you know what they mean.
- Give the participant time. Silence is not a sign of inability.
- Ask closed (yes/no) questions if open questions create communication difficulty, but offer open questions first.
- Confirm meaning by reflecting back: "I think I heard you say X — is that right?"
- If written response is easier, offer pen and paper or a device to type on.

Common error to avoid: Speech difficulty does not mean cognitive difficulty. A participant with aphasia may have full cognitive capacity and may feel patronised by simplified language. Follow their lead.

2.5 Psychosocial Disabilities

Psychosocial disabilities relate to mental health conditions — including depression, anxiety, schizophrenia, bipolar disorder, and PTSD. These conditions are often invisible. Participants may not disclose them, or may not identify as having a disability at all.



Study design considerations

- Review your topic for potential triggers. Studies on trauma, violence, poverty, and family breakdown carry a higher risk of distress.
- Prepare a referral list of mental health support services in the study area. Share it with all participants.
- Build a debriefing step into the interview close.

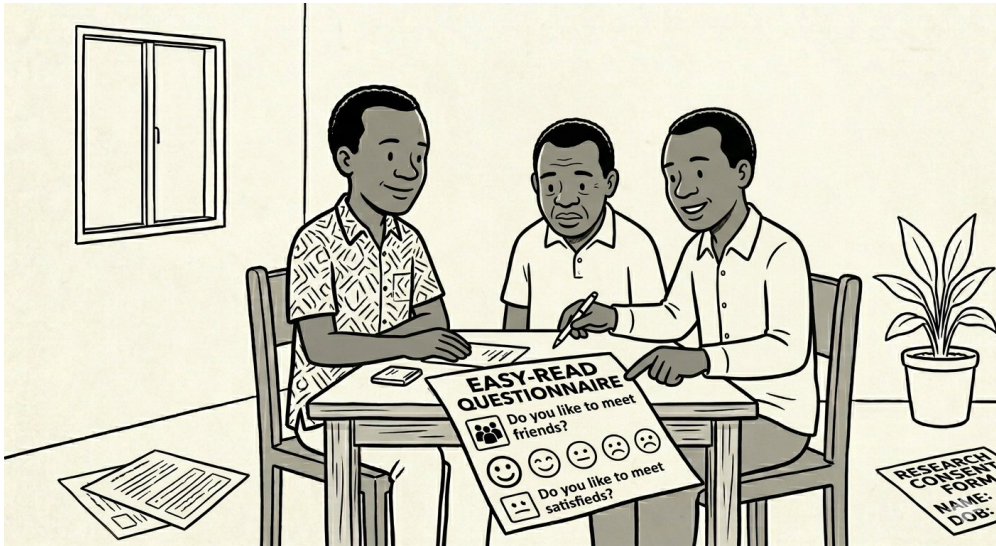
During the interview

- Watch for signs of distress: agitation, tearfulness, withdrawal, or confusion. Pause and check in.
- Use the STOP protocol if a participant becomes distressed: Stop the interview. Tell them it's okay to pause. Offer water and a moment. Provide the referral list. Resume only when they are settled.
- Do not probe or push for more detail than the participant offers.
- Avoid clinical or diagnostic language: ask about "experiences" rather than "symptoms" or "episodes".
- Keep the environment calm: reduce background noise, limit bystanders, use a private space.

Confidentiality reminder: Explain confidentiality clearly: "What you tell me will not be shared with your employer, your family, or any government office."

2.6 Intellectual Disabilities

Intellectual disabilities affect cognitive functioning and adaptive behaviour. They include a wide range of experiences. Do not assume the extent of a person's understanding from their appearance or diagnosis.



Tool adaptation

- Use easy-read format: short sentences, one idea per sentence, common words, and supporting images where possible.
- Test your easy-read tools with people with intellectual disabilities before fieldwork begins.
- Reduce the number of response options. Use three-point scales rather than five-point scales where possible.
- Avoid hypothetical questions — they are harder to process than questions about actual experience.

During the interview

- Speak at a moderate pace. Do not rush.
- Use clear, simple sentences. Pause between questions.
- Repeat questions using different words if the participant does not respond, rather than repeating the same phrasing.
- Watch for acquiescence bias: use multiple question formats to check consistency.
- Include open-ended questions: "Tell me about..." can reveal more than closed yes/no questions.

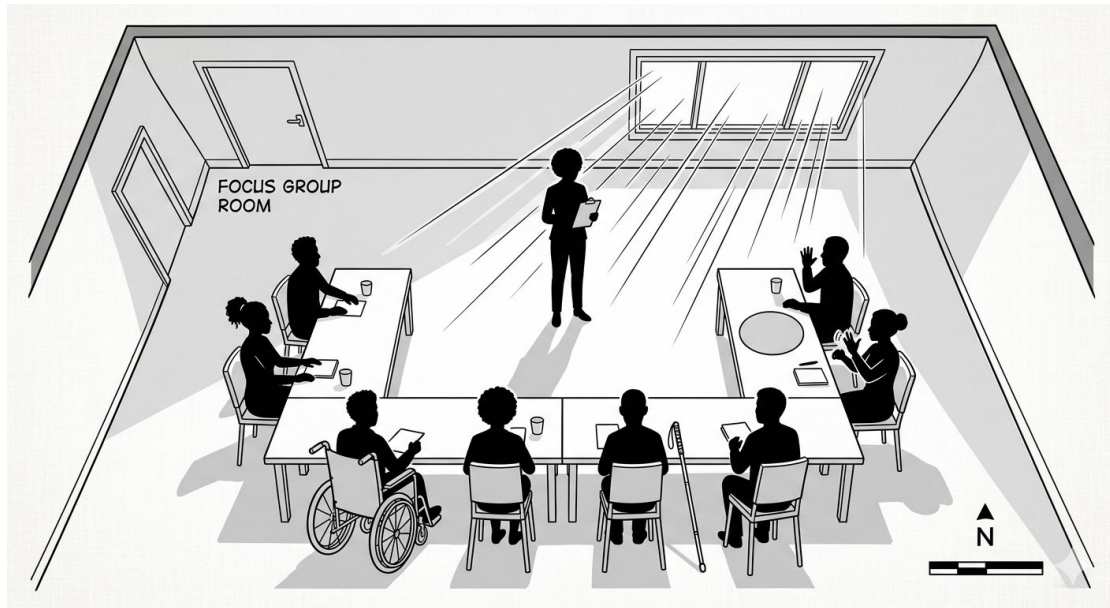
Consent and support persons

- Where a parent or carer is present, direct your questions to the participant, not the support person.
- Obtain both the participant's assent and the carer or guardian's formal consent.
- If the support person answers on behalf of the participant without the participant's input, note this in your data.

Quality check: After the interview, note in your field log whether the participant appeared to understand the questions, whether support was needed, and any concerns about data quality.

Part Three: Disability-Inclusive Focus Groups

Focus groups present specific challenges for disability inclusion. They rely on verbal interaction in a group setting, which can disadvantage participants with hearing, speech, or cognitive differences. With preparation, these barriers can be reduced significantly.



3.1 Group Composition

- Avoid mixing disability types without planning for this in advance. A group with both Deaf (signed) and hearing participants requires simultaneous interpretation.
- Disability-specific groups can produce richer discussion, but may limit the range of perspectives.
- Mixed groups can work well when the topic is not disability-specific and all participants can communicate in the same medium.
- Keep groups small: six to eight participants maximum in disability-inclusive settings.

3.2 Venue and Setup

- Arrive early and check the space. Remove physical obstructions. Confirm that chairs are moveable.
- Arrange seating in a circle or U-shape so all participants can see each other.
- Ensure good lighting, particularly for participants who lip-read or use sign language.
- Minimise background noise: turn off fans or air conditioning that hum loudly.
- Identify the accessible toilet and brief all participants on its location at the start.

3.3 Facilitation Techniques

Situation	Adapted technique
Deaf or hard of hearing participants	Use sign language interpreters. Speak one at a time. Use a talking stick or card system to manage turn-taking.
Participants with speech impairments	Allow more time per speaker. Use written contributions for complex points.
Participants with visual impairments	Describe all visual stimuli verbally. Use names rather than pronouns when referring to other participants.
Participants with psychosocial disabilities	Keep the environment calm. Have a co-facilitator available to support anyone who becomes distressed.
Participants with intellectual disabilities	Use simple prompts. Break complex questions into parts. Acknowledge all contributions without judgement.
Mixed groups	State group norms at the start: one person speaks at a time, no completing others' sentences, all contributions are valued.

3.4 Recording and Note-Taking

- Always obtain explicit consent for audio or video recording from all participants.
- If consent to record is refused, assign a dedicated note-taker.
- For groups with sign language users, video recording is essential to capture signed contributions.
- During transcription, note the disability category of speakers only if it is relevant to analysis and participants have consented.

Part Four: Data Management and Analysis

4.1 Disaggregating Data by Disability

Disaggregated data allows you to identify differences in outcomes, experiences, and needs between people with different disability types, and between people with and without disabilities.

Minimum disaggregation variables

- Disability status (yes / no / not stated).
- Disability type (using the six WG-SS domains as a starting point).
- Sex (male / female / non-binary / prefer not to state).
- Age group (at minimum: under 18, 18–34, 35–59, 60+).
- Location (urban / rural / peri-urban).

4.2 Handling Sensitive Data

- Disability status is sensitive personal data. Treat it with the same care as health, financial, or identity data.
- Store disability-related data separately from identifying information such as names and contact details.
- Apply anonymisation before sharing data with any third party.
- Follow your institution's data protection policy and national law. In South Africa, this means compliance with POPIA.

4.3 Reflexivity and Bias in Analysis

Disability data is vulnerable to several forms of bias. Note these in your methods section.

Bias type	How to manage it
Acquiescence bias	Cross-check yes/no responses with open-ended questions. Note where interview support was used.
Proxy bias	Flag data collected via a carer or family member rather than the participant directly. Analyse separately or with caution.
Selection bias	Note which people were unable to participate and why. Report this as a limitation.
Interviewer influence	Train researchers to avoid leading questions and to follow the script consistently.

Part Five: Checklists

Pre-Fieldwork Checklist



- Research question reviewed for disability relevance.
- Washington Group Short Set included in the survey.
- Tools tested with at least one person per disability category.
- Easy-read and large-print versions of tools prepared.
- Audio version of consent form prepared.
- Sign language interpreter engaged if needed.
- Accessible venue confirmed: ramps, toilets, seating.
- Referral list for psychosocial support prepared.
- All field staff trained on disability etiquette.
- Data protection procedures reviewed with the full team.

Interview Checklist

- Greeted the participant and confirmed their name.
- Introduced all people present in the room.
- Read or provided the information sheet in the participant's preferred format.
- Completed teach-back to confirm understanding of consent.
- Confirmed consent and documented it appropriately.
- Asked: "Is there anything that would help you take part today?"

- Completed WG-SS at the start of the interview.
- Adapted the interview method based on WG-SS responses.
- Allowed the participant to set the pace.
- Closed with debriefing and provided referral list.
- Completed a field log note after the interview.

Focus Group Checklist

- Venue checked for accessibility at least 24 hours in advance.
- Seating arranged in a circle or U-shape.
- Lighting confirmed for lip-reading and signing.
- Background noise minimised.
- Interpreters briefed and in position.
- Group composition reviewed for communication compatibility.
- Accessible toilets identified and communicated to participants.
- Recording consent obtained from all participants.
- Note-taker briefed and in place.
- Facilitator reviewed adapted facilitation techniques for group composition.
- Debriefing time built into the session plan.

Part Six: Legal and Policy Framework

6.1 The UN Convention on the Rights of Persons with Disabilities (CRPD)

The CRPD was adopted in 2006 and ratified by South Africa in 2007. It is the primary international human rights instrument for disability. Key principles include respect for inherent dignity, non-discrimination, full participation, and equality of opportunity.

For researchers, the CRPD establishes that research involving people with disabilities must: be conducted with their participation, not merely about them; protect their rights to privacy and confidentiality; contribute to evidence that advances their rights; and disaggregate data to make disability visible in findings.

6.2 South Africa: Promotion of Equality and Prevention of Unfair Discrimination Act (Act 4 of 2000)

PEPUDA prohibits unfair discrimination on the grounds of disability. In a research context, this means that research design, participation requirements, and data collection methods must not place people with disabilities at an unfair disadvantage.

Prohibited practice	Compliant alternative
Excluding disabled participants because access is "too complex".	Invest in access: interpreter fees, accessible venues, and adapted tools are legitimate research costs.
Collecting data only via written questionnaire.	Offer verbal, visual, and signed alternatives.
Publishing findings that misrepresent disability as inherently negative.	Frame disability within a rights and capability perspective.
Failing to obtain informed consent due to assumed incapacity.	Use supported decision-making and accessible consent procedures.

6.3 Other Relevant Frameworks

- **Persons with Disabilities Act, 2024 (PDA 2024) — Malawi** — Act No. 4 of 2024. Replaces the Disability Act of 2012. Prohibits discrimination against persons with disabilities, guarantees reasonable accommodation, strengthens employment protections, enhances inclusion in social protection programmes, and mandates MACODA to ensure people with disabilities are incorporated into national programmes. It also consolidates the Disability Trust Fund.
- **Zimbabwe Disabled Persons Act (1992, amended)** — requires accommodation and equal access for people with disabilities.

- **Zambia Persons with Disabilities Act (2012)** — affirms the right to participate in all aspects of civic life, including research.
- **ILO Convention 159 on Vocational Rehabilitation and Employment** — relevant for labour market research involving persons with disabilities.
- **SADC Protocol on Gender and Development** — includes disability as a dimension of inclusion in regional development research.

About Zonge Research International

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Zonge Research International is a social research and advisory firm registered in South Africa with operations across Malawi, Zimbabwe, Zambia, Mozambique, and South Africa. Our core thematic areas include disability inclusion, labour markets, disaster risk reduction, climate change, migration, and digital inclusion.

We work with governments, international organisations, NGOs, and academic partners to produce research that advances the rights and wellbeing of marginalised communities across Southern Africa.

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