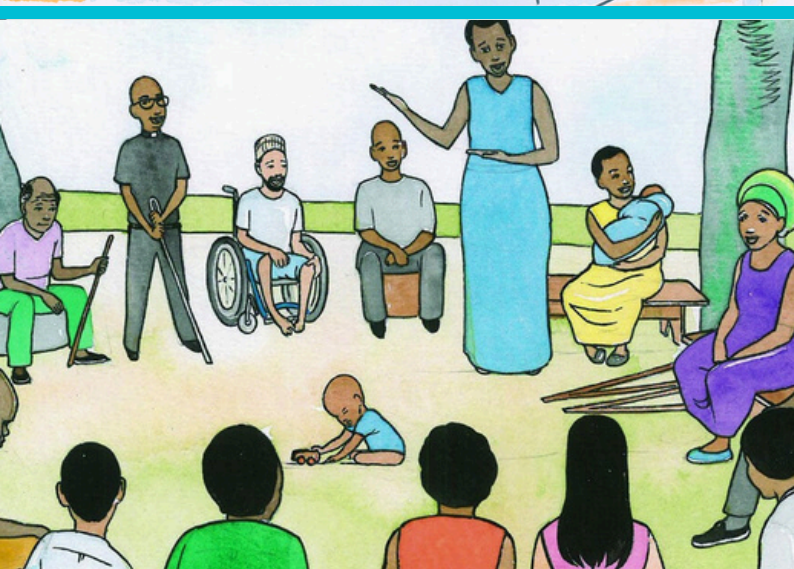


Fact Sheet



Disability Inclusive Health Research



Why Disability Inclusive Health Research?

Globally, 1.3 billion people (16%) experience significant disability. Despite the UN Convention on the Rights of Persons with Disabilities (CRPD) and the Sustainable Development Goals (SDGs) to “leave no one behind”, most people with disabilities continue to face barriers to health care, education, employment, and full participation in society. In addition, many research studies still fail to meaningfully include persons with disabilities. To generate solutions that are ethical, inclusive, and relevant, researchers need practical knowledge and skills to engage persons with disabilities.

What is Disability Inclusive Research?

- Research that intentionally includes persons with disabilities in all stages of research as study participants, co-researchers, and decision-makers.
- Follows the principle of “Nothing About Us Without Us”, ensuring accessibility, participation, and representation of persons with disabilities throughout the research process, from design and data collection to analysis and dissemination.
- Uses co-development, designing research tools, methods, and programs together with persons with disabilities and their representative organizations.
- Recognizes that persons with disabilities are not only subjects of research but experts in their own lived experiences and are critical partners in generating solutions.



Principles of Disability Inclusive Research

- **Participation and empowerment:** persons with disabilities are involved as researchers, advisors, and participants.
- **Accessibility:** research methods, tools, venues, and materials are accessible to all.
- **Respect for diversity:** includes physical, hearing, visual, cognitive, psychosocial and multiple disabilities.
- **Co-development:** researchers and persons with disabilities collaborate in designing and conducting studies.
- **Collaboration:** partnerships with organizations of persons with disabilities and other stakeholders in disability research are prioritized.
- Recognizes that disability **intersects** with gender, age, poverty, and culture.

The Disability Research Group (DRG)

The [Disability Research Group](#) (DRG) at the MRC/UVRI & LSHTM Uganda Research Unit conducts research to improve the health, development, and quality of life of persons with disabilities in East Africa.

The DRG's objectives are to:

- Conduct implementation research to improve the health and well-being of persons with disabilities.
- Build capacity and create an East African Disability Research Centre, led and co-developed with researchers with disabilities.
- Promote equity, diversity, and inclusion in research, education, and employment.





Partnerships

Disability-inclusive research requires strong partnerships with persons with disabilities, OPDs, researchers, and policymakers. The DRG has active collaborations with:

- **Academic partners:** [International Centre for Evidence in Disability](#) at the London School of Hygiene & Tropical Medicine, Makerere University, Kyambogo University, University of Rwanda, Nairobi University, Stellenbosch University, and Ghent University.
- **Organizations of Persons with Disabilities:** Uganda National Association of the Blind (UNAB), Uganda National Association of the Deaf (UNAD), Uganda National Action on Physical Disability (UNAPD), National Union of Disabled Persons of Uganda (NUDIPU), Spina Bifida and Hydrocephalus Association of Uganda (SHA-U).
- **Government and policy bodies:** National Council for Persons with Disabilities, Ministry of Health, Ministry of Gender, Labour and Social Development, Ministry of Education and Sports.
- **Civil society and service partners:** AMREF Health Africa, AVSI Foundation, CoRSU hospital, CURE Hospital, Katalemwa Cheshire Home, Light for the World, Neurokids, Our Useful Rehabilitation Services, Raising Voices, SURE Prospect Primary School, Kyanninga Child Development Centre, Adara Development, Born on the Edge, Child and Family Uganda, COMBRA, Humanity and Inclusion in Uganda, Imprint Hope.

Ongoing and Recent Research Projects

- **Disability Inclusive Youth (DIY):** co-creative study to enhance inclusion of children and youth with disabilities in health research in East Africa.
- **The Missing Billion:** intervention trial to improve access to health care for persons with disabilities through community groups and capacity building of healthcare workers.
- **Obuntu bulamu:** peer-to-peer support intervention to improve inclusion of children with disabilities in primary schools.
- **Navigating Violence, Gender and Disability:** longitudinal study on experiences and prevention of violence among children and youth with disabilities.
- **Improving Continence Management for Children with Spina Bifida:** co-developing an intervention model to improve the implementation of kidney-saving and continence management services for children with spina bifida in Uganda.
- **The PENDA Internship Programme:** promoting learning and employment opportunities for persons with disabilities in research.
- **Young Africa Works:** a disability inclusive research collaboration documenting the education and employment experiences of youth with disabilities in Ghana, Ethiopia, Kenya, Nigeria, Rwanda, Senegal and Uganda.
- **The PAIN feasibility study:** use of virtual reality glasses to reduce child pain and fear during painful medical procedures in children with physical disabilities at CoRSU hospital in Uganda.

Explore these research projects on [our website](#).



Practical Steps for Researchers

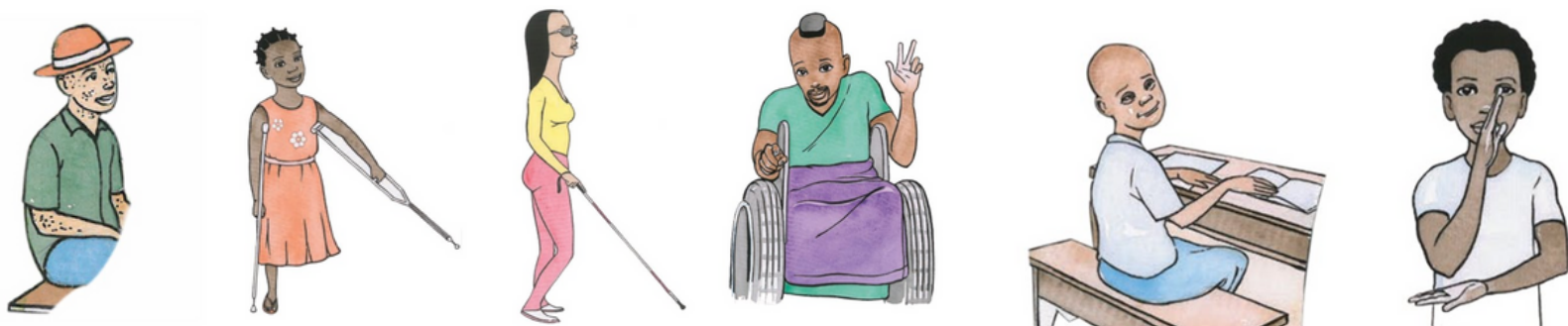
- **Study design:** involve persons with disabilities and their representative organizations as co-researchers or advisors from the start and throughout the research process: in the design, development of tools, generating the data, validating findings, and discussing how data are presented. For example, the Missing Billion project co-designed a healthcare worker training manual, and in the DIY study, young persons with disabilities collect and analyze data with health researchers.
- **Inclusive recruitment and participation:** actively recruit and include persons with disabilities as research assistants, enumerators, advisory members, and co-researchers, and engage Organizations of Persons with Disabilities (OPDs) to identify participants with disabilities. The DRG's dedicated advisory groups of OPD representatives and young persons with disabilities support our research teams in making studies disability-inclusive.
- **Sensitization and training:** train research teams on disability rights, etiquette, and inclusion practices. Use person-first language and disability rights wording rather than deficit language. The DRG provides sign language classes to all MRC/UVRI & LSHTM Unit staff and facilitates disability inclusive health research trainings.
- **Ethics:** promote a culture of respect, confidentiality, and equal participation.
 - Adopt ethical approaches that address autonomy, dignity, and protection from exploitation or misrepresentation beyond just consenting. In the PAIN study, the DRG explored ways to reduce fear and pain among children with disabilities during medical procedures, considering ethical consenting and assenting processes.



- Ensure information sheets and consent forms are accessible and participation is voluntary. [The DRG prints all documents in braille, large print and easy-read formats.](#)
- Acknowledge participants' expertise through fair compensation, recognition in outputs, or co-authorship when appropriate. [For example, the DIY youth researchers were paid for their work, have co-authored papers, and presented study findings at conferences.](#)
- Consider compensation for time and transport of personal aids and sign language interpreters. [Some DRG staff have personal assistants who are compensated.](#)
- Provide referral to disability specific and general health services for participants. [For example, the CIC, Baby Ubuntu, Navigendi and Obuntu Bulamu study partners provide specialized health services and assistive technology for children with disabilities, as well as counselling services for study participants and staff.](#)

• Accessibility

- Use [Universal Design](#) in all office and research spaces, and the design of study materials. [The MRC/UVRI & LSHTM Uganda Research Unit has made the DRG office accessible and offers meeting rooms which are accessible for staff and study participants with disabilities.](#)
- Provide tools such as screen readers, magnification software, and speech-to-text applications, as well as flexible working hours for staff with mobility difficulties. [For example, the PENDA internship programme provides assistive technology and flexible working hours for interns.](#)
- Choose venues that have ramps, elevators, and accessible toilets for persons with physical disabilities and braille and tactile signposting for persons with visual impairments, and a quiet space for persons with cognitive or psychosocial impairments.
- Ensure sitting arrangements accommodate people using wheelchairs or mobility aids.



- Check that lighting and acoustics support people with low vision or hearing impairments.
- Provide sign language interpreters (SLI) and/or real-time captioning at events. [At the DRG, we have SLI on staff and hire additional SLI for events.](#)
- Offer assistive listening devices or use amplification for clear communication.
- Make sure virtual participation options, such as Zoom meetings, have automatic captioning.
- Ensure all communication materials, including invitations, presentations, feedback forms, are available in accessible formats such as braille, large print, or easy-to-read versions, as well as accessible PDF versions. Guidance on accessible formatting can be found on the [LSHTM website](#).

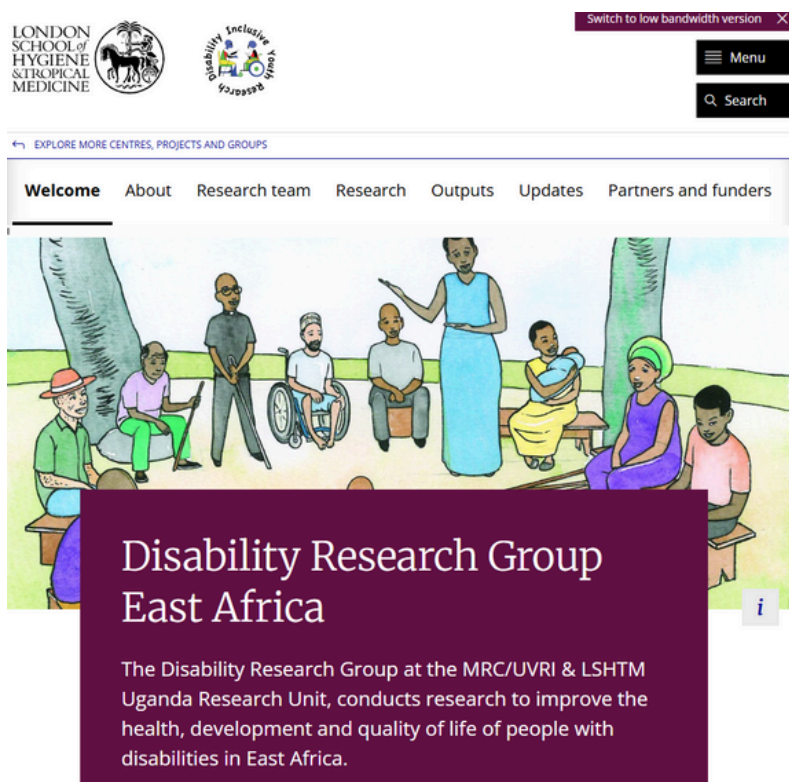
• Disability data

- Engage OPDs in designing data tools and interpreting findings to ensure accuracy and context relevance. [At the DRG, we consult our advisory group consisting of OPD representatives, government, civil society and other key stakeholders throughout the research process.](#)
- Collect disability-disaggregated data and analyse how disability interacts with gender, age, and socio-economic factors, using recognized tools such as the Washington Group Short Set of Questions (WG-SS) or the [Washington Group/UNICEF Child Functioning Module](#) to identify persons with disabilities. [The DRG includes the WG-SS in all studies. The Unit's General Population Cohort has also included the WG-SS.](#)
- Train data collectors on disability sensitivity and how to ask WG questions respectfully. [The DRG offers training for organisations interested in using the WG questions and other research-related disability inclusion training.](#)
- Use inclusive data collection methods (e.g., accessible questionnaires, sign language interpreters, or easy-to-read formats). [The DRG promotes the use of participatory and mixed-methods research; for example, surveys, interviews, observations, transect walks, photo voice, participatory film, drawing, and participatory workshops.](#)



- Store data securely and protect identities, especially for participants with psychosocial or intellectual disabilities.
- During analysis, cross-tabulate data to explore how disability intersects with gender, age, education, and income levels, as well as any other variables of interest to the study. [In the Navigendi study, the DRG specifically looks at intersections between factors such as gender, violence, and disability.](#)
- **Inclusive dissemination:** share findings in accessible formats (community feedback meetings, braille summaries, or radio talk shows in local languages), and involve organisations of persons with disabilities in the dissemination. Various examples of participatory film and photo voice projects of the [Baby Ubuntu](#), [Obuntu Bulamu](#), [Young Africa Works](#) and DIY studies can be found on the [DRG website](#).

Further Information



Learn more on the [Disability Research Group](#) website.



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