

Seminar 4:



The ethics of neurodevelopmental disorders research

9 November 1pm-2.30pm (London/GMT)

The three presentations in this seminar explore ethical issues in the study design and engagement of participants with neurodevelopmental disorders and their families in research to inform service development and delivery in low- and middle-income public health and community settings.

Chair: Sharon Kleintjes, University of Cape Town, South Africa

Panel and presentations:

- **Ruth Tsigebrhan**, Addis Ababa University, Ethiopia
'Exclusion criteria versus ethical principle of justice in conducting research in a low-income setting'
- **Ashok Mysore Visweswariah**, St. John's Medical College Hospital, India
'The spectrum of challenges in conducting research for the early identification of autism spectrum disorders'
- **Zsófia Szlamka**, King's College London, UK
'Who has the right to empower? The case of caregivers of children with neurodevelopmental disorders'

The following questions will form the basis of the panel discussion. Seminar attendees are invited to submit questions when they [register](#) or by [email](#), or during the live discussion.

1. **How can we apply equitable distribution of research benefits to adults with NDDs in a low-income setting?** For example, in equal selection of participants, equal investigation of the health care needs or the outcomes of treatment of adult people with NDDs without unnecessary burden or abuse.
2. **How can we improve ethical engagement and participation of families and communities in NDD research?** Research design and resourcing needs to support participant understanding of and engagement in research in community settings, particularly when research findings have implications for clinical care.
3. **Who should decide on empowerment outcomes, and what is best for those to be empowered in NDD research?** Experts may define this within the realms of their profession, while caregivers may feel knowledgeable about NDDs by experience. Contextual issues may also influence caregiver views on empowerment. When such different perspectives exist, whose knowledge and experience is taken as the baseline for empowerment through research?

This is the fourth of five seminars on the theme 'Ethical issues arising in research with people with mental health conditions'. Details of the full series are available at: www.gfbr.global/gfbr-2021-seminar-series