

Ethical issues arising in research with people with mental health conditions

Seminar series 2021



Case study: Who has the right to empower? The case of caregivers of children with neurodevelopmental disorders

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Description of the research project

When I started my PhD project, I was then planning to study caregiver interventions for neurodevelopmental disorders (NDDs) in Ethiopia. My project was supposed to be technical: about cross-cultural and cross-contextual issues in intervention adaptations and implementations. My first study (Study 1) was indeed looking at these questions from a global perspective through the lens of the World Health Organization's Caregiver Skills Training. In the pilot stage of this exploratory and qualitative work questions around service development and caregiver empowerment came up. I decided to change my focus and investigate empowerment more in depth, using a multiple case study approach. I conducted two case studies, one in Ethiopia (Study 2) and another in Argentina (Study 3), focusing on perspectives of empowerment and service development for families with NDDs across contexts and income settings. In this case study I will be focusing on Study 1 and 2.

Background

Caregivers of children with NDDs often advocate for health, social, and financial support and the rights of their child (Boshoff et al., 2016). Empowerment of persons with disabilities and their families has been identified by the World Health Organization (WHO) as one of the key elements of community-based rehabilitation (World Health Organization, 2010). Different approaches exist to empowerment, including community-based empowerment highlighting societal power imbalances (Spreitzer, 2008); and economic empowerment targeting the economic well-being of individuals and communities (Jiménez-Solomon et al., 2016). Finally, psychological empowerment focuses on the skills and resources of an individual, including advocacy skills (Cattaneo & Chapman, 2010).

Engaging in advocacy is described to be shaped by caregivers' access to cultural and social capital and resources (Trainor, 2010). Caregivers often rely heavily on their educational and professional background to advocate and to access services (Taylor et al., 2019). Barriers to being an advocate also include cultural differences between health providers and caregivers (Boshoff et al., 2016), or caregivers feeling uncomfortable to speak up publicly (Jegatheesan et al., 2010). The socio-economic status of caregivers can pose further limitations in advocating for their children because of work schedules, financial resources and understanding of their children's rights (Lalvani, 2012).

Study 1 was an explorative, phenomenological study we investigated the meanings of empowerment; stakeholder perceptions on the role that advocacy and empowerment play in service development; and the use of evidence for advocacy and empowerment in relation to service development for families of children with NDDs. The study questions were applied to the WHO's Caregiver Skills Training. Twenty-five semi-structured individual interviews were conducted in English or in Spanish with clinicians, researchers, caregivers of children with a NDD, and representatives of WHO or Autism Speaks. Three key themes were developed: meanings of empowerment, advocacy for services, and caregivers as active stakeholders in services. Many participants defined empowerment as a journey, within the realms of their profession: as having

skills to improve the child's symptoms or as economic empowerment for example. However, caregiver participants expressed that an expert-oriented view on empowerment fails to acknowledge what caregivers think they need and how they define empowerment. They argued that caregivers do indeed have an intuitive knowledge regarding NDDs. Other participants thought that empowerment is a set of milestones in which both caregivers and professionals take part. This understanding of empowerment can bridge the gap between experts' and caregivers' perspectives as it defines empowerment as a journey, as a process. Caregiver participants thought that there is a gap between rights of families having a member with a NDD and services and professionals available and added that one of the goals of empowerment is to overcome this gap.

Based on the results of this study, we further investigated the role of empowerment in service development for families with NDDs in a case study in Ethiopia. 63 semi-structured qualitative interviews were conducted in Amharic or English with caregivers of children with NDD; community health extension workers; representatives of non-governmental organisations working with families and children with NDDs; researchers and representatives of local health, education, and social care authorities. Four main themes were developed: the experiences and challenges of mothers; how people think about NDDs and the state of inclusion; empowerment, inclusion, and advocacy to drive service development; power in the context of research in Ethiopia; and building an infrastructure meeting the needs of families with NDDs.

Ethical issues

The first overarching dilemma across Study 1 and 2 is about the question as to who has the right and the social capital to initiate the empowerment of someone else; who can decide on empowerment outcomes, and what is best for those to be empowered. Empowerment, in its essence, is about moving control and the ability to act from those who have power to those who currently do not. These studies show that there is a difference in how experts and caregivers view empowerment. Experts tend to define it within the realms of their profession: an empowered caregiver means someone who is taught about professional perspectives on NDDs and is able to manage symptoms efficiently from a biomedical approach. However, caregivers expressed that they are indeed knowledgeable about NDDs by experience and by intuition. They emphasised the difficulty to exercise their rights: for example, how to have access to integrated schools and services. Secondly, informants also emphasised that through an empowering process caregivers would become self-confident, independent and less reliant on services and on others. This definition is based on largely Western values of being able to function independently. Perspectives from more collectivist communities and contexts where family members may depend more on one another economically or in terms of social capital are missing.

When such different perspectives exist, the question arises as to whose knowledge and experience is taken as the baseline for empowerment. Researchers and interventionists should be taking a rights-based and caregivers-first approach, so that the knowledge and expertise of caregivers can form the basis of their empowerment. A caregiver-first approach would facilitate that caregivers step up as advocates for their and their children's rights and for better services. A culturally sensitive concept of empowerment would allow for the inclusion of needs and perspectives of a wider range of caregivers and stakeholders from non-Western backgrounds.

Thirdly, using Lukes' three faces of power approach, in both studies there was a hidden agenda: who is asking the research questions and who is interpreting them? In both studies there were gatekeeper organisations who the researcher invited for participation and they did not wish to take part or were hesitant whether to participate. Some explained that they wanted to protect their members from the foreign eye, while others were afraid of the lengthy and technical participant information sheets and consent forms that did not promise any incentive on how the research would directly serve as a benefit for their community. Others added that they had previously participated in research led by international researchers, however, their contribution was not acknowledged in publications, conference invitations or funding.

The researcher's positionality had clearly influenced who was willing to share perspectives and to what extent. Research ethical boards do not currently require the researcher to show proof of

dissemination and direct benefit to the subjects of research and therefore dissemination depends on the willingness of the researcher. A way in which this could be overcome is by making participant consent forms more power balanced: not only would participants sign and consent to take part, but using an added clause to the form the researcher would agree to disseminate research findings locally.

Conclusion

Empowerment of caregivers of children with developmental disorders can be a key element of service development. There are at least two ways in which the concept of empowerment could be better operationalised: firstly, by taking caregiver perspectives as a baseline to understanding needs; secondly, empowerment practices should be developed in a culturally sensitive manner.

- Boshoff, K., Gibbs, D., Phillips, R. L., Wiles, L., & Porter, L. (2016). Parents' voices: 'why and how we advocate'. A meta-synthesis of parents' experiences of advocating for their child with autism spectrum disorder. *Child: Care, Health and Development*, 42(6), 784–797.
- Cattaneo, L. B., & Chapman, A. R. (2010). The process of empowerment: A model for use in research and practice. *American Psychologist*, 65(7), 646.
- Jegatheesan, B., Fowler, S., & Miller, P. J. (2010). From symptom recognition to services: How South Asian Muslim immigrant families navigate autism. *Disability & Society*, 25(7), 797–811.
- Jiménez-Solomon, O. G., Méndez-Bustos, P., Swarbrick, M., Díaz, S., Silva, S., Kelley, M., Duke, S., & Lewis-Fernández, R. (2016). Peer-supported economic empowerment: A financial wellness intervention framework for people with psychiatric disabilities. *Psychiatric Rehabilitation Journal*, 39(3), 222.
- Lalvani, P. (2012). Parents' participation in special education in the context of implicit educational ideologies and socioeconomic status. *Education and Training in Autism and Developmental Disabilities*, 474–486.
- Spreitzer, G. M. (2008). Taking stock: A review of more than twenty years of research on empowerment at work. *Handbook of Organizational Behavior*, 1, 54–72.
- Taylor, S., Wright, A. C., Pothier, H., Hill, C., & Rosenberg, M. (2019). It's like I have an advantage in all this: Experiences of advocacy by parents of children with disabilities from professional backgrounds. *J. Soc. & Soc. Welfare*, 46, 159.
- Trainor, A. A. (2010). Diverse approaches to parent advocacy during special education home—School interactions: Identification and use of cultural and social capital. *Remedial and Special Education*, 31(1), 34–47.
- World Health Organization. (2010). *Community-based rehabilitation: CBR guidelines*. <https://apps.who.int/iris/handle/10665/44405>
- World Health Organization. (2018). *International classification of diseases for mortality and morbidity statistics (11th Revision)*. <http://id.who.int/icd/entity/1516623224>

In 2021 GFBR hosted a series of five online seminars on the broad theme 'Ethical issues arising in research with people with mental health conditions'. This case study was prepared for the seminar 'The ethics of neurodevelopmental disorders research'. Recordings of the seminar series are available at www.gfbr.global.