
Negotiating consent throughout the research process. Participation on the participant's terms.

Anne Lindblom*¹

¹Karlstad University, Sweden; University of Eastern Finland (kau;uef) – 65188 Karlstad, Sweden;
Yliopistokatu 2 P.O. Box 111 FI-80101 Joensuu, Finland, Sweden

Abstract

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The purpose of this presentation is to discuss negotiation of consent and participation in a research project on the meaning of music for First Nations children diagnosed with Autism Spectrum Disorder, ASD, in British Columbia, Canada, and to obtain comments and feedback from the scientific community.

Background

Informed consent is a strong ethical principal in any research project. However, when the participant has a disability, it can be difficult for the researcher to know if the participant actually understands what participation in the project entails. In my project, I have negotiated consent and participation with the participating five children throughout the research process. The participants are vulnerable, not only because of their disability, but also due to marginalization in a society where colonial residue is ever-present in daily life.

Methodology

This is an ethnographic study inspired by Indigenous Research Methodologies. Interviews were conducted in 2013 and follow-up interviews, observations, video-filmed observations and field notes in 2014. Interviews were transcribed and analyzed from five research questions and the results made in to mind-maps from every individual interview. These mind-maps were used as a mutual focal point in the follow-up interviews to disseminate results and ensure correct interpretation. Relevant sequences from the film material were analyzed in the software ELAN and the hand-written field notes typed on the computer.

Results

The material illustrates how consent and participation is negotiated in multiple ways with the participants throughout the research process. This was done by written consent, by asking about participation during the interview or observation, by using the mind-map, and by picking up on signals from the participant. By ensuring their informed decisions to continue their participation, power imbalance was addressed and their rights were respected, which is particularly important when conducting research within Indigenous contexts.

*Speaker

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