How to ask research consent or assent of children who do not communicate with words

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Children who do not communicate with words have typically been left out from studies, and if they are included, most often the consent for participation has been asked from their guardians. Participants’ voluntariness is, however, one of the cornerstones of ethically sound research. I will also point out how children’s right to be protected and right to participate are best actualized if the child is asked consent or assent concerning participation in research in the way which is suitable for the child.

In this presentation, I will examine the methodological viewpoints of asking assent of children who do not communicate with words, by using previous research literature and my ongoing PhD study. I have videotaped small disabled children’s and nurses’ interaction in habilitation nursing setting and the aim of the study is to identify the significant factors of supporting the child’s agency.

Previous literature has notified three essential preconditions for ethical and successful asking of the assent. Since the child’s assent is not enough (if she/he is not cognitively capable of giving the real informed consent), the first one is informing the child’s guardians so well that they don’t prevent the child’s participation because of unnecessary worries. The second one is the researcher’s skills to create a relationship and interaction with the child. This requires enough time, contact with the child’s immediate adults, and using the communication methods suitable for that particular child. The third one concerns the actual methods of asking the assent. The methods should be understandable for the child, and it should be easy for him/her to cancel the assent, if she/he wants to. It is also important to see the getting of assent as an ongoing process.

In my own study I asked assent from five children (aged 3-8 years) with cognitive and/or communication problems. In the presentation I will describe the assent process and the pictured information sheets and cancellation pictures used in my study. I also discuss the consequences of these methodological choices for my study’s results.

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