Development of a Digital Decision Support Tool to Aid Participation of Children With Disabilities in Pediatric Rehabilitation Services: Explorative Qualitative Study

# Details

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20 children (6-17 years) and 8 young people (19-30 years) living with disabilities-

## Implications For Stakeholders About

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# Abstract

Background: Building a health care system in accordance with the rule of law requires child-centered care, where children andyoung people, regardless of ability, are allowed to participate in visits with their health care professionals. As part of an overallproject focusing on developing and implementing a digital decision support tool to increase the participation of children withdisabilities in pediatric rehabilitation, this study brings new knowledge as to how this specific patient group views participation.

Objective: The aim of this formative study was to explore the experiences of children and young people with disabilities concerning increasing their participation in the pediatric rehabilitation services.

Methods: The formative study had an explorative design, based on a latent qualitative content analysis with an inductive approach. Interviews were conducted with 20 children (6-17 years) and 8 young people (19-30 years) with disabilities about their experiences of participation in pediatric rehabilitation services.

Results: A total of 3 categories emerged reflecting the participants’ possibilities of participation in the pediatric rehabilitation services: to feel involved, to feel independent, and to work in partnership. To feel involved meant being listened to and being connected, to feel independent meant being admitted and being enabled, and to work in partnership meant being supported andbeing able to entrust others with the decision making. With the overall theme moving toward empowerment of children in pediatric rehabilitation, a true feeling of participation can be experienced.

Conclusions: The views of children and young people with disabilities are that children should be given the prerequisites for empowerment by being allowed to feel involved and independent as well as to work in partnership to experience true participation in the pediatric rehabilitation services. This finding is essential in the design of a digital decision support tool based on the children’s needs and perspectives

# Outcome

"The results thus indicate that the digital decision support tool can support children’s self-efficacy and autonomy to create greater possibilities for participation in rehabilitation services. The digital communication tool needs to be constructed in such a way to meet these children’s developmental, intellectual. and cognitive levels, so that they have the capacity to obtain and understand the information needed to participate in their own care. The desire to feel independent, involved, and being able to work in partnership with adults needs to be addressed and incorporated into the digital tool." (Authors, in Principal Findings)