



Participation and Mental Health (PMH) in habilitation for children and youth with disabilities

THANK YOU to all the children, parents and habilitation professionals who make this research programme possible!!

Information about the research programme's result

About this research programme

CHILD-PMH is a research programme where children and parents answer questions about mental health and participation once a year for four years. This research is a collaboration between several universities and regions in the country. CHILD-PMH started because there was a lack of knowledge about mental health in children with disabilities and about their participation in various activities. Increased knowledge about mental health and participation is important in order to develop new and effective interventions.

Parents have answered questions in the programme's first part – to follow children's functioning over time. Unfortunately, Covid 19 happened in the middle of our data collection process which reduced the number of answers we anticipated receiving. Also, we planned to interview the children but that could not happen because of the pandemic. The second data collection phase will happen this autumn, 2021 when we hope to meet the children themselves.

Parents' answer about their children

In total there were answers about 161 children, 53 boys and 104 girls and some did not answer that question. Most children have regular contacts with a habilitation 1 to 5 times a year and with the municipality 1 to 2 times a year. All children have one or more disabilities, the most common ones being difficulties understanding and learning as other children, talking and communicating as other children, and difficulties moving about.

Most children have a good life according to the parents' valuations, i.e., high wellbeing when they rated the children's life on a scale from worst possible to best possible life.

The parents were asked about the children's participation in everyday activities at home, close to home, at school, and in the community. For each type of activity, they were asked if the child was involved in the activity, their engagement and whether they participated in the activity. When answering they were to compare with other children of the same age. The answers showed that:

- Children often participate in home activities and school activities
- Children are more engaged in school activities

- Children are less likely to participate in activities outside the home
- Children are less engaged when they participate in activities outside the home

Answers about the family

The parents answered questions in a section of the questionnaire called Strengths and Difficulties in the Family. Among other things, they answered 13 questions about how they think and feel about their child. Most of the parents had mostly positive thoughts about their child and about themselves as competent parents. They were then asked questions about the child's siblings, relationships with others and the child's social life. Finally, they were asked about what support there is for the child from professionals. They were again mostly positive about the support they receive. Despite this, quite a few parents wished for more parent support to their child and quite a few also thought that they had to struggle a lot to get the support they wanted.

The parents were also asked questions about how they experience the habilitation staff work. They answered five questions. For each question, they evaluated who decides and plans, and how much on a scale from "habilitation decides most things" to "we decide most things". They feel that they can decide quite a lot and that they receive good information when it comes to:

- Decisions on what to assess about the child
- That the habilitation tries to understand the child's functioning in its everyday life
- Decisions about whose goals and interventions the child should be given

The parents do not think that they can decide as much or receive good information when it comes to:

- Decision on intervention methods for the child
- Support to the family

How do we proceed?

We will ask the same questions to the parents in the autumns of 2021, 2022 and 2023. This will make it possible to see if and how the child's mental health and participation change and how the situation as a family changes. We can also see whether the support that parents receive from the habilitation is experienced differently. We are interested in seeing how changes in the child, in the family and the support they receive from habilitation are connected.

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