



Research profile at Jönköping University

Participation and Mental Health (CHILD-PMH) Program Report 2019

Mats Granlund



INSTITUTET FÖR HANDIKAPPVETENSKAP
SWEDISH INSTITUTE FOR DISABILITY RESEARCH

li.u LINKÖPING
UNIVERSITY



JÖNKÖPING UNIVERSITY
School of Health and Welfare



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**Region
Jönköpings län**



**Region
Västmanland**



Region Örebro län

**Region
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Participation and Mental Health (CHILD–PMH) progress report 2019

Program overall:

The program is financed through a program grant from the large state funding agencies in Sweden. The Swedish Research Council administer the funding in collaboration with Forte and Vinnova. Jönköping University is lead partner in the program, other partners are Linköping University, Örebro University/Region Örebro County, Mälardalen University, Australian Catholic University and Bloorview Research Institute. In addition, habilitation services, parents and children in five different geographical regions are involved. The program is organized as follows:

- Program steering group with members from all research institutions plus representatives for interest organizations for persons with disabilities, and habilitation services (see appendix 1 for group members)
- Advisory groups at four out of five geographical regions. The advisory groups are led by researchers and contain members representing children, families, and habilitation professionals. The task of advisory groups is to collaborate with the researchers in all steps of the research process, formulating research questions, designing studies, implementing studies, interpreting results and disseminating results.

The program has two different parts: 1) A longitudinal study where we follow children with disabilities from two age cohorts concerning mental health and participation, 2) Habilitation studies where we use a co-production/inclusive design to investigate how the active participation of children and parents in the habilitation intervention process can be enhanced.

In 2019 the program steering group has met twice and the advisory groups in four regions have been constituted. During the year general tasks for the program have concerned hiring staff at all sites, establishing collaboration with habilitation services and divide working tasks within the program among researchers. In addition, a manual for inclusive research, originally developed in Australia, has been translated and adapted to Swedish conditions with the aim to support the advisory groups in their work. Information material for parents and children using habilitation services about the project has been developed.

After negotiating with habilitation services in the five participating regions, four regions consented to participate in both program parts while one region only wanted to participate in the longitudinal study. Advisory groups have been constituted in the four regions that will participate in both program parts.

Contracts between research partners have been signed which allows for allocating money to partners and hiring staff at different universities. Ethical application has been written and sent to the Swedish Research Ethical Authority in October and approved in December.

Economy:

In December we checked the expenses and money left in the program and we follow the plan. Not all partners have yet required the money for year 2019.

Problems experienced:

An administrative problem experienced is contract development and signing. It has taken more than ten months for university lawyers to agree on formulations concerning immaterial right. Now, finally the contract is signed by all partners. The delay in contract signing has led to that staff have been hired at a slower rate than expected. This fact has in its turn led to that the workload on starting up the program on researchers at Jönköping University has increased. At the end of the year the situation is now getting better. On the positive side, less money than expected has been used by LiU, ÖU and MdH in 2019.

Doctoral students are now employed in Jönköping and Linköping and the recruitment process is ongoing at Mälardalen. We have also used other funding to hire staff working in Gävleborg (one of the sites), to supplement financing for a doctoral student at Mälardalen University and support a research assistant and a post doc for data collection in Jönköping. The research assistant is also partly financed by the habilitation services. The other funding used is internal money to be used for our collaboration within the Swedish Institute for Disability Research. This funding is short term and will only cover 2020 and 2021 (until June 30). Considering the amount of data collection required in the longitudinal part we probably need to find additional financial resources for the last two data collection points in the longitudinal study. The recruitment process of a doctoral student in Region Örebro County is complicated. An alternative is discussed in which a doctoral student will be employed at JU but with one of the tasks to collect data in Örebro. How to proceed will be decided in January.

Ethical application was returned with two corrections to be made before acceptance. One concerned information letters to children that were judged to be too complex. The other concerned a misunderstanding of text about focus group members. A supplementary application was submitted, the whole application was approved in December.

Added value:

We have attracted interest from other researchers that are willing to share workload in the program provided that they have access to data. Anna-Karin Axelsson, Anna Ullenhag and Pia Ödman are responsible for the validation of FUNDES-CHILD and will work with participation studies based on FUNDES data. Several international researchers are involved in the systematic reviews planned. In one of the data collection sites the region will finance a doctoral student in their own research unit. This student might work as a data collector within the program provided access to data.

There are several opportunities to link the program to other research programs/projects internationally. Christine Imms and Mats Granlund are involved in a large Australian research program that recently received funding **CP Achieve**. The program is focussed on adolescents and young adults (aged 10 – 30 years) with cerebral palsy. The aims are to understand and address the health care and service needs of this group. One focus is mental health. At Centre for Augmentative and Alternative Communication (CAAC) at University of Pretoria a group of researchers are working with how to involve children using AAC and their care providers more in the intervention process. A further collaboration is planned.

Doctoral students will have supervisors at more than one university, and sometimes more than one country, aimed to build stronger research networks.

Longitudinal study:

Three researchers from Mälardalen (Lena Almqvist), Linköping University (Henrik Danielsson) and Jönköping University (Lilly Augustine) are coordinating the work within this program part. During the year the following activities have been done/are ongoing:

A systematic review of longitudinal studies of mental health in children with disabilities is currently implemented including several program researchers and additional experts. The work is organized by Henrik Danielsson and Christine Imms. So far title and abstract screening are completed, and full text exclusion-inclusion is ongoing.

An analysis of concepts used when studying mental health in children with disabilities is ongoing. A problem discussed is how to separate/discriminate mental health problems from mental health illness as well as from the subgroup Neurodevelopmental Disorders as they appear under the heading Mental Disorders in DSM V as well as ICD 11. A presentation of the problems met have been presented in a breakfast seminar of the IACD conference in the USA in September 2019.

Two packages of instruments for data collection have been completed (for children and care providers). The work was led by Karina Huus and Anna Karin Andersson. Two of the instruments in the care provider package need supplemental validation. The FUNDES-CHILD participation questionnaire has during the year been tested for content validity and data collection for psychometric validity testing will be collected next year. Responsible are Anna-Karin Axelsson, Anna Ullenhag and Pia Ödman who will join the project as independent researchers. After the validation they will be a part of the team analyzing the longitudinal data. The FSS instrument used to assess the family environment need to be tested for psychometric validity. Master students in psychology writing their final theses have agreed to perform these tests provide that it is within the time frames for their work. Register data from Hab Q will be used. In the children's package of questionnaires the validation of the participation instrument PMP was completed 2019. The work was coordinated by Karina Huus.

Concerning data collection, a plan for training data collectors for performing structured interviews with children is developed, training will take place in the beginning of March (directly linked to the planned start of data collection). Except for program researchers, experts on involving children in data collection will participate, Ellen Backman Halmstad University and Juan Bornman, University of Pretoria. A manual for administrating the data collection is under development based on the manual for the instrument PMP.

Concerning recruitment of children and care providers all information material to children, care providers and professionals are completed except for short, streamed presentations of the study for parents and children and professionals respectively. Planning of how to recruit participants with help of habilitation services is ongoing. Although the ethical regulations say that we can contact families directly when provided with contact information we will recruit via habilitation services. They think that to keep their relations with families positive, they like to send out our invitation letters to parents with an accompanying letter from the habilitation services rather than letting us (researchers) sending the letters. Recruitment will start in January.

Data management plan is under development coordinated by Lena Almqvist and concerns data sheet, how to merge data, meta data document etc. We have opened a safe place for storing data in JU File share. It is possible to share data with Canada and Australia without special permission since there are considered safe countries in terms of IT and therefore the same rules as in Europe is applied. International collaborators can work in data, but all data will be stored in JU share files.

Problems experienced:

The Hab Q is not functioning as well as expected. WE have therefore decided to collect more data than planned prospectively. As a consequence, the time and resources spent on data collection need to be extended. When we know how many children/families that provide informed consent we need to decide if we can include all who consented or if we need to randomize a sample

SDQ (Strength and Difficulties Questionnaire) will be used in its original form due to restriction in how to use it stated by the instrument developers. We will use original phrasing and scales but will try to adapt administration by a manual combined with graphic symbol support.

SSF the questionnaire about family environment was planned to be used by retrieving data from HabQ. Due to the low coverage rate we have to collect these data prospectively. However, before the main study additional psychometric testing of the Swedish version is necessary. We will retrieve data from Hab Q for this testing but probably also some collection of new data is necessary during spring 2020.

Habilitation studies

Researchers from JU (Karina Huus and Anna Karin Andersson), ÖU (Lars-Olov Lundqvist and Susann Arnell) and Gävle/JU (Patrik Arvidsson) are coordinating this part of the program.

In 2019 and 2020 the program plan states that a systematic review, a first data collection of data on engagement in the intervention process and focus groups should be implemented.

A systematic review of interventions aimed at increasing children and care providers involvement in the intervention process in habilitation is currently implemented. During the year a PICO has been developed for the research questions of the review, consultations with the library regarding search terms, databases etc is ongoing and reviewers for abstract screening will be invited early next year. Responsible for organizing the review are Anna Karin Andersson, Karina Huus and Charlotte Karlsson.

During 2019 instruments for collecting data on how children and care providers perceive their engagement in encounters with habilitation professionals have been developed. In addition, interview guides/vignettes for focus groups are under development and information materials to be distributed by habilitation services have been developed. This work is organized by Karina Huus and Anna Karin Andersson.

Much time have been spent on constituting advisory groups in all regions and preparing material to support the work of the advisory groups. In all regions most members of the groups (children, care providers, professionals) have been recruited. We have received internal money that makes it possible to provide small honorariums to advisory group members. The advisory group in Jönköping has had a first meeting. Persons attending the meeting were: Karina, Charlotte, AKA (researchers), one adolescent, one parent, two professionals (Linda and Markus). One region, that only plan to take part in the longitudinal study is now considering if an advisory group is good also for just the longitudinal study.

Problems experienced:

Recruiting members to advisory groups have been a problem in some sites but according to the latest report this problem is soon solved.

Systematic review is delayed due to the heavy workload on JU staff during 2019. This is a result of the delay in signing the contract and thus that hiring staff at LiU, ÖU and MdH have been delayed.

Next year 2020

Overall, we are entering 2020 as planned. The spring will be used to start data collection both in the longitudinal part och the program and the habilitation studies plan of the project. Now when contracts are signed, and staff are hired at all sites (almost) we have more resources to finalize the preparations before starting data collection. This preparation phase is very important and will mean intensive work from January to the end of March. Among other things we need to: finalize all information material, recruit participants for both program parts and train data collectors. In addition, member of advisory groups needs to meet, and we need to have days where we prepare the members of advisory groups for their important tasks.