



Participation and Mental Health (CHILD - PMH) program update fall 2024

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Participation and Mental Health (CHILD-PMH) program update, September 2024

Purpose and aim

Participation, mental health and mental health problems

A relatively high prevalence of mental health problems as well as participation restrictions in everyday activities are reported for children with disabilities compared to other children. Children with participation restrictions tend to have lower wellbeing. Mental health can be defined as a lack of mental health problems along with positive functioning in everyday life activities. In recent years the dual continua model (Keyes, 2010) has been introduced in which mental health is seen as a separate but related construct to mental health problems. In this program we have adopted this model and tried to relate it to mental health in children with disabilities (Granlund et al, 2021). Participation is related to wellbeing/mental health and can be seen as a factor that directly affects mental health and indirectly protects from mental health problems. By collecting prospective data on both participation, mental health problems and mental health longitudinally from children and families, information about the mental health of children with disabilities with a range of severities and factors hypothesized to affect mental health can be obtained.

Involvement in the intervention process

Children with disabilities are exposed to/take part in different interventions for long time periods, sometimes throughout their entire life. Children and families report a higher degree of wellbeing if they are actively involved in and can influence all steps of the intervention process from defining problems/challenges that are important to address, explaining problems, setting goals, designing interventions, implementing interventions, and evaluating the outcome of interventions (Granlund & Imms, 2024). Several studies show that children and families report that they are not as involved in the intervention process as they would like to be. Involvement contains at least two dimensions, in the interaction between professionals and child/care providers. First, building a trustful relationship, and second, building capacity by gaining knowledge and skills in problem solving and self-advocacy. By collecting data on children's and parents' involvement in the intervention process we aim to develop and evaluate professional training courses and organizational changes that enhance child and care provider involvement in the intervention process in habilitation intervention.

Participation and mental health

Functioning is a transactional process involving both the child with disability and persons and objects in the environment that over time influence each other where changes in the child lead to changes in the environment and vice versa. It means that when working with mental health problems, and mental health and how they impact on participation across childhood we must have information about both the child and factors in the environment longitudinally over time.

Mental health, mental health symptoms and mental illness

In this program, mental health problems, rather than mental disorders, are in focus since problems that are under the diagnostic threshold for a mental disorder can cause difficulties with everyday functioning. In addition, mental health problems (sadness and conduct problems) will be separated from impairments often described as mental health problems (hyperactivity and communicative problems). If not, the prevalence is probably overestimated since many screening

instruments of behavior problems/mental health problems also include ratings of hyperactivity and peer problems/communication.

Relating mental health and mental health problems to the fPRC framework

How participation, mental health problems and participation-related intrinsic and extrinsic factors interact over time in transactional patterns is less well known. Nor is it well known if and how services are provided to children and parents directly affects the participation outcome and mental health of children.

Participation in the intervention process

Earlier studies indicate that high child and care provider involvement in the intervention process may promote wellbeing both in child and care providers (e.g. Dunst et al, 2019). Collaborative problem solving/coaching is a key ingredient in parent-professional collaboration in habilitation services. How the organization of the habilitation process is related to the engagement of children and care providers in individual sessions has not been studied. In addition, the impact of child engagement in implementing intervention on intervention outcomes is not well researched.

Participation as a unifying program construct

In this research program the relationship between the two participation dimensions, attendance and involvement, is investigated in depth in relation to mental health and mental health problems of children and young people with disabilities. The two dimensions of participation are also applied to the environments where children meet service systems, e.g. habilitation services or social services. Our previous studies indicate that assessment instruments and methods for family-professional encounters are needed that are designed to support children in reporting their own participation and perceived mental health problems and support parents in being active in planning and implementing support. A key issue for success in this work is that children and families not only are research subjects but also are actively involved in planning and implementing the research.

Inclusive research

Inclusive research cannot be translated into one particular way of doing things; the options are extensive (Walmsley, 2004). Some characteristics and principles for inclusive research can be seen (Walmsley and Johnson, 2003): In the first part of the program, the longitudinal study, children and care providers have been consulted about the content and format of assessment instruments and formulating information materials. In addition, new or revised instruments have been developed based on children and parent feedback. The second part of the program, habilitation interventions, is more directly designed to be inclusive. Advisory boards with adolescents, care providers, professionals and researchers have been formed in participating regions. These advisory boards have provided advice and took part in decision making about the research process under the whole program period. In addition, the experiences of members in the advisory boards have been discussed in focus groups.

The program has four sub-aims:

- (i) To investigate *the longitudinal interrelationships between the two dimensions of participation – attendance and involvement in a life situation*– in order to identify aspects of the two participation dimensions, as well as mental health problems and wellbeing that can be addressed through interventions aimed at improving mental health.
- (ii) To investigate *the common trajectories of participation, mental health problems, mental health/wellbeing and factors related to these pathways in children and adolescents (4-18 years of age) with impairments or long-term health conditions*. The intent is to identify or verify factors that can be targeted for intervention.

- (iii) To investigate *how children and parents perceive that they participate in the different steps of the intervention process and/or group programs*– in order to identify aspects of the process that can be targeted for intervention.
- (iv) To develop and evaluate *interventions aimed at increasing child and family participation in the intervention process*.

The program involves more than twenty researchers that are involved in one or more projects or in linked projects (see table 2). This is a necessary condition for a creative program moving forward.

Table 1: Participating researchers

| Jönköping University, CHILD | Linköping University | Mälardalen University | Örebro Region | Bloorview Research Institute | Murdoch research Institute, Melbourne University |
|--|---|---|--|-------------------------------------|---|
| Mats Granlund Karina Huus Lilly Augustine Anna Karin Axelsson Karin Bertills Charlotte Karlsson Linda Sjödin | Henrik Danielsson Magnus Ivarsson Lina Homman | Lena Almqvist Anna Ullenhag Anna Karin Andersson Jennifer Gothilander Camilla Eriksson *Torun Täljedal (at Uppsala University) | Lars-Olov Lundqvist Susann Arnell Eva Resare | Gillian King | Christine Imms Jacinta Pennacchia |

Associated researchers linked to the program

Associate professor Lin-Ju Kang, Chang Gung University, Taiwan
 Rob Brooks, PhD, Leeds-Beckett University, UK
 Will Farr, PhD, Sussex Community NHS Foundation Trust
 Professor Dana Anaby, McGill University, Canada
 Professor Shakila Dada, University of Pretoria, South Africa
 Professor Dido Green, Jönköping University

Design and method of the longitudinal study

A longitudinal prospective study following children in two age cohorts (children with disabilities followed from 4-6 (2019) to 10-11 years of age and followed from 10-12 (2019) to 16-17 years of age. In total four waves of data (one data collection per year).

Participants: Children and their families for the prospective study were recruited from the two age cohorts from five regional habilitation centers that consented to participate (Östergötland, Örebro, Västmanland, Jönköping and Gävleborg). All children within the specified age ranges, in 2019, in these centers were used as a basis for recruitment, about 2400 children. The estimated external attrition rate was 75%. Due to the Covid pandemic the initial external attrition was higher than expected (90%). For this reason, among families consenting, we decided not to collect data directly from the children in the first wave. However, for the second, third and fourth wave we included structured interviews with children. The amount of newly arrived refugee families from Middle East/Africa have affected the characteristics of the population of children

with disabilities in Sweden. A rough estimation based on our sample indicates that somewhere in between 30 to 40 % of the population have this background.

| Participating families | 2020/2021 respondents | 2021/2022 respondents | 2022/2023 respondents | 2023/2024 |
|------------------------|----------------------------------|-----------------------------------|----------------------------------|-------------------------------|
| Cohort 1 | 81 care providers 0 children | 44 care providers 21 children | 40 care providers 12 children | Data collection not completed |
| Cohort 2 | 80 care providers 0 children | 58 care providers 46 children | 54 care providers 28 children | Not completed |
| Total | 161 care providers 0 children | 102 care providers 67 children | 94 care providers 40 children | |

Procedure: In the prospective study families providing informed consent were followed with yearly collection of data on mental health problems (Strengths and Difficulties Questionnaire; (SDQ), participation(FUNDES Child-SE and Picture My Participation (PMP)), wellbeing (Cantril's ladder and new self-rating questionnaire) and factors hypothesized to affect mental health, e.g perceived school environment, perceived stress in families, and encounters with the habilitation services.

Data were collected via web-based questionnaires and/or structured telephone interviews completed by parents. Data from children was during spring 2022 and spring 2023 collected with the help of structured face-to-face interviews or zoom based interviews.

Data analyses and statistics

The analyses of the longitudinal data are dependent on the sample size also considering the distribution of the data, the amount of missing data, reliability of the tests, and the strength of the associations in the model generated. Missing data will be handled with multiple imputation by chained equations (MICE).

Design and method for interventions aimed at increasing child and parent involvement in the intervention process (Aims iii and iv):

Design and method

The studies are aimed at increasing child and parent *participation in the intervention process* with a special focus on increasing professional and parental clinical use of the that enhance child and family involvement in the habilitation process. A co-production inclusive research paradigm is implemented using scoping and systematic reviews, focus groups with children, parents and professionals and co-produced interventions as displayed in Figure 1 (as of fall 2023 we are implementing studies aiming at affecting the habilitation process to increase the active participation of children and care provider is ongoing):

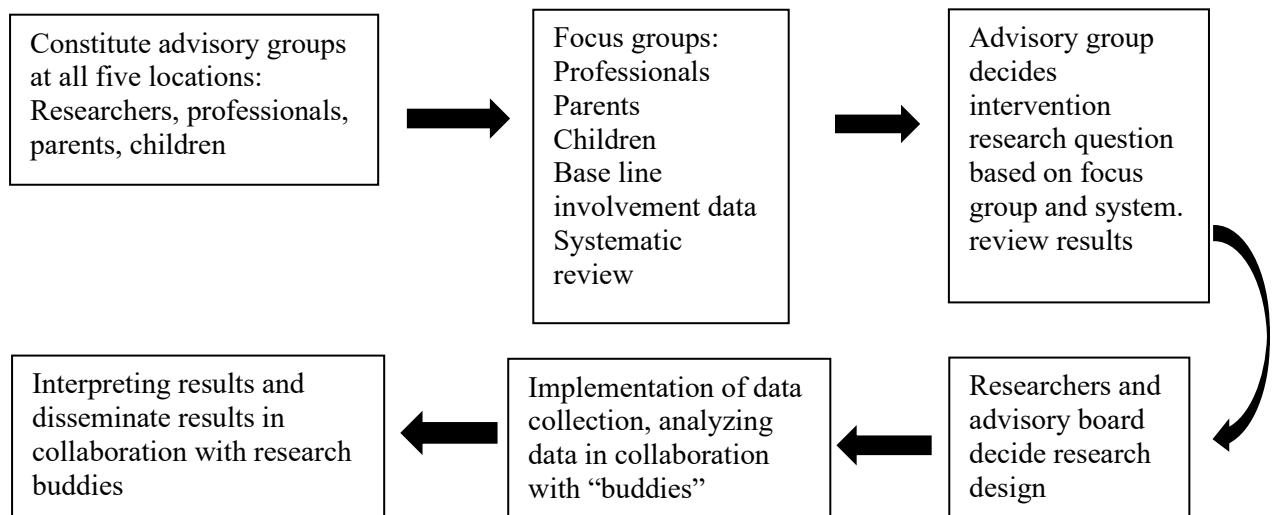


Figure 1: Flow chart of research process in habilitation interventions

Participants: Participants are professionals working in four regional habilitation centres primarily situated in the regions where the participating Swedish universities are situated, along with the children and parents who have contact with these centers. At the habilitation centers (Jönköping, Östergötland, Örebro, and Gävleborg) services are provided by multi-professional teams, including professional groups such as physiotherapists, occupational therapists, speech therapists, nurses, psychologists, social workers, and physicians.

Procedure: Following a co-production inclusive research paradigm, all steps in the research process from defining research questions to disseminating research results include researchers, habilitation professionals, parents and children as co-researchers. The advisory groups have been formed at each participating center (n= 4) and a co-production manual for the steps above is used to guide the process. The overall research aim is to increase child and parent involvement in the intervention process - this sets the limit for the particular aims and research questions that each local group can pursue.

Based on the results of the focus groups and our systematic review, small intervention studies aimed at increasing aspects of family and child involvement in the habilitation process have been developed in collaboration with stakeholders and are now implemented within the four sites.

The interventions are focused on the different steps of the process, increasing frequencies of planning meetings that children attend, child involvement in identifying problems to work with, child involvement in goal setting to child involvement in designing and implementing intervention methods.

Linking the two parts of the program

The two parts of the program are theoretically hypothesized to be related. An important prerequisite for wellbeing is to experience perceptions of control over your life circumstances. In addition, we know that there is a relatively strong relationship between participation and wellbeing. This relationship is probably applicable both to child in context and to child/care provider and professional collaboration. Active participation in the intervention process by children with disabilities and their care providers (primarily parents) probably will lead to perception of control over services and interventions received which in turn will affect wellbeing. The two parts of PMH are linked by three

strands of research: 1) Adaptations and validation of existing assessments instruments and development of new instruments for screening participation and wellbeing aimed at facilitating the active involvement of children with disabilities and care providers in the intervention process, 2) Investigation of new routines and ways of working aimed at supporting the active involvement of children with disabilities in the intervention

Appendix 1 Publications in CHILD-PMH

Articles in refereed journals

1. Augustine, L., Lyngnegård, F., Adolfsson, M., & Granlund, M. (2021) The Utility of ICF construct as a statistical tool- Operationalizing mental health as an indicator of adolescent participation. *Disability and Rehabilitation* DOI: [10.1080/09638288.2021.1884295](https://doi.org/10.1080/09638288.2021.1884295)
2. Balton, S., Arvidsson, P., Granlund, M., Huus, K., & Dada, S. (2022) Test-retest reliability of Picture My Participation in children with intellectual disability in South Africa. *Scandinavian Journal of Occupational Therapy* <https://doi.org/10.1080/11038128.2020.1856922>
3. Granlund, M., Imms, C., King, G., Andersson, A.K., Augustine, L., Brooks, R., Danielsson, H., Gothilander, J., Ivarsson, M., Lundqvist, L-O., Lyngnegård, F., & Almqvist, L. (2021). Definitions and Operationalization of Mental Health Problems, Wellbeing and Participation Constructs in Children with NDD: Distinctions and Clarifications. *International Journal of Environmental Research and Public Health*
4. Hwang AW, Chang, CH, Granlund, M., Imms, C., Chen, CL, Kang, LJ (2020) Longitudinal trends of participation in relation to mental health in children with and without physical difficulties. *International Journal of Environmental Research and Public Health*
5. Augustine, L., Lyngnegård, F., & Granlund, M. (2021) Trajectories of self-rated Participation, Mental Health and Mental Health Problems in Adolescents with Self-reported Neurodevelopmental Disorders. *Disability and Rehabilitation*
6. Axelsson, A.K., Ullenhag, A., Ödman, P. (2021). A Swedish Cultural Adaptation of the Participation Questionnaire Functional Scale of the Disability Evaluation System – Child version. *Disability & Rehabilitation*,1-8. doi: 10.1080/09638288.2021.1917704
7. Dada, S., et al (2020). Agreement between participation ratings of children with intellectual disabilities and their primary care givers. *Research in Developmental Disabilities*
8. Danielsson et al (2023). A Systematic Review of Longitudinal Trajectories of Mental Health Problems in Children with Neurodevelopmental Disabilities. *Journal of Developmental and Physical Disabilities*
9. Hong Zheng, Bornman, J., Granlund, M., Zhao, Y., Huus, K. (2023) Agreement between children with long-term health conditions and their primary caregivers on reports of perceived participation. *Frontiers in Rehabilitation Sciences*
10. Ivarsson, M., Danielsson, H., Andersson, A-K, Gothilander, J., & Granlund, M. (2023) Structural Validity and Internal Consistency of the Strengths and Stressors in Parenting (SSF) Questionnaire in Parents of Children with Developmental Disabilities. *Scandinavian Journal of Psychology*
11. Kang, L-J, Lin, P-Y., Granlund, M., Chen, C., Sung, W-H., Chiu, Y-L. (2023) Development and usability of an app-based instrument of participation in children with disabilities. *Scandinavian Journal of Occupational Therapy* DOI: [10.1080/11038128.2022.2083014](https://doi.org/10.1080/11038128.2022.2083014)
12. Prinsloo, P., Dada, S., Bastable, K., Raghavendra P., and Granlund, M. (accepted) The Application of the Family of Participation-Related Constructs (fPRC) Framework to AAC Intervention Outcomes in Children with Complex Communication Needs: A Scoping Review. *Augmentative and Alternative Communication*
13. Täljedal T, Granlund M, Almqvist L, Osman F, Nore'n Selinus E, Fängström K (2023) Patterns of mental health problems and well-being in children with disabilities in Sweden: A cross-sectional survey and cluster analysis. *PLoS ONE* 18(7): e0288815. <https://doi.org/10.1371/journal.pone.>

14. Gothilander, J., Ullenhag, A., Danielsson, H., & Axelsson, A. K. (2023) Reliability of FUNDES-Child-SE - measuring participation and independence of children and youths with disabilities, *Scandinavian Journal of Occupational Therapy*, DOI: [10.1080/11038128.2023.2237214](https://doi.org/10.1080/11038128.2023.2237214)
15. Ivarsson, M., Andersson, A. K., & Almqvist, L. (2023). Self-rating via video communication in children with disability—a feasibility study. *Frontiers in Psychology*, 14, 175
16. Antoniadou, M., Granlund, M., & Andersson, A.K. (2024). Strategies Used by Professionals in Pediatric Rehabilitation to Engage the Child in the Intervention Process. *Physical and Occupational Therapy in Pediatrics*
17. Täljedal, T., Granlund, M., Osman, F., Selenius, E., & Fängström, K. (2024) Parenting children with disabilities in Sweden: a cluster-analysis of 1 parenting stress and sufficiency of informal and formal support. *Frontiers in Psychology*
18. Ullenhag, Imms, C., Anaby, D., Kramer, J., Girdler, S., Gorter, J., Ketelaar, M., Elliot, C., & Granlund, M. (2024). How can we reach long-lasting inclusive participation for all? A vision for the future. *Child: Care, Health and Development*
19. Granlund, M., & Imms, C. (2024) Participation as a means: Implications for interventions. *Frontiers in Rehabilitation Sciences*
20. Kilgour, G., Lu, A., Kozelj, N., Tracy, J., Hickey, L., Granlund, M., Morgan, P., Shields, N., Drake, G., Cleary, S., Bonyhady, B., Johnston, L. & Imms, C. (2024). Participating together in CP-Achieve: Experiences, opportunities and reflections from a collaborative research team of lived experience experts and health care professionals. *Childhood, A Journal of Global Child Research*. is <https://doi.org/10.1177/09075682241269682>
21. Gothilander, J., Axelsson, A. K., Danielsson, H., Almqvist, L., & Ullenhag, A. (2024). Factor structure of FUNDES-Child-SE measuring the participation and independence of children with disabilities. *Child: Care, Health and Development*, 50(4), e13306. <https://doi.org/10.1111/cch.13306>

Master thesis work published in DiVA

Two-year thesis:

1. Aranti, A. (2021) Perceptions and Experiences of Social Participation in Physical Activities Among Youths with Physical Disabilities in Greece. : A qualitative Empirical Study (Dissertation). Retrieved from <http://urn.kb.se/resolve?urn=urn:nbn:se:hj:diva-54137>
2. Moes, L. (2021) The relationship between mental health in adolescents having self-reported neurodevelopmental disorders and sources of parental knowledge: A cross-sectional study (Dissertation). Retrieved from: <http://hj.diva-portal.org/smash/get/diva2:1576029/FULLTEXT01.pdf>
3. Nikolopolous, M. (2021) Health care professionals' perceptions about family engagement in rehabilitation process.: A mixed method study. (Dissertation). Retrieved from: <http://hj.diva-portal.org/smash/get/diva2:1583535/FULLTEXT01.pdf>
4. Rehman, N. (2021) Will adolescents with Neurodevelopmental difficulties differ in mental well-being and mental health problems in relation to Other disabilities?

(Dissertation) retrieved from: <http://hj.diva-portal.org/smash/get/diva2:1621117/FULLTEXT01.pdf>

5. Antoniadou, M. (2023). <i>Strategies of Professionals in Pediatric Rehabilitation to Engage the Child in Method Implementation and Outcome Evaluation/Re-assessment : An Empirical Study Involving Greek Professionals</i> (Dissertation).
<https://urn.kb.se/resolve?urn=urn:nbn:se:hj:diva-61794>

One-year thesis:

1. Antoinadou, M. (2022) Strategies used by professionals in pediatric rehabilitation for engaging the child in the intervention process. (Dissertation). Retrieved from:
<http://hj.diva-portal.org/smash/get/diva2:1651878/FULLTEXT01.pdf>
2. Kemps, L. (2022) Including children with ID in research interviews – a scoping review (Dissertation). Retrieved from:
<http://hj.diva-portal.org/smash/get/diva2:1653490/FULLTEXT01.pdf>
3. Torres Cabo, E. (2021) Measuring mental health in children with disabilities. The use of the two continua model. (Dissertation). Retrieved from: <http://hj.diva-portal.org/smash/get/diva2:1572078/FULLTEXT01.pdf>

Manuals and other support material

1. Huus, K., Berglund, I., Stensson, M., Möller Christensen, B., Lyngnegård, F. (2020) *Inkluderande forskning med barn och familjer – guider och checklistor*. Jönköping: CHILD, Jönköping University
2. Huus, K-, Dada, S., Bornman, J., Imms, C., & Granlund, M. (2020) *Manual Picture my Participation – structured interview material to allow children with ID to self-report participation*. Jönköping and Pretoria; CHILD and CAAC