CHILD
Research profile at Jönköping University

Participation and Mental Health (CHILD - PMH) program update fall 2023

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Research profile at Jönköping University

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Participation and Mental Health (CHILD-PMH) program update, September 2023

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 (Einfeld et al, 2011; Gorter et al, 2014). 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 (Arvidsson et al, 2014) 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, submitted). 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

To understand how transactional processes involving mental health problems, and mental health impact on participation across childhood is essential to identify appropriate interventions for vulnerable groups.

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 can cause difficulties with everyday functioning. In addition, mental health problems (sadness and conduct problems) will be separated from impairments (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. 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 can also be 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 this work is that children and families 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. 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 provide advice and make decisions about the process.

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 accessible *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 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
Professsor Dido Green, Jönköping University

Design and method of the longitudinal study

<u>Longitudinal prospective study following children in two age cohorts</u> (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.

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
Cohort 1	81 care providers 0 children	44 care providers 21 children	40 care providers 12 children
Cohort 2	80 care providers 0 children	58 care providers 46 children	54 care providers 28 children
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 are 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 that may arise from within the child, family, school, and encounters with habilitation services.

Data are 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.

Data analyses and statistics

The analyses of the longitudinal data will be 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):

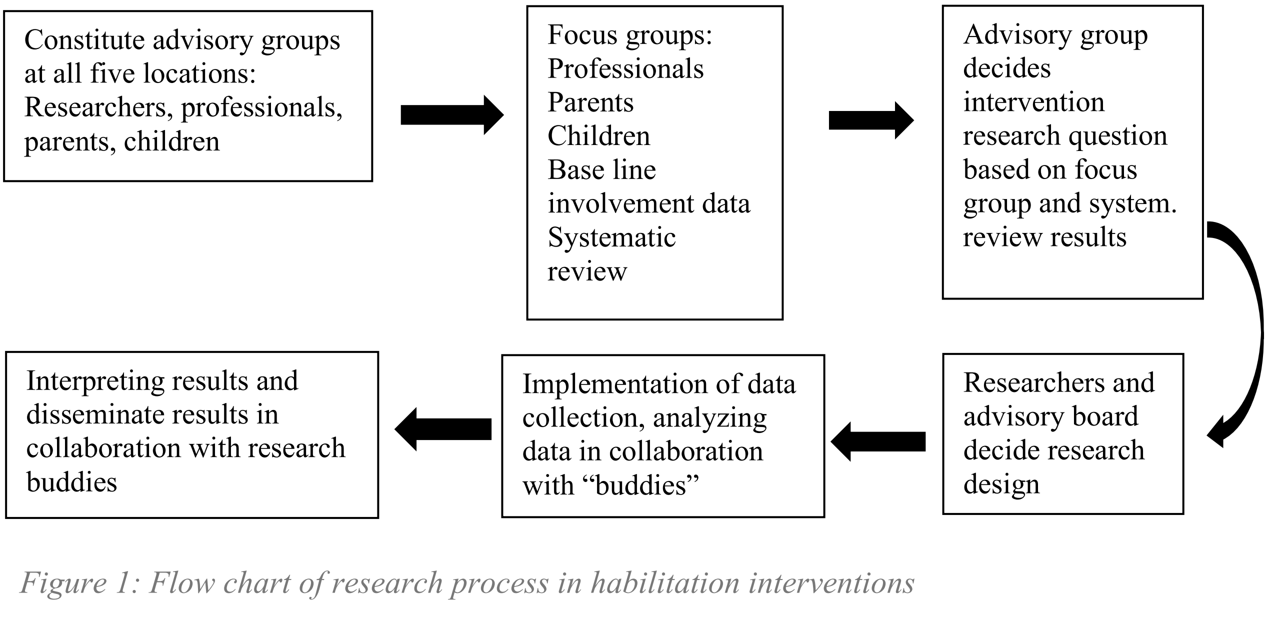

Figure 1: Flow chart of research process in habilitation interventions

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 centres. 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. 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.

Preliminary results for CHILD-PMH (based on research questions)

1) *To investigate the longitudinal interrelationships between the two dimensions of participation – attendance and involvement in a life situation*

We have used data from the longitudinal study LoRDIA to investigate the longitudinal relationships between the two dimensions of participation over three time points for adolescents with and without self-reported NDD (Augustine et al, 2021). Concerning participation, adolescents with self-reported NDD rate their participation lower than adolescents without NDD, but this difference decreases with age. Gender differences increased with age, with girls reporting higher participation. Social participation with peers is relatively stable over three time points while participation in home activities increases, especially for boys.

Longitudinal analyses of FUNDES data (care provider rated) and PMP data (self-ratings children) from PMH not yet analyzed.

2*) 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.*

A first cross-sectional study of the relationship between mental health problems and wellbeing has been published (Täljedal, Granlund et al, 2023). The aim was to identify patterns of mental health problems and well-being in children with disabilities in Sweden, and investigate how parental background (migration, education), and child cognitive level were related to these patterns. Cluster analysis was used to analyze parents' ratings of conduct problems, emotional symptoms, and prosocial behavior on the Strengths and Difficulties Questionnaire (SDQ) in children with disabilities (n = 136). The influence of parental background (migration, education) and child cognitive level on cluster membership was explored through multinomial logistic regression. Five clusters of mental health patterns emerged. Three clusters had mean ratings near or past clinical cut-off for one each of the SDQ-subscales. One cluster had difficulties on all three subscales. Greater child cognitive difficulties increased the likelihood of low prosocial behavior (OR 2.501, $p < .001$) and of difficulties on all three subscales (OR 2.155, $p = .006$). Parental background did not influence cluster membership. Children with disabilities display varying patterns of mental health problems and wellbeing. Relatively high well-being (as indicated by high prosocial ratings) can occur simultaneously with mental health problems. Awareness of the complexity of mental health patterns among children with disabilities is important. Screening and support for emotional symptoms and prosocial behavior deficits should be considered for children with conduct problems.

Regarding the longitudinal trajectories of mental health problems, data from the systematic review of longitudinal studies of mental health problems in children with disabilities (Danielsson, Imms et al, 2023) reveal that:

- Few studies are based on self-reports, proxy ratings are much more common.
- Mental health problems in children with neuro-disability are often stable over time. In almost half of the longitudinal studies included in the review, change was smaller than 10% when comparing the first and last datapoint.
- When a change occurred, it was more likely to be in the form of an upward trajectory for internalizing problems, mirroring findings in children with typical development (Costello

et al., 2011), and a downward trajectory for many outcomes that could be described as externalizing behaviors.

- Outcomes measured using the two most commonly applied scales (CBCL and SDQ), show that children with ADHD and ASD tend to start at higher levels of internalizing and externalizing problems, than other diagnostic groups.
- It was more common that children with ADHD or ASD were the populations of interest than those with primary physical disorders, such as CP or SB.
- Most studies have focused on middle childhood – ages 5 to 15 years, with only a few studies beginning to follow children in earlier childhood or later adolescence.

Concerning factors related to the trajectories of mental health problem the systematic review reveals that:

- Few of the included studies reported information on specific variables mediating or moderating the direction of trajectories over time.
- Many of the factors found to be associated with the longitudinal trajectories of mental health problems in children with child-onset disabilities in the present review are similar or identical to factors identified in studies with typically developing children.
- Some factors identified are more closely related to the disability itself, e.g., the severity of insistence of sameness or other autistic traits in children with ASD, the presence of comorbid conditions (ID and/or ASD), and other aspects of child functioning (e.g., communicative functioning and/or adaptive behavior).

The longitudinal study of adolescents with self-reported NDD using LoRDIA data (Augustine et al, 2021) reveals that self-ratings of hyperactivity are more stable over time than ratings of emotional problems/sadness for both for adolescents with and without NDD but with higher initial levels for adolescents having self-reported NDD. The stability in ratings of hyperactivity supports the idea that hyperactivity more is a sign of impairment than a mental health problem (Granlund et al, 2021). Emotional problems have an increasing trend with difference between groups decreasing. The statistical correlations between participation frequency and importance (a proxy for involvement) and mental health (as measured with MHC-SF) are strong while the negative correlations between aspects of participation and mental health problems are low. Girls rate more problems than boys, especially at 17 years of age. The pattern of relations between mental health, mental health problems and participation confirm the dual continua hypothesis and that participation primarily is related to mental health with a weaker relation to mental health problems.

Using Taiwanese data the “Longitudinal Trends of Participation in Relation to Mental Health in Children with and without Physical Difficulties” (Hwang, Chang, Granlund, Imms, Chen, Kang, 2021) have been investigated. The study aimed to investigate the longitudinal relationship between independence in activities (capability) and frequency of attendance in activities, in relation to perceived mental health problems in children with and without PD. The participants were a convenience sample of parents of 77 school children with PD and 94 TD children who completed four assessments with a one-year interval between each assessment. Parents of these children were interviewed with the Functioning Scale of the Disability Evaluation System - Child version (FUNDES-Child). Three dimensions of mental health problems - loneliness, acting upset, and acting nervous - were rated by parents with the Child Health Questionnaire (CHQ). Linear trend was tested by repeated-measure ANOVA. The results revealed different longitudinal patterns of independence and frequency of attendance over time for children with PD and TD. Frequency of attending activities seemed to be more important than independence in performing activities for experiencing less mental health problems. Children high in attending activities report fewer mental health problems partly independent of capability/independence of the child.

The findings highlight the need for supporting children’s actual attendance in daily activities which may benefit their later mental health.

Our ideas that: wellbeing can occur simultaneously as having mental health problems and that wellbeing has a stronger positive relationship to participation than the strength of the negative relationship to mental health problems is supported by the results of several of the cited studies. Maybe participation interventions can enhance wellbeing and protect from mental health problems? This remains to be proven.

3) *To investigate how children and parents perceive that they participate in the different steps of the intervention process and/or group programs* (identify problems, explain problems, set goals, design, and implement methods).

Because of the low number of participants triangulation aimed at finding similarities between data sources (children, parents and professionals in both parts of the program) and data collection methods (two questionnaire studies, focus groups and a scoping review) have been used here.

As part of the longitudinal study care providers to the children in the two cohorts respond to the five questions about their involvement in the intervention process. Involvement is rated on a five-point scale from 1) professionals make plans and decide alone to 5) parents make plans and decide alone. Data from the first data collection show that care providers rate that they make up a plan for child assessment (Q1) and decide on a plan for support and intervention (Q3) in collaboration with professionals. Concerning (Q2) involvement in child assessment, opportunities for family members to receive support (Q4), and family involvement in planning and deciding on intervention methods (Q5) there is larger variability and lower mean ratings. The same pattern is seen in the ratings from care providers providing responses anonymously in the second part of the program (habilitation intervention part). Overall the result indicates that parents are more involved in planning and goal setting decisions (activities usually occurring in the habilitation plan meeting) than in decisions and planning regarding how to implement and evaluate decided support/interventions (occurring partly after planning meeting).

In the habilitation intervention part of the program care providers and children were asked to rate their engagement in a single session with professionals, and also to rate their involvement in the process. A preliminary analysis of the data shows a tendency that children rate items related to their knowledge and understanding of intervention methods lower, e.g “I can imagine how the intervention plan should work”, I estimate that I can manage the intervention tasks” and “I feel I was actively involved in planning” lower than items that concern goals.

Focus groups/individual interviews with children, care providers and professionals were analyzed with a deductive content analysis based on the steps in the intervention process; 1) Assessment/identifying problems, 2) Explaining problems/set goals, 3) Design and implement method, 4) Evaluate method implementation and goal attainment. In addition, support and intervention focused on the family were discussed. The deductive content analysis of the focus groups indicates that the subcategories stakeholders identified are the same areas as the questionnaires “Involvement in the process” and PRIME. That is, regarding involvement in the process care providers and children are especially concerned about their involvement in decisions and planning regarding the implementation of interventions. Themes within these steps of the process concern clarity and concreteness, understanding why interventions are done and the individualization of information and goals.

A scoping review (Antoniadou, Granlund & Andersson) (in review after revisions) aimed to investigate the strategies used by professionals in pediatric rehabilitation to engage children in every step of the intervention process, including assessment, goal setting, planning and implementation of the intervention, and results evaluation. In total, 20 studies were included in the review. Pediatric professionals reported that therapeutic use of self and their own engagement in the intervention facilitated the establishment of a supportive relationship. Providing clear explanations about their role and therapy rationale developed positive expectations. By making the child feel successful within-session and outside-session activities, professionals enhanced child mastery. Professionals' strategies were abstractly described and primarily concerned clinic-based interventions. Further research is needed to investigate strategies that are effective in the different steps of the intervention. More observational, longitudinal studies are required to capture fluctuations in in-session engagement.

4) *To develop and evaluate accessible interventions aimed at increasing child and family participation in the intervention process*

The work of deciding on which changes interventions aim at, deciding on intervention content and how to evaluate interventions is done in the four regions. An overarching theme seems to be how to increase the active engagement of children and care providers in planning and implementing support and intervention. Interventions are implemented and evaluated during fall 2023 and spring 2024.

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 process, and 3) change of organizational routines and professionals way of working aimed at having more goals of intervention focused on participation and the active involvement of children and care providers in the intervention process.

Instruments:

FUNDES Child-SE - Child (Functioning Scale of the disability evaluation system) based on the CASP (Child and adolescent scale of participation) measure used for proxy ratings was originally validated in Taiwan reporting good validity and reliability. In Sweden, scales concerning engagement in activities attended and barriers have been added after forward and backward translation. Cognitive interviews have been undertaken to investigate content validity (Axelsson et al, 2021). Test-retest of a new version (20 items) (Gothilander et al,2023) show acceptable reliability and construct validation (CFA) is ongoing (Gothilander et al, submitted.). The instrument includes four scales: 1) level of independence in performing activity, 2) frequency of attending activity, 3) engagement in activity and 4) barriers for participation.

Picture My Participation (PMP) used for self-ratings has been validated with data from South Africa, China, and Sweden. Content as well as construct validity is acceptable to good (2019, 2020, 2021). Questions are asked about frequency of attending, engagement, and are asked to select 3 important activities. For these, questions are asked about facilitators and barriers for participation.

Styrkor och stress i föräldraskapet (SSF) based on Family Impact Questionnaire (FIQ) (Donenberg & Baker,1993) In a validation study data from both HabQ data and the first wave in CHILD-PMH was used for testing construct validity and test-retest validity. Regarding construct validity a validation article is published (Ivarsson et al, 2023). Results confirm the original factor structure.

Validating PRIME

Based on the COSMIN manual the PRIME measure is being validated for Sweden. In a pilot study content validity has been investigated. Construct validity and internal consistency is currently being analyzed with data collected fall 2021 (Lundqvist et al).

Young people with disability and complex communication needs (CCN) face barriers in accessing services to address poor mental wellbeing or mental health problems (di Marco & Iacono, 2007). This may be, in part, due to a lack of appropriate screening or assessment tools and outcome measures for this population. A systematic review is implemented to identify and evaluate the psychometric properties of mental health screening and assessment tools used with people with CCN. (Pennachia, Imms, Coghill, & Granlund, in progress).

Identifying and evaluating instruments measuring mental health in children with disabilities – a scoping review (Torres Cabo, Ivarsson, & Granlund, in progress) Data bases were searched for studies using measures of mental health/wellbeing with children with disabilities, The measures identified in the studies were analyzed based on the broad definition of wellbeing provided by Keyes dual continua model. The result reveals that few measures cover emotional wellbeing, psychological wellbeing, and social wellbeing. Frequently measures are not adapted to the target group.

An ongoing project aims to develop an adapted version of Keye's MHC-SF (Mental health continuum-short form) questionnaire in collaboration with students with mild ID. In focus groups the students have provided input on item content and scale used. A preliminary instrument covering the three aspects of wellbeing, emotional, psychological and social, is currently being tested for psychometric validity through structured interviews with children in wave three and four of the CHILD-PMH data collection. The data also allow for a test of concurrent validity using parents proxy ratings of their children's life satisfaction (Cantril's Ladder), (Ivarsson, Almqvist, Eriksson & Granlund, in progress).

Assessment routines:

In a survey study, researchers who conducted structured interviews with children with disability in CHILD-PMH responded to questions about the type and degree of spontaneous adaptations of material and procedure when interviewing the children with developmental disabilities. Type and degree of adaptations is related to child and interviewer factors (Ivarsson, Danielsson, Almqvist, Imms & Palmqvist, in progress).

A quasi-experimental study in collaboration with children in PMH investigating the effect of common forms of adaptations aiming at lowering cognitive demands in self-rating scales of mental health problems and thereby making them accessible for children with intellectual disability (Ivarsson, Danielsson, Almqvist, Imms & Palmqvist, in progress).

A mixed methods study aims to understand key stakeholders' experiences of communicating about mental health and mental health problems with persons having CNN who use AAC. The study also aims to identify the extent to which the language (words, concepts, ideas) required to communicate about mental health or mental health problems is available and accessible to those with CCN (Pennachia, Imms, Coghill, & Granlund, in progress).

Kang et al (2023) have developed and evaluated the usability a web-based application of PMP where structured interviews with children were done with the help of an interface The feedback indicated that the interface was simple to operate by the healthcare workers and was attractive and motivating to children.

Ivarsson et al, (2023) investigated the feasibility of administering a self-rating instrument measuring participation, Picture My Participation (PmP), via a video communication tool (Zoom), to children with DD. Materials and methods: PmP was administered to 17 children with DD (mean age 13 years). The pictorial representations of activities and response options in PmP were displayed in a shared PowerPoint presentation, enabling nonverbal responses with the annotate function in Zoom. Child and interviewer perceptions of the interview were measured through questionnaires developed for the purpose. Results: All the children completed the interview. Most PmP questions were answered, and no adverse events were registered. Technical issues could generally be solved. No special training or expensive equipment was needed for the interviews. Conclusion: Interviewer-guided self-ratings of participation and related constructs through video communication may be a feasible procedure to use with children with DD from age 11.

Organizational routines and professionals' way of working:

Traditionally many interventions for children with disability have been focused on lessening impairments in body functions and ability to perform skills. Is this still the state of the art in research and practices? Two scoping reviews have studied what researchers interested in clinical applications and interventions publish concerning goals of communicative interventions focusing on the use of AAC for persons with CCN and studies concerning the mental health and mental health problems of persons with CNN using AAC.

A scoping review of communication intervention studies using AAC (Prinsloo et al, 2023) aimed to summarize and map the AAC intervention outcomes for children with complex communication needs onto the Family of Participation-related Constructs (fPRC) framework. The scoping review identified 270 studies for inclusion, and the data gathered was extracted and mapped onto the fPRC framework. The results indicate that although many studies have reported on participation-related constructs such as activity competence and context, there is still insufficient focus on attendance and involvement (appr 20% of the studies), whole almost all measured skills. Hence, future research in the field of AAC is needed on participation as on outcome of intervention.

Considering that few studies describing mental health and mental health problems in persons using AAC a scoping review aimed at review existing knowledge about the mental health, mental health problems, and predictors thereof, for people with CCN who use AAC (Östvik, Granlund & Rösland-Seim, in progress). After searching databases using inclusion/exclusion criteria and a "hand search" of references nine studies were included. The low number of studies identified indicate a research gap concerning children and youth using AAC and mental health/mental health problems. One reason might be that using AAC is a functional description rather than a diagnostic category, and children using AAC can be found in many diagnostic groups. Most prevalence studies are based on diagnostic groups. The low number of studies also indicate that probably few people who use AAC and have mental health problems today receive support adapted to their need for AAC to communicate.

Most measures of participation are proxy ratings where parents or other important care providers rate the participation of children with disabilities. These ratings are then used as a basis for intervention. There is a need for self-rating instruments where children themselves can rate their participation. Such self-ratings can lead to children getting more control over decisions made about what participation problems to work with. To investigate whether children's ratings make a difference. Two studies have investigated the degree of agreement between children and parent's ratings of participation with the help of PmP (Dada et al, 2020, Zheg et al, 2023). The results of the studies show that children's ratings can't be predicted based on parental ratings. A conclusion is that it is important that professionals invite children to self-rate their participation.

Appendix 1 Publications in CHILD-PMH

Articles in refereed journals

1. Augustine, L., Lygnegård, 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
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, AK., Augustine, L., Brooks, R., Danielsson, H., Gothilander, J., Ivarsson, M., Lundqvist, L-O., Lygnegård, 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., Lygnegård, 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*
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