CHILD
Research profile at Jönköping University

Participation and Mental Health (CHILD - PMH) program update spring 2025

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Research profile at Jönköping University

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Participation and Mental Health (CHILD-PMH) program update, April 2025

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 also 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 (Arvidsson et al, 2014 Arvidsson et al; Augustine et al, 2021) 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 often 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, as well as participating in a systematic review study on capacity building (Ryan et al, 2025), we have aimed 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 a disability and persons and objects in the environment that influence each other over time, where behavior and behavior changes in the child lead to changes in the environment and vice versa (Bickenbach et al, 2023). It means that when working with mental health problems, and mental health and how that **impact** participation across childhood, we need information about both child factors 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 (Granlund et al, 2021). In addition, mental health problems (sadness and conduct problems) have been clearly delimited from impairment-related constructs by excluding aspect of functioning such as hyperactivity and communicative problems. Since partly the same criteria are used for NDD problems and mental health problems, this might lead to an

overestimation of mental health problems among children and youth within the NDD spectrum. In a recently accepted study (Ivarsson et al, 2025) from our program, we can see that in longitudinal studies of mental health problems, data on mental health problems are seldom explicitly separated from data also used in defining NDD problems.

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 pathways is less well known. In this program we have used data from our own longitudinal study, data from *The Gothenland Millenium Cohort* study as well as cross-sectional register data from the BarnULF and ULF national surveys (Statistics Sweden) on living conditions to investigate the relations between mental wellbeing, mental health problems and participation.

Nor is it well known, if and how services are provided to children and parents directly affects the participation and mental health of children. In our program, we have related data on children's mental health problems and mental wellbeing to parental ratings of how they experience their involvement in the habilitation process, as well as their ratings of family stress and family strengths.

Participation in the intervention process

Earlier longitudinal studies indicate that high child and care provider involvement in the intervention process may promote wellbeing both in children 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 overall and in individual sessions has not been studied. In the program, we have asked parents to rate their involvement in the habilitation process once a year for four years. We have collaborated with habilitation centers in four regions in this work.

Participation as a unifying program construct

In this research program, the relationship between the two participation dimensions, attendance and involvement (Imms, Granlund et al, 2017), 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. Our previous studies indicate that assessment instruments and methods for family-professional encounters are needed. These instruments should be designed to support children in reporting their own participation, mental wellbeing and perceived mental health problems, and also support parents' active involvement in planning and implementing support. A key issue for success in this work is that children and families are not only research subjects but also actively involved in planning and implementing the research. Active involvement can be enhanced both by how professionals relate to children and parents and by using adapted instruments and procedures when interacting with the children. Both these two aspects have been addressed in the program.

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 the formulation of information materials. In addition, new or revised instruments concerning participation, mental health, and family stress have been developed based on child 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 taken part in decision-making about the research process throughout the whole program period. In addition, the experiences of members of the advisory boards have been discussed in focus groups (Huus et al, in prep.). In a parallel program in Australia, Cp-Achieve, in which researchers from PMP took part, the experience of inclusive research has led to an article collaboratively authored by people with disabilities and researchers (Kilgour et al, 2024). In conjunction with collecting data about the mental health of young people who use AAC (Augmentative and Alternative Communication) for interacting with others (Pennacchia et al, submitted a) we have also published a paper on how to adapt the research process to individuals using AAC (Pennacchia et al, submitted b).

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 who are involved in one or more program projects or 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	Gillian King	Christine Imms David Coghill Jacinta Pennacchia

Associated senior researchers linked to the program

Associate professor Lin-Ju Kang, Chang Gung University, Taiwan
Professor Dana Anaby, McGill University, Canada
Professor Shakila Dada, University of Pretoria, South Africa
Professsor Dido Green, Jönköping University
Dr Vera Kaelin, Umeå University

Design and method of the longitudinal study

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

Participants: For the prospective study, children and their families were recruited from the two age cohorts from five regional habilitation centers that consented to participate (Östergötland, Örebro, Västmanland, Jönköping and Gävleborg). All children in these centers within the specified age ranges in 2019 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 much higher than expected (90%). For the same 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 waves, we included structured interviews with children. The number of newly arrived refugee families from the Middle East/Africa has affected the characteristics of the population of children with disabilities in Sweden. A rough estimation based on our sample indicates that somewhere between 30 % to 40 % of the population has this background. All survey materials were translated into the frequently occurring languages

Participating families	2020/2021 respondents	2021/2022 respondents	2022/2023 respondents	2023/2024
Cohort 1 Younger children	68 care providers 0 children	44 care providers 21 children	40 care providers 12 children	36 Care providers 32 children
Cohort 2 Older children	71 care providers 0 children	58 care providers 46 children	55 care providers 31 children	44 care providers 13 children
Total	139 care providers 0 children	102 care providers 67 children	95 care providers 43 children	80 care providers 45 children

Procedure: After being invited through gatekeepers at habilitation centers, families that provided 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 (SSF), and encounters with the habilitation services.

Data was collected via web-based questionnaires and/or structured telephone interviews completed by parents. Data from children was collected during spring 2022, spring 2023, and spring 2024 with the help of structured face-to-face interviews or zoom-based structured interviews.

Data analyses and statistics

The type of analyses done on the longitudinal data is 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.

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 methods that enhance child and family involvement in the habilitation process. A co-production inclusive research paradigm is implemented using scoping (Antoniadou et al, 2023) and systematic (Andersson et al, in prep.) reviews, focus groups with children, parents, and professionals, and co-produced interventions as displayed in Figure 1 (as of spring 2025 we have completed some of these interventions but are still implementing two interventions aiming at affecting the habilitation process to increase the active participation of children and care providers):

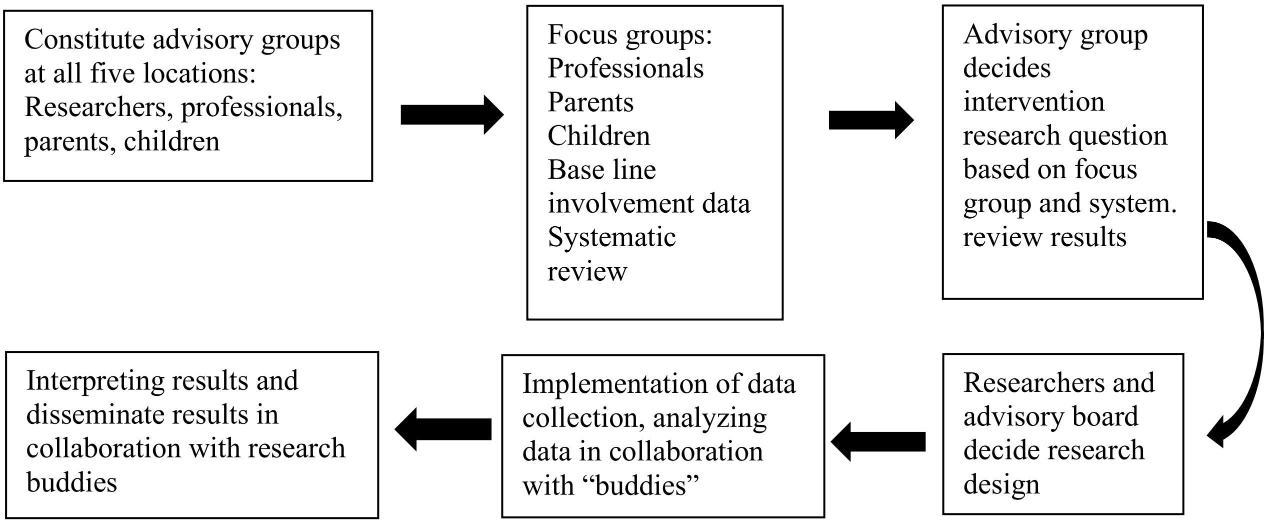

Figure 1: Flow chart of research process in habilitation interventions

<u>Participants:</u> Participants were professionals working in four regional habilitation centers 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.

<u>Procedure:</u> 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 (Huus et al, xx). The overall research aim is to increase child and parent involvement in the intervention process - this sets the limit for the 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 have been implemented within the four sites.

The interventions are focused on the different steps of the process, with aims such as increasing frequencies of planning meetings that children attend, child involvement in identifying problems to work with, child involvement in goal setting and finally 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 Gothenland Millenium Cohort study* 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 participation data from FUNDES (care provider rated) show that both attendance restrictions and involvement restrictions (as compared to children without disabilities) are stable over time, with higher restriction ratings in the younger cohort. In addition, parent proxy ratings of attendance and involvement restrictions are higher for activities outside home and school, with especially high restrictions in social activities. This pattern is stable over time.

Concerning child self-ratings of participation, longitudinal analyses of attendance and involvement scores over three time points show that self-rated participation is stable over time. Due to the relatively stable mean values of total score in attendance and involvement, an alternative analysis was applied based on change scores for single items. Using data from the first and second PMP data collections (child self-ratings) and the second and third data collections respectively, the tendency for change in different activities was analyzed on an individual level. Overall, most items reveal a less stable pattern with changes in both positive direction (towards higher scores) and negative direction (towards lower scores). Overall, the changes had a weak tendency towards lower ratings over time. The negative changes, especially for attendance, concerned activities implemented in home/family environments.

Unpublished in-depth analyses of the conceptual structure of the two participation measures FUNDES (proxy-rated) and PMP (self-rated) reveal that items for attendance ratings form into a higher number of factors (based on contextual similarities) than involvement ratings for both measures. These results in combination with the lower change scores for involvement compared to attendance indicate that attendance and involvement are conceptually distinct with attendance capturing contextual information (e.g. role expectations related to age) to a larger extent while involvement seems to have a stronger dependency on person characteristics (e.g. the same individuals seem to exhibit higher or lower involvement partly independent of context). In the longitudinal analyses, there was a weak tendency that the number of activities with greater changes between time points was higher for attendance than for involvement.

To further analyze the involvement construct, we are now taking part, with Vera Kaelin, Umeå University as lead author, in investigating how adolescents talk about involvement experiences. The study is based on data from 33 qualitative studies where children with disabilities have described their involvement experiences. Five themes were found with intensity of involvement here and now being the main theme, surrounded by four themes focusing on different contextual aspects of the experience (Kaelin et al, submitted).

<u>Conclusion question 1:</u> The results reveal that participation, as rated by parents (proxy-ratings) and children (self-ratings), is relatively stable over time. In comparison to children without disabilities, participation (both attendance and involvement) is lower, and participation restrictions are greater. A strong tendency is also that activities taking place outside the home and school show lower participation/greater restriction for both attendance and involvement.

Attendance and involvement show different structural patterns, with attendance having a stronger link to the context of the activity, while involvement partly seems to follow the child. This means that some children seem to exhibit higher involvement, independent of what activity they participate in. A central feature in involvement seems to be the degree of involvement here and now in an activity. For children talking about their involvement, this experience of being involved is related to dimensions of experiences, e.g. achievement and sense of belonging.

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.*

Concerning wellbeing/mental health, data was collected from parents and children with the help of Cantrill's ladder (assess perceived life satisfaction) over all four time points. This instrument was considered too general in the information provided, and therefore a self-report measure of wellbeing based on a simplified version of Keyes' MHC-SF, with 9 items, was developed and added in wave III and IV. The ratings made by parents and children do not overall show a strong correspondence, and therefore we present parental ratings and self-ratings separately. For children (self-report), the results from the three waves of data collection with Cantrill's ladder show that the ratings are relatively high and stable over time. Children's self-ratings with the new wellbeing measure over two time points also show stability.

Mental health problems were assessed with the help of SDQ. The questionnaire was administered both to parents (proxy report at each wave) and children (self-ratings older cohort at waves 2,3 and 4). Due to difficulties with responding to questions, some children did not participate. In the analysis, items that could also be interpreted as questions about symptoms of a specific NDD diagnosis or impairment) were removed. Thus, the subscales of hyperactivity and peer problems were not included in the analyses. The results of the children's self-ratings reveal that most children rate low levels of emotional problems and conduct problems, but higher ratings of prosocial behaviors. There is a decreasing trend over time for all types of behavior problems. Concerning parental ratings, levels are stable over time at a bit higher level than children's ratings. The prosocial scale in SDQ (parent ratings) predicts higher ratings of life satisfaction made by parents as well as frequency of attendance in activities rated by parents. The negative relations between conduct problems and participation/life satisfaction are lower. The prosocial scale is however negatively correlated with emotional problems.

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 the clinical cut-off for each of the SDQ-subscales. The children in one of the clusters 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. This study shows that 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 both emotional symptoms and prosocial behavior deficits should be considered for children with conduct problems.

In another cross-sectional study (Homman, Augustine & Granlund, submitted) based on register data from the Statistics Sweden national living conditions surveys (ULF and Barn-ULF) was used to test the applicability of the dual continua model (Keyes, 2002) to explain mental health wellbeing as well as mental health problems in adolescents with disabilities. Latent class analysis was performed. Possible factors influencing mental wellbeing were investigated, including participation. The analyses supported the dual continua model. Overall, in classes with lower mental wellbeing and higher mental problems adolescents with NDD were overrepresented. High participation in everyday activities was more frequently seen in classes with higher mental wellbeing for both adolescents with and without disability.

A longitudinal study of adolescents with self-reported NDD using data from *The Gothenland Millenium Cohort study* (Augustine et al, 2021) reveals that self-ratings of hyperactivity are more stable over time than ratings of emotional problems/sadness for both 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 is more a sign of impairment than a mental health problem (Granlund et al, 2021). Emotional problems increase. while the differences between groups decrease. 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 lower. Girls rate more problems than boys, especially at 17 years of age. The pattern of relations between mental health, mental health problems, and participation confirms the dual continua hypothesis and that participation is primarily 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) has 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. The frequency of attending activities seemed to be more important than independence in performing activities for experiencing fewer mental health problems. Children high in attending activities were rated as having 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.

The adapted Swedish version of FUNDES (FUNDES-CHILD.SE) was used in a cross-sectional study to investigate predictors of parent-rated attendance, involvement, and independence for children with disabilities (Axelsson eta al, 2025). The strongest predictor for all three variables was the child’s level of comprehension when interacting with others.

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 data points.
- 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 problems 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).

Conclusion question 2: The results of our studies support the idea that wellbeing can occur simultaneously as mental health problems and that wellbeing has a stronger relationship to participation than to mental health problems. The weak correspondence between child and parental ratings of wellbeing/life satisfaction indicates that it is important to also ask the children themselves. Ratings of prosocial behavior made by parents and/or the children tend to co-vary with higher life satisfaction and less conduct problems, as well as less parent-rated participation restrictions. Less conduct problems are also related to less reported parental stress. The relationship between ratings of life satisfaction and participation indicates that participation primarily affects well-being/life satisfaction rather than decreasing mental health problems. If participation interventions can enhance wellbeing and protect from mental health problems 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 traditional large sample quantitative analyses were not possible. 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 at four time points.

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 responding 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 concerning the child (activities usually occurring in the habilitation plan meeting) than in decisions and planning regarding family support, and partly how to implement and evaluate decided child support/interventions (occurring partly after planning meeting). The ratings of involvement made by parents are relatively stable over the four time points.

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 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 the development of 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/setting goals, 3) Design and implementation 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.

An inductive qualitative analysis of how young people with disabilities experience their involvement in the habilitation process (Karlsson et al, 2025) shows that how young people perceive participation in the habilitation process is based on environmental factors, such as information provision, and that the professionals strive for the young people’s voices to be heard by including them in planning. In conclusion, the important aspects of participation are a young person-friendly environment and individual support from adults.

A scoping review (Antoniadou, Granlund & Andersson, 2023) 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, with a special focus on distance coaching. More observational, longitudinal studies are required to capture fluctuations in in-session engagement.

Conclusions question 3: The habilitation process is rated as partly family and child-centered. The five items in the "involvement in the process" have median ratings of three, shared responsibility where parents rate some influence over the process. The involvement of child and family is rated higher for the four items related to child interventions and lower for the items related to interventions with a family focus. The same trend is seen in the deductive analyses of focus group data. Of special concern are the families having children with behavior problems (conduct). They rate their satisfaction with the support they receive from professionals lower, their informal support lower (Täljedal et al, 2024) as well as their involvement in the family support provided lower. Young people with disabilities experiences of their participation in the process (Karlsson et al, 2025) confirm the same pattern. The process is partly family/person-centered but individual professionals must learn not only to build a trustful relationship with children and families but also apply strategies that build the capacity for autonomous problem-solving in children and parents

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

The collaborative work of deciding on what changes in the habilitation process interventions should aim at, deciding on intervention content and how to evaluate interventions were implemented in the four regions. The research questions and design of the studies were done by the regional reference groups over a time period of 10 to 18 months. An overarching theme of the interventions designed seems to be how to increase the active engagement of children and care providers in planning and implementing support and intervention. The decided interventions were implemented and evaluated in 2024 and are still ongoing in two regions. The interventions are focused on single steps of the habilitation intervention process from inviting families to planning meetings to implementing methods for child goals.

- The first study aimed to increase the proportion of habilitation planning meetings that children attended (Karlsson & Granlund, in prep.). All meeting documentation requires that the persons who attended are documented. A count of the proportion of meetings the child attended in the last six months before the change was implemented was done, the children attended between 30 and 40% of the meetings. A change in invitation documents and routines was implemented. The "old routine" was that an invitation was sent to the family together with a material asking about child difficulties. In the new routine, the same document was sent to the families, but the children were sent an individual invitation with a picture-based questionnaire asking questions to the child about desired changes. When the proportion of planning meetings was calculated after installing this change the proportion of meetings that children attended had raised to 70%. However, due to a change in routines the whole process of planning was later changed and the separate invitation to children was not used.
- A second study aimed at increasing child involvement in selecting problems to work with and formulating one or several goals for intervention (Augustine & Huus, in prep.). A preparatory meeting where the child met with one professional to discuss what they liked to work with was initiated for some children. As a support the professionals used the PEGS material developed to support children in rating their competence in performing everyday activities and then based on those ratings select one or two everyday activities to work with. Finally, a preliminary goal was formulated. The child-generated problems and goals were brought to the habilitation planning meeting to be discussed. The goals set at the meetings were collected and analyzed for content. The results reveal that some of the goals decided upon at the planning meetings were based on child-generated ideas, but the majority of the goals were not based on child priorities. The analysis of goals revealed that many intervention goals were formulated as methods rather than goals. It also revealed that few goals were focused on participation problems. Goals set by

children in collaboration with professionals tended to be formulated as goals more frequently than goals formulated solely by professionals and parents.

- A third study aimed at motivating and supporting the children in implementing strategies/methods for reaching decided goals (Andersson & Granlund, in prep.). A manual for guiding professionals in how to coach children and families in implementing methods "on distance" was developed based on the CPS (collaborative problem-solving). Once a month the professionals met with the researchers to discuss their work with coaching based on the manual. Preliminary results reveal that the manual was useful and that professionals applied techniques for distance coaching in regular short meetings via Zoom or FaceTime. The child reached his goal of maneuvering his electrical wheelchair better which allowed him to independently visit a local store for shopping.
- A fourth ongoing study aims to explore the impact of two distinct needs assessment models on children's participation in the needs assessment process (Lundqvist et al, 2024).

  A prospective observational study comparing responses from children subjected to two different needs assessment procedures survey-based and meeting-based. Supplementary data is collected from the children's parents/guardians and healthcare professionals. Data collection methods will include questionnaires, interviews, and document analysis of individual habilitation plans. We aim to recruit 120 children aged 7–17 diagnosed with ASD but without intellectual disability, with 60 undergoing the survey-based needs assessment and 60 undergoing the meeting-based assessment. The primary outcome measure will be the perception of participation in the needs assessment procedure. Secondary outcomes will include the children's quality of life and mental health; the parents' knowledge of their child's strengths, abilities, and special needs; and the parents' perception of the quality of collaboration with the habilitation team.

In a study led by Taiwanese researchers (Liao e al, 2025), we have evaluated the utility of using a collaborative problem-solving strategy (Björck, 2017, Granlund & Imms, 2024) to involve children and parents in participation interventions. Children (with support from parents) selected participation problems to work with, explained problems, set goals for intervention, and contributed to the design of a method to reach the goal. Participants reported that collaborative problem-solving is feasible, and most children have reached their goals.

<u>Conclusions question 4:</u> The implementation difficulties in the studies illustrate the difficulties with implementing changes within habilitation organizations in Sweden. The organizations are constantly in some form of change, e.g. new routines, changes in documentation systems, political decisions, e.g. not allowing a child to be put on a waiting list for more than one week. This internal competition among organizational tasks and goals is stressful for professionals. The interventions that the reference groups developed were in all regions based on a voluntary basis where professionals could spend time on the interventions if they estimated that they had time for it. Thus, it was very difficult to recruit professionals to the interventions. In one region it was decided on an organizational level to try out a new way of working (autism team intervention). Concerning the interventions, two of the four interventions could only be implemented as case studies (study 2 and 3). Overall, the results of the interventions indicate that effects on child involvement in the habilitation process can be seen also after only small changes to routines in encounters with children and families. The results also indicate that professionals have difficulties with setting goals and supporting the implementation of interventions.

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,

e.g. the meaningfulness and feasibility of child interventions (Dunst et al, 2019). In addition, we know that there is a relatively strong relationship between participation and wellbeing (Augustine et al, 2021; Homman et al, submitted). This relationship is probably applicable both to the 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

Developing, adapting, and validating 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. A construct validation (CFA) study of FUNDES -SE Child- (Gothilander et al, 2024) revealed that confirmed the subscales. The included four scales are: 1) level of independence in performing activity, 2) frequency of attending activity, 3) engagement in activity, and 4) barriers for participation. The activities rated are the same for all subscales. An interesting result is that more factors were identified in the frequency of attendance than for the level of involvement. It might indicate that attendance has a stronger relation to the environment than the involvement ratings that more strongly mirror personal characteristics.

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 (Arvidsson, Huus, Dada et al., 2019, 2020, 2021, 2024). Questions are asked about frequency of attending, engagement, and children are also asked to select 3 important activities. For these, questions are asked about facilitators and barriers to participation. Primarily the frequency (attendance part) has been validated. Studies validating the engagement/involvement ratings are needed. Preliminary data show the same pattern (more factors found for attendance ratings than for involvement ratings) that is found for FUNDES, rating it indicates that these two dimensions are partly independent of each other and may need different types of intervention. Although the mean self-ratings of attendance and involvement are stable over time, an analysis of item level reveals a considerable variability in how different items are self-rated over time. This variability needs to be further investigated.

Styrkor och stress i föräldraskapet (SSF) based on Family Impact Questionnaire (FIQ) (Donenberg & Baker,1993) has been validated. In the validation, data from both HabQ (a former habilitation register) and the first wave in CHILD-PMH were used for testing construct validity and internal consistency. Regarding construct validity a validation article is published (Ivarsson et al, 2023). Results confirm the original factor structure if two misfitting items are taken out.

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 are currently being analyzed with data collected in fall 2021 (Lundqvist et al).

Information about mental health and mental health problems for young people with disability and complex communication needs (CCN) is limited (Östvil et al, 2024). Young people with 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 scoping review has been implemented to identify and evaluate the psychometric properties of mental health screening and assessment tools used with people with CCN. (Pennacchia, Imms, Coghill, & Granlund, 2025). A new project focusing on mental health and mental health problems in young people with CCN is currently in the planning stage.

In the submitted study" Identifying and evaluating instruments measuring mental health in children with disabilities – a scoping review" (Torres Cabo, Ivarsson, & Granlund, in review) databases 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 most measures cover only emotional wellbeing, while few cover emotional wellbeing as well as psychological and social wellbeing. Frequently, measures are not adapted to the target group. Therefore, as a part of the program, we aim 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 (in total 9 items) is currently being tested for psychometric validity through structured interviews with children in waves three and four of the CHILD-PMH data collection, with the addition of some more children (ethical approval obtained). The results show that the new instrument is unidimensional. The data also allow for a test of concurrent validity using parents' proxy ratings of their children's life satisfaction (Cantril's Ladder), (Ivarsson, Danielsson, 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 children with developmental disabilities. Type and degree of adaptations are related to child and interviewer factors (Ivarsson, Danielsson, Almqvist, & Imms, 2025). The study has resulted in a survey instrument intended to support researchers and clinicians in reflecting on the adaptations they use when doing structured interviews with children having cognitive difficulties.

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 (Pennacchia, Imms, Coghill, & Granlund, submitted).

Kang et al (2023) have developed and evaluated the usability of 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. 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. 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. 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 (Adair et al, 2015). 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 published 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), while almost all measured skills development(capability). Hence, future research in the field of AAC is needed on participation as on the 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, 2024). 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, Zheng 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. A collaborative problem-solving approach to the habilitation intervention process aimed at capacity building with the aim to support children and families to become more independent in solving participation problems have been presented and discussed (Granlund & Imms, 2024). It is now followed by a systematic review of studies aimed at characteristics of capacity building interventions (Ryan, Anaby, Granlund et al, 2025)

A scoping review of interventions focused on increasing child and family involvement and effects of such intervention on children and families (Andersson et al, in prep.) is ongoing. Preliminary results reveal that most interventions focus on involving children more in setting their own goals for habilitation interventions. Few interve3ntion focus on the effects of being involved in assessment or in implementing interventions oon knowledge and skills necessary for autonomous problem solving in parents and children.

Conclusions linking program parts: Our studies on adapting instruments and routines reveal that children and youth with disabilities (including children with intellectual disability) can rate their frequency of attending activities as well as their involvement when attending and mental health/mental health problems if instruments and procedures are adapted. Regarding organizational routines our studies show that relatively few previous studies have been focused on evaluating the effects on the knowledge and skills necessary for autonomous problem solving and participation of families and children when involving children and parents in the habilitation process. Some studies have focused on adapting instruments and a few on adapting routines for how to involve children to a larger extent. Fostering capability in the intervention process is enhanced by adhering to 4 principles: 1) an individualized approach with real-world applications 2) youth fostering a preferred future 3) youth taking ownership for change and 4) an ongoing process. However, previous studies have primarily been focused on building rapport between professionals and clients rather than on building capacity in the children to manage their own problems. Further research is needed concerning both how to adapt assessment instruments and how to adapt intervention process routines for children with disabilities. In addition, research is needed in how to facilitate a paradigm shift from focusing on skills development in habilitation interventions towards how to facilitate participation interventions.

Appendix 1: Publications in CHILD-PMH, or from the associated program CP-Achieve, and the PMP project relevant for CHILD-PMH

Articles in referred journals

1. Arvidsson, P., Dada, S., Granlund, M., Imms, C., Shi, L. J., Kang, L. J., ... & Huus, K. (2021). Structural validity and internal consistency of Picture My Participation: A measure for children with disability. *African Journal of Disability (Online), 10*, 1-8.
2. 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
3. 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
4. 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*
5. 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*
6. 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*
7. 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
8. 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
9. Dada, S., et al (2020). Agreement between participation ratings of children with intellectual disabilities and their primary care givers. *Research in Developmental Disabilities*
10. 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*
11. Li, L., Møller Christensen, B., Falkmer, M., Zhao, Y., & Huus, K. (2023). Content validity of the instrument 'Picture My Participation' for measuring participation of children with and without autism spectrum disorder in mainland China. *Scandinavian Journal of Occupational Therapy*, 1-11.

12. 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*
13. Zheng, H., Bornman, J., Granlund, M., Zhao, Y., & Huus, K. (2023). Participation of children with long-term health conditions compared to that of healthy peers: a cross-sectional comparative study. *Scandinavian Journal of Occupational Therapy, 30*(3), 334-343.
14. 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*
15. 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
16. Prinsloo, P., Dada, S., Bastable, K., Raghavendra P., and Granlund, M. (2024) 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*
17. Täljedal, T., Granlund, M., Almqvist, L., Osman, F., Norén 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.
18. 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
19. 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
20. 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*

21. 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*
22. 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*

23. Granlund, M., & Imms, C. (2024) Participation as a means: Implications for interventions. *Frontiers in Rehabilitation Sciences*

24. 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*

25. Kang, L-J., Granlund, M., Dada, S., & Huus, K. (2025). Perceived activity competence and participation in everyday activities of children with and without neurodevelopmental disorders. *Physical and Occupational Therapy in Pediatrics*

26. Liao, HF., Liao, Y-T., Chen, L-C., Wu, Y-T., Kang, L-J., Granlund, M., & Björck, E. (2025) Collaborative goal-setting approaches to support participation of children with special educational needs. *Pediatric Physical Therapy*

27. Lundqvist, L-O, et al (2024) Evaluating the impact of needs assessment models on autistic children´s participation in the habilitation process: protocol for a prospective observational study. *BMJ Open* doi:10.1136/bmjopen-2024-089135
28. Pennacchia, J., Östvik, J., Dutia, I., Walsh, M., Coghill, D., Granlund, M., & Imms, C.(2025) Assessing mental health of people with complex communication needs: a systematic review., *Journal of Communication Disorders (2025),* DOI: https://doi.org/10.1016/j.jcomdis.2025.106494
29. Östvik, J., Rösland-Seim, A., & Granlund, M. (2025) Mental health and Mental health Problems among AAC users: A Scoping Review. *Augmentative and Alternative Communication*
30. Shi, L., Granlund, M., Zhao, Y., & Huus, K. (2022) Barriers and facilitators to participation in everyday activities for children with intellectual disabilities in China. *Child: Health, Care and Development*
31. Shi, L., Granlund, M., Zhao, Y., & Huus, K. (2024) Construct validity of the simplified Chinese version of the instrument 'Picture My Participation' *Scandinavian Journal of Occupational Therapy* DOI: 10.1080/11038128.2024.2348816
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37. Ritoša, AS., Almqvist, L., Danielsson, H., & Granlund, M. (2023): Profiles of State and Trait Engagement of Preschool Children, Early

38. 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*

39. Karlsson, C., Andersson, A-K., Lundqvist, L-O., & Huus, K. (2025). Participation in the habilitation process from the perspective of young people. *Scandinavian Journal of Disability Research*

40. Augustine, L., & Huus, K. (in prep.) Empowering Children in Habilitation: Outcomes of Participatory Goal Setting

41. Karlsson, C., & Granlund, M. (in prep.) Do the way children are invited to (re)habilitation planning meetings matter for attending and setting goals: a comparison of two routines

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</div
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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

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Manuals and other support material

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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
3. Andersson, AK, & Granlund, M (2024) *Vägen till mitt mål - a manual for supporting children and family in implementing decided interventions.* Jönköping: CHILD, Jönköping University