CHILD

Research profile at Jönköping University

Participation and Mental Health (CHILD - PMH)

Program update spring 2022

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Participation and Mental Health (CHILD-PMH) program update, august 2021

Purpose and aim

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). Most research focusing on children with impairments and/or long-term health conditions, has involved predefined target groups with respect to diagnosis and/or type of disability (Imms et al, 2017). However, several studies report that if children are clustered in profile groups based on everyday functioning, (i.e. participation pattern or problem behaviors), few diagnostic-specific problems with everyday functioning are detected (Lygnegård et al, 2019, Pinto et al, 2018). 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 affect mental health and indirectly protect from mental health problems. In the ICF-CY based framework "Family of participation related constructs" (fPRC) (Imms, Granlund et al, 2017) participation has been conceptualized as having two dimensions: "attendance" and "being involved while being there". 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.

Participation and mental health

Most studies of participation at an individual level have an emphasis on the *attendance* of persons with impairments or long-term health conditions in the same everyday activities as people without impairments. *Involvement*, the second dimension of participation is defined as the degree of involvement when present within a situation. Engagement is the main operationalization of involvement used in this program. The two dimensions of participation in the fPRC framework are related to intrinsic and extrinsic factors. Intrinsic person-related concepts include, among other factors, *activity competence/capability* (Imms et al, 2017). *Activity competence* is defined as the ability to execute the activity being undertaken according to an expected standard (WHO, 2007), and includes cognitive and physical as well social and emotional skills. All participation occurs within a contextualized activity setting. *The activity setting* is personal and relates to the meaning of (or personal interpretation of) people, place, activity, objects and time in which the participation is set (Batorowicz et al, 2016). *Environment* is external to the person and refers to the broader objective social and physical structures in which we live, e.g. home, leisure and school environments as well as attitudinal.

Members of the group have undertaken prospective longitudinal studies of participation, in children in need of special support or impairments, with young children

(Gustafsson et al, 2018; Sjöman et al, 2020), school aged children (Imms & Adair, 2017; King et al, 2010,2013) and adolescents with mild disabilities (Lygnegård et al, 2018). The results indicate that levels of participation (both attendance and engagement) are relatively stable over time while the profile of activities that children and adolescents participate in, changes with societal expectations and life roles (Lygnegård et al, 2018; Imms & Adair, 2017). Environmental factors such as socio-economic status, family coherence and parent-child interaction patterns are strong predictors of level of participation. Level of participation do not predict changes in participation patterns as evidenced by the stable levels of participation nor how participation is related to mental health. Understanding how transactional processes involving mental health problems, and mental health impact on participation across childhood is essential in order to identify appropriate interventions for vulnerable groups.

Mental health, mental health symptoms and mental illness

Mental health problems in children and adolescents, subthreshold symptoms for mental health problems or risk factors for future mental health issues are important to identify. Several cross-sectional studies indicate that groups of children and youth with different types of impairments and long-term health conditions are overrepresented when mental problems are surveyed (e.g. Harrowell et al, 2017). Preliminary longitudinal data concerning adolescents with self-reported Neurodevelopmental disorders NDD from the LoRDIA (Longitudinal Research Development in Adolescence) program indicates that, on average, conduct problems decrease with time while emotional problems increase (Augustine et al, 2021). In this program, mental health problems, rather than mental disorders, are in focus since also problems that are under the diagnostic threshold can cause difficulties with everyday functioning.

Relating mental health to the fPRC framework

Several cross-sectional studies, both our own (Gustafsson et al, 2018; King et al, 2013; Lygnegård et al, 2018) and others (Aydogan, 2012) indicate that there is a moderate negative relationship between participation and mental health problems. Using self-ratings, proxy ratings, and/or observations, studies have found that children and adolescents with mental health or behavior problems also have lower participation both in terms of attendance in activities and involvement while attending. However, there are also indications that children's positive sense of self as well as responsive adults, positive family atmosphere (King et al, 2009) and positive peer interaction (Sjöman et al, 2016) can enhance experiences of participation despite behavior problems. The results provide preliminary indications of that the relation between participation and wellbeing is strong and that a high degree of wellbeing might protect from mental health problems. 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

Our studies of school aged children with mild intellectual disability (MID) show that children with MID can be taught goal setting strategies that lead to goal attainment and higher ratings in self-determination (Garrels & Arvidsson, 2019) that in turn seems to affect engagement in school activities. Studies based on growth curve modelling by Dunst and his colleges (2009, 2012) show that families report higher wellbeing and better child functioning when they have been collaborating with professionals who work in a family centered fashion with a focus on family involvement in the intervention process. In a Swedish study, Huus et al (2017) reported that parents to children with mild intellectual disability who rate the support from social services and habilitation services as very useful also rate their need for support lower and their self-efficacy in being a parent higher. The results indicate that high child and care provider involvement in the intervention process may promote wellbeing both in child and care providers. Children with disabilities can be involved to a large extent in assessment (Dada, Arvidsson et al, accepted) if methods and instruments used in the intervention process are adapted to the characteristics of children and families. We are now validating two participation measures. One measure, FUNDES Child-SE based on parent reports of their child's frequency of participation in activities and perceived engagement in activities attended (Axelsson, et al, 2021; Gothilander et al., in prep). The second measure on self-ratings of participation though structured interviews with children Picture My Participation (PMP) (Arvidsson et al, 2019, 2021). By using both tools we can obtain data on differences in child and care provider perceptions of participation. Earlier studies indicate that their perceptions differ, and that the child's own voice is important in intervention decisions (Liao et al, 2019; Dada et al, 2020).

Regarding the influence of professionals' engagement with parents and children in the intervention process, both the treatment process literature (Armitage, Swallow, & Kolehmainen, 2017) and the literature on theory-based program evaluation (Harachi et al., 1999) stress the importance of identifying active ingredients and program processes, and the mechanisms by which these elements of the program affect desired outcomes (King et al, 2019). Studies have pointed both to the importance of a program structure that facilitate care provider and family involvement (Bailey et al,2005, Dunst et al 2009) and to the importance of creating a supportive program atmosphere with multiple opportunities for social interaction, and personal growth; (King et al., 2016;). In addition, collaborative problem solving is a key ingredient in parent-professional collaboration in habilitation services (Ylvén & Granlund, 2015). 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

The relationship between the two participation dimensions, attendance and involvement, will be investigated in depth and considered in relation to mental health and mental health problems of children and young people. We argue that there are both impairment/diagnosis specific problems and universal problems on body, activity and participation levels (Wallander & Varni, 1998). The closer we get to participation the more different diagnostic groups have in common. Is it the same for mental health problems? Different impairments may generate partly different solutions for the same everyday problem that is experienced. Is this applicable also to mental health problems? In addition, we argue that by supporting participation of the child and family in everyday environments, children and adolescents with impairments and/or long-term health conditions will gain higher wellbeing and perceive fewer mental health problems (Palisano et al, 2012). The two dimensions of participation can also be applied to the environments where children meet service systems, e.g. habilitation services or social services. Does the child and family attend planning meetings and are they engaged when they do attend? Our previous studies indicate that assessment instruments and methods are needed that are adapted to support children in reporting their own participation and perceived mental health problems and support parents in being active in planning and implementing support (Adair et al, 2019; King et al, 2015).

Inclusive research

Inclusive research cannot be translated into one particular way of doing things; the options are extensive (Walmsley, 2004). However, some characteristics and principles for inclusive research can be seen. (Walmsley and Johnson, 2003): The research problem must be one that is owned by disabled people (not necessarily initiated by them). It should be relevant to people with disability; It should be collaborative, people with disabilities should be involved in the process of research and should exert some control over process and outcomes. The questions asked, process used, and reports given must be acceptable to people with disabilities. In this program children and adolescents with disabilities and their care providers primarily have been included in the second part of the program, i.e. habilitation intervention studies. In the first part of the study, 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 study, habilitation interventions, is more directly designed to be inclusive. Advisory groups with adolescents, care providers, professionals and researchers have been formed in participating regions. These advisory groups provide advice and make decisions about the process (see flowchart page 13). Ethical permission is also obtained for a qualitative study in which participants in the reference groups will be interviewed about their perceptions of participating as co-researchers in an inclusive research study

Program description

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.*

An ethical approval from the National Agency for Ethical Wetting has been obtained for the first three aims in 2019. A supplementary ethical application is necessary for the fourth aim since content and form of interventions are not yet decided. In Table 1 the revised time plan for the whole program is presented.

Program part	2019	2020	2021	2022	2023	2024
Longitudinal study	Ethical approval	Data collection 1	Cont. data collection 1 and start 2	Cont. data collection 2 and start 3	Cont. data collection 3	Finalizing analyses
Habilitation intervention studies	Ethical approval and focus groups	Base line measures, focus groups and planning of interventions	Focus groups and planning of interventions	Interventions and evaluation of interventions	Interventions and evaluation of interventions	Writing up and integrating results
Steering group meetings	X X	X	X	X	X	X

Table 1: Time plan and implementation

The time plan shown is a revised plan based on the Covid pandemic situation. Changes concern how data are collected and the number of data collection points in the longitudinal study. In the habilitation intervention studies the number of focus groups in the first phase has changed and partly been substituted with individual interviews.

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 Andersson Anna Karin Axelsson Frida Lygnegård Karin Bertills Charlotte Karlsson Linda Sjödin	Henrik Danielsson Magnus Ivarsson Lina Homman Pia Ödman	Lena Almqvist Anna Ullenhag Jennifer Gothilander Camilla Eriksson *Torun Täljedal (at Uppsala University)	Lars-Olov Lundqvist Susann Arnell Eva Resare	Gillian King	Christine Imms Jacinta Pennacchia

Table 2: Participating researchers

Researchers linked to program

Associate professors Ai-Wen Hwang and 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

Supplementary projects and projects linked to the program

In a large research program running for 6 years there are always several activities ongoing at the same time. Some of these activities are planned while other are necessary to add based on circumstances not controlled by the program or because of opportunities that show up. Below are some of these activities named. Short abstracts for each activity are presented in appendix 1.

Studies aimed at validating assessment instruments used in the program

Validating Styrkor och Svagheter i Familjen (SSF/FIQ) for use in the longitudinal study
Validating FUNDES participation instrument for use in the longitudinal study
Validating PRIME for use in the involvement in the intervention process study

Studies aimed at developing procedures and methods for involving children and care providers in research as subjects or co-researchers

Methodology for adapting data collection involving children with disabilities, based on data on assessors' strategies from the longitudinal study and a systematic review of adaptations done in longitudinal studies (Magnus Ivarsson, Henrik Danielsson, Lena Almqvist, Christine Imms)

Developing and testing web-based solution for structured interviews of children with cognitive impairments (Anna Karin Andersson, Lena Almqvist, Magnus Ivarsson)

Including children with ID in research interviews – a scoping review (Master student Lisa Kemps, supervisor Ellen Backman)

Experiences of being involved in inclusive research and testing a manual for inclusive research methodology in collaboration with care providers, children, and habilitation professionals, CP-ACHIEVE (Australia) and CAAC (South Africa)

Testing strategies for inclusive research methodology in collaboration with CP-ACHIEVE (Australia) and CAAC (South Africa). (Malin Stensson, Berit Möller Christensen, Juan Bornman) A questionnaire concerning inclusive practice in research is currently being developed and will be tested this fall (2021) on all CHILD researchers.

Investigating the perceptions and experiences of children, parents and professionals who have participated in CHILD-PMH as co-researchers – evaluating an inclusive design (Karina Huus, Frida Lygnegård). Members of the reference groups in CHILD-PMH have been involved in forming questions for focus groups, recruiting participants for focus groups, interpreting the results of focus groups interviews and planning interventions aimed at enhancing child and family participation based on the results. This study aims to investigate perceptions of reference group participants with the help of a qualitative interview study using semi structured interviews with data analyzed with a thematic analysis.

Studies supporting the further implementation of CHILD-PMH program

Identifying and evaluating instruments measuring mental health in children with disabilities – a scoping review (master student Estrella Torres Cabo, Mats Granlund)

Developing measures for asking persons who use AAC to report mental health problems and mental health (Jacinta Pennacchia, Christine Imms, David Coghill, Mats Granlund)

Strategies used by professionals in pediatric rehabilitation for engaging the child in the intervention process 2022 (master student Marianna Antoniadou, supervisor Mats Granlund)

Developing and testing an adapted measure for assessing mental health in children with cognitive impairments is ongoing, ethical permission obtained (Magnus Ivarsson, Lilly Augustine, Lena Almqvist, Camilla Eriksson, Mats Granlund)

Studies aimed at testing program questions using other data than CHILD-PMH but having strongly related aims

Mental health problems, capability and attendance for children with physical impairments. In collaboration with Chang Gung University, (Taiwan) (Mats G and Christine I)

Trajectories of self-rated Participation, Mental Health and Mental Health Problems in Adolescents with Self-reported Neurodevelopmental Disorders. (Lilly Augustine)

The utility of ICF for statistical analyses of mental health data. Using LoRDIA data (Lilly Augustine)

Mental health in children with NDD – comparing flourishing and languishing children with self-reported NDD. Using LoRDIA data (master student Lotte Moes)

Mental health in children with NDD or physical disabilities – a comparative study. Using LoRDIA data (master student Nida Rehman)

Mental health and social networks. Using LoRDIA data (master student Estrella Torres Cabo)

Perceptions and Experiences of Social Participation in Physical Activities Among Youths with Physical Disabilities in Greece -a qualitative study (master student Aikaterini Aranti)

Professionals' perceptions of care providers and children's engagement in encounters and how they as professionals enhance engagement in clients. Data collected in Greece (master student Marios Nikolopoulos)

Using the ICF as a common language for statistical analyses of mental health (Lilly Augustine, Frida Lygnegård, Mats Granlund)

Studies partly using CHILD-PMH data for other aims but strongly related to program aims

The mental health of children with disabilities with a migrant background and the wellbeing of their care providers (Torun Täljedal, Mats Granlund, Lena Almqvist)

Design and method of the longitudinal study

Changes following from the Covid pandemic and lock-down

Because of the Covid pandemic data collection in the longitudinal study was postponed spring 2020 and has started in November/December 2020. The first wave of data collection is based only on web-based questionnaires of paper-based questionnaires from care providers because of quarantine restrictions. The postponed data collection provided the opportunity to use researcher time to a collaboration around a "position paper" in which researchers engaged in the longitudinal data collection discussed the constructs mental disorder, mental health problems, mental health/wellbeing and participation (Granlund et al, 2021) In addition a systematic review of longitudinal studies of mental health problems in children with disabilities is ongoing (Danielsson, Imms et al, submitted). The review is registered in PROSPERO to facilitate publishing of the results. Most researchers in the longitudinal study participate as reviewers. Finally, by using data from other ongoing longitudinal studies, where researchers from the program participate, hypotheses regarding the relationship between mental health problems, mental health and participation have been tested (Hwang et al, 2020; Augustine et al, 2021).

Longitudinal prospective study following children in two age cohorts (children with disabilities followed from 4-6 (2019) to 10-11 years of age and followed from 10-12 (2019) to 16-17 years of age.

Participants: Children and their families for the prospective study were recruited from the two age cohorts from five regional habilitation centres that consented to participate (Östergötland, Örebro, Västmanland, Jönköping and Gävleborg). All children within the specified age ranges, in 2019, in these centres were used as a basis for recruitment, about 2400 children. With the help of the habilitation centres, written information about the study was sent to all families by researchers. Families expressing interest to the researchers by providing written consent from both parents participated. Children were asked for assent. 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. We relied on only collecting data from care providers with the help of web-based questionnaires or paper versions posted to care providers. Another reason for attrition is that 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 indicate that somewhere in between 30 to 40 % of the population have this background. We therefore added a second round of recruiting children and care providers to the first wave in which all information material and questionnaires have been translated to Arabic, English and Somali. Second data collection also include structured interviews with children.

Participating families	2020/2021 respondents	2021/2022 respondents
Cohort 1	81 care provid., 0 children	40 care provid., 15 children
Cohort 2	81 care provid., 0 children	47 care provid., 40 children
Total	162 care provid., children	87 care provid., 55 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 factors hypothesized to affect mental health that may arise from within the child, family, school and encounters with habilitation services.

Families are asked to provide information with approximately one year between data collections on an individual basis. Data are collected via paper based or web-based questionnaires and/or structured telephone interviews completed by parents. Interpreter service can be arranged for parents that do not speak Swedish. However, no family has so far asked for this service, they tend to ask relatives for language support instead. Data from children was during fall 2021 and spring 2022 collected with the help of structured face-to-face interviews with parent attendance if necessary for support. Interviews were done by researchers. In the structured interviews a Talking Mats procedure with picture/symbol support will be used for children having cognitive, speech and /or physical impairments that make a traditional structured interview difficult to apply. This approach has been trialled in conjunction with the validation of the PMP (Arvidsson et al, 2019, 2021). Still not all children have managed to participate in interviews (either partly or completely).

Instruments: Questionnaires concerning the outcomes participation and mental health are collected from both children (SDQ, PMP, EQ5D-Y sadness scale, Wellbeing/Cantril's ladder) and parents (FUNDES Child-SE, SDQ, EQ5D-Y sadness scale). For data collection 3 a measure of mental health based on children's self-rating a measure is under development. The supplementary ethical approval is approved.

Questionnaires concerning factors hypothesized to affect participation and mental health problems (predictor variables) collected from families can capture children's health related quality of life (EQ-5D-Y all scales except for sadness); family impact questionnaire (FIQ/SSF). In addition, questions about parents' perceptions of involvement in the habilitation process (Björck-Åkesson & Granlund, 1995) is collected. Proxy ratings of children's impairments is made with the help of the Ten Question Screen (TQS). Children's perceptions of school environment, peers and social contacts on the net will be collected from children from wave 2 and on. Several researchers are involved in analyzing these data.

In addition to the measures named above, there is retrievable information from the HabQ register on whether the families have participated in basic family support regarding five different areas: 1) information and counselling to care providers, 2) psychosocial counselling to parents, 3) support to actively participate in habilitation planning, 4) parenting group, and 5) support in coordinating services and support. This data is only available for those children whose parents are registered in HabQ. See Table 3 for instruments used in the longitudinal study.

Outcome Measures	**Setting/type covered**	**Aspect of construct rated**	**Proxy or self-rating**
FUNDES Child-SE (prospective) participation	Home, community, school	Independence in performing Frequency of attending Engagement when attending	**Proxy rating by parents**. Using other children same age as comparison
PMP (prospective) participation	Home, community, (school)	Frequency of attending Engagement when attending	**Child self-rating** with symbol support and Talking Mats
Wellbeing – Cantril's life satisfaction ladder	One item	Overall wellbeing – scale from 0 to 10 illustrated on ladder	**Proxy young cohort**, **Child self-rating** older cohort
SDQ (prospective) Mental health problem + prosocial	Hyperactivity, conduct, emotional, peer problems, prosocial	Scale from no problem to severe problems. Primarily hyperactivity, emotional and prosocial used	**Proxy young cohort, Child self-rating older cohort**
EQ5D-Y (prospective) only anxiety/depression part)	Scales "pain and discomfort" and "worried, sad or unhappy"	Scale (3 grades no problems to lot of problems)	**Proxy young cohort, Child self-rating old cohort**
Environmental factors	**Measure/subscale**	**Aspect rated**	**Proxy or self-rated**
FUNDES Child-SE	Items about barriers in environment	Perceived facilitator or barrier	Proxy rated
PMP	Items about barriers and facilitators in environment	Perceived facilitator or barrier	Child self-rating
SSF/FIQ (Prospective)	Family Dynamic predictors	Feelings 13 items, Social im. 6 items Economy 5 items Partner 5 items Siblings 6 items Stress 2 items	Self-rated family
Items from **HBSC** (prospective) • Friends real • Friends net	Peer environment	1 item 3 items	Self-rated child
Items from **HBSC** (prospective) • School/teacher • Peers in school	School environment	3 items 3 items	Self-rated child
SSF/FIQ (prospective)	Perception Service provider	Contact with professionals 5 items	Self-rated family
Family involvement	Habilitation process (prospective)	Interaction with professionals 5 items	Self-rated family
Child factors			
Body level Static predictors	• GMFCS parental rating • Ten Question screen	Motor capacity Ten questions about impairments	Tested/professional Parent rating of child
Activity competence Dynamic predictors	FUNDES Child-SE (prospective)	Capability (independence)	Professional/parent
Family demographics		Living, circumstances, education, family composition	Parent information

Table 3: Instruments used in longitudinal study Note; FUNDES Child-SE = Functioning scale of the disability evaluation system, PMP = Picture My Participation, SDQ = Strength and Difficulties Questionnaire; EQ5D-Y = Euro Quality of Life 5 dimensions youth version, SSF = Styrkor och svagheter i föräldraskapet, HBSC = Health Behavior in School Children, GMFCS = Gross Motor Functioning Classification system short version

Validation and psychometric properties

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 (Hwang AW, Yen CF, Liou TH, Bedell G, Granlund M, Teng SW, Chang KH, Chi WC, Liao HF, 2015) 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). Data has been collected in Sweden for test-retest of a new version (20 items) (Gothilander et al, submitted) and construct validation (CFA) (Gothilander et al, in prep.). 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. Ethical permission to use and adapt the scale has been obtained (Dnr 2017/496-31).

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 importance of activity. In addition, questions are asked about facilitators and barriers for participation. Now adapted for use in web-based structured interviews

Strength and Difficulties Questionnaire (SDQ) was originally designed to be completed by parents (Goodman, 1997). It has five subscales whereof four describe mental health problems and one prosocial skill. SDQ has satisfactory internal consistency and test-retest reliability (Goodman, 2001). SDQ is currently being validated in Sweden for young adolescents with self-reported neurodevelopmental problems using self-ratings from another longitudinal study. Interrater agreement is acceptable between parents and adolescents. The agreement is lower for the general population between teacher and adolescent ratings. However, for the group of students with self-rated neurodevelopmental difficulties the agreement is higher, indicating that SDQ fits a clinical sample better than a typically developing sample (Augustine et al, 2021). Analyses further indicate that SDQ is a well-functioning instrument over time, but dependent on sufficient sample sizes in order to detect differences. In this program the original wording and lay out is kept. For some children this is too difficult to respond to

Euro Quality of Life 5 dimensions youth version (EQ5D-Y) has been validated in a cross-national study involving 8 countries (Sweden is one of them) (Ravens-Sieberer et al., 2010), It includes five dimensions; mobility, looking after myself, doing usual activities, pain and discomfort and feeling worried, sad or unhappy. In the study by Ravens-Siebrer et al (2010) self-reported SDQ ratings were used for a known group comparison. The dimensions “pain and discomfort” and “feeling worried, sad or unhappy” identified children with high ratings in SDQ. Both these dimensions are used in the study.

Styrkor och stress i föräldraskapet (SSF) based on Family Impact Questionnaire (FIQ) (Donenberg & Baker,1993) will be validated with the help of de-identified data extracted from the HabQ. A previous Swedish study reported good to acceptable reliability (Cronbach’s alpha) (Falck & Ternert, 2016). Ethical permission for validation using both HabQ data for testing construct validity and a new data collection for test-retest validity is approved. Regarding construct validity a validation article is submitted (Ivarsson et al). Results confirm original factor structure.

Health Behavior in School Children (HBSC). Data on health behaviors has been collected in schools since 1983, and now covers cross sectional collections (11-, 13- and 15-year-olds) in approximately 40 countries (Roberts et al, 2009). Scales vary between items. In this study questions concerning perceived school environment, peers in school and peers in leisure time and on the net will be used. Questions regarding teacher support was piloted prior to the 2009/2010 study and questions gathered in HBSC were also tested in seven countries showing a good loading (Torsheim et al., 2010). Questions regarding peers have been used since 1993 in HBSC, and with the current scale from 2005. It has been used in multiple studies and validated both in a Norwegian study (Torsheim, Wold, and Samdal 2000) and in a cross-national study, including 7 countries, indicating a good factor loading with 66% explanation in one factor (Torsheim et al, 2010). Some of the peer relations items are taken from the Intensity of electronic media communication questionnaire in the HBSC. The electronic media communication questionnaire consists of 4 questions about: how often you have online contact with a close friend; or with friends from a larger friend group; friends you got to know through the internet but didn't know before; and other people than friends. Of these 4 questions, 2 were previously used and validated by EU Kids online and Net Children Go mobile project (Mascheroni & Olafsson (2014). These items are difficult to respond to for some children.

Cantril's life satisfaction ladder comprises one item on general wellbeing and is used in WHO surveys of children. Respondents are presented with the picture of a ladder with steps ranging from 0 to 10 and asked to indicate where on the ladder they 'feel they are standing at the moment with the top of the ladder (10) representing the best possible life and the bottom (0) representing worst possible life. Only 'the situation today' will be used. Levin and Currie (2014) report good validity and reliability when used with an adolescent sample. Because of that Cantril contains only one item it will be supplemented by the instrument MHC-SF (Mental Health Continuum-Short Form, an instrument based on Keye's dual continua model and designed to assess mental health. An adapted version is under development.

Family involvement in the habilitation process was originally developed and used in the USA (Bailey et al, 1992). A Swedish version was used by Björck-Åkesson and Granlund (1995). The instrument contains five items about involvement in assessment decisions, participation in the assessment procedure, goal setting and intervention as well as one item about family support. Parents and professionals rate the current state as well as the ideal state in terms of involvement. A comparison of pairs of parental and professional ratings revealed no differences in how the current state was rated, indicating a relatively good inter-rater reliability (Björck-Åkesson & Granlund, 1995). In the program only the present state ratings are used.

Data analyses and statistics

The analyses of the longitudinal data will be 1) latent growth curve analysis of trajectories over time, and 2) longitudinal cluster analysis to investigate if/how development over time differs for particular groups of children. Additional exploratory analyses with multi-level modelling and structural equation modelling will also be conducted. These exploratory analyses require at least 200 participants to be reliable, but more complex (more variables or more clusters found) models require even more participants. The required sample size is dependent on the distribution of the data, the amount of missing data, reliability of the tests, the strength of the associations in the model and the complexity of the model. Given our recent experiences from large scale longitudinal studies requiring active consent from both parents as well as the Covid pandemic we experienced a large amount of missing data (90%). 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):

Changes following from the Covid pandemic and lock-down

The pandemic has not affected the part of the program focusing on increasing child and care provider involvement in the intervention process to the same extent as the longitudinal study. There have however been effects on how the focus groups have been implemented. So far primarily focus groups with professionals and parents have been implemented. With children focus groups partly has been changed to individual meetings. The meetings have been conducted primarily as zoom meetings with a shift to live meetings spring 2022. As with the longitudinal study much time have been spent on reorganizing plans and more time have been spent on a systematic review of interventions aimed at increasing child and care provider engagement in the habilitation process (Andersson et al, in prep.).

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 systematic review, focus groups and co-produced interventions as displayed in Figure 1:

Flow chart of research process in habilitation interventions

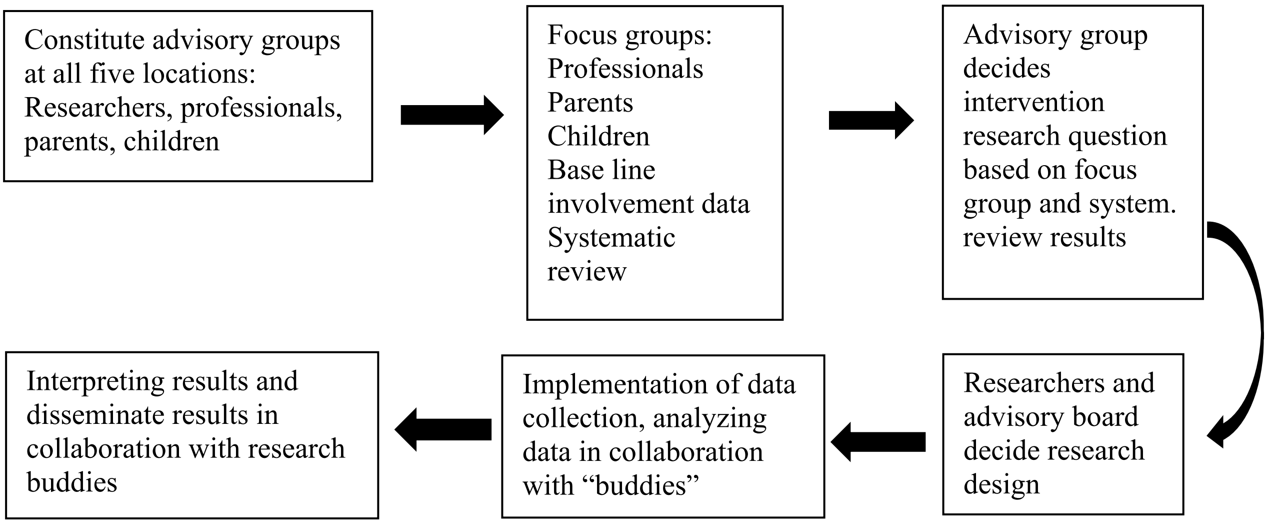

Figure 1: Flow chart of research process in habilitation interventions

Participants: Participants are 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.

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 group 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. Because of the co-production design, it is not possible to provide a detailed description of the design of each study at the four local sites at this stage for the steps after constituting the advisory groups and implementing the focus groups. Amendments or supplementary ethical applications will be submitted.

The first two and a half years (fall 2019 - to spring 2022) have been primarily used for planning and implementing a systematic review, the advisory groups have been constituted. However, also data from focus groups with children, parents and professionals concerning how to enhance child and family engagement in the intervention process have been collected. Advisory group members were recruited locally with the help of habilitation centers and organizations for persons with disabilities. Participants of the focus groups were recruited by posting information on habilitation websites and by having professionals and parents in advisory groups distribute information about focus groups to parents. Children aged 12 years or older have participated in focus groups or individual interviews after providing informed consent. Content of focus groups was based on bullet point lists of summaries of the result of earlier studies by our group and findings from a systematic review of studies that aimed to enhance child and family involvement in the intervention process. In the focus groups, group leaders and observers (researchers) have summarized the discussion and conducted a member check by presenting summaries to participants. Data collected has been analyzed with content analysis. 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 are under development and will be implemented 2022-2024 within the four sites. These intervention studies are currently being planned. In addition to focus groups the first and second year was used to collect base line data on child and family involvement with the Family involvement questionnaire and PRIME. These data have been collected from child, parent and professionals at each site in conjunction with consecutive encounters per professional. Data was collected with no person information. Participants were informed verbally and in text and asked to fill in questionnaires. Filling in the questionnaire implied informed consent.

Instruments used in the habilitation studies:

To evaluate the effects of the interventions, each study will include measures based on the specified outcomes and intervention methods used. To evaluate the outcome of the interventions on child and family engagement in the intervention process the PRIME suite of measures will be used. These are an easily completed measures of client engagement as perceived by children (PRIME-C), parents (PRIME-P) and service providers (PRIME-SP). To assess habilitation center effects, parents' perceptions of "Family involvement in the habilitation process" will be assessed before and after intervention for all involved families. See Table 4 for instruments used for baseline measure of involvement before intervention in all sites. Probably items from FOS (Family Outcome Survey will be added.

Outcome Measure	Respondent group	Aspect of construct rated	Proxy or self-rating
Items from Prime -C	Child	Perceived engagement in one session	Child rate items
Items from Prime - P	Parent	Perceived engagement in one session	Parent rate items
Items from Prime-SP	Professional	Perceived engagement in client in one session	Professional rate items
Perceived family involvement in habilitation process	Parent and professionals	Perceived involvement overall in collaboration with professionals	Parent rate items

Table 4: Measures of involvement in the intervention process

Psychometric properties

The psychometric properties of the PRIME measures (C, P, and SP) are currently being evaluated by the developers in Canada. In Sweden, the PRIME instruments have been translated using a backward translation procedure. The PRIME instruments have been validated by asking respondent groups to use the instruments in the 4 habilitation centers without any links to personal information. The Family involvement questionnaire has been validated in conjunction with research studies in the USA (Bailey et al, 1992 and in Sweden (Björck-Åkesson and Granlund (1995) and is now used in conjunction with PRIME in the validation study. Preliminary validation data of PRIME within the program reveal that children with disabilities have difficulties with understanding the item format and content as well as the scale having both a negative and positive endpoint illustrated by a positive and negative statement. However, 35 children have responded. Overall, they rate the items high, that is on the positive side. The variance is relatively narrow, but some differences are seen. Data from parents and professionals are currently being analyzed.

Data analysis and statistics

Data on items from the "PRIME measures" for the respondent groups professionals, children and parents and data the "Perceptions of Family Involvement" from all studies pre-post will be aggregated per local site and used for pre-post comparisons using traditional multi variate analyses. The type of analyses used in the studies will vary dependent on number of participants and design used.

Preliminary results for CHILD-PMH so far – based on research questions

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

Data collection is soon to be finalized for the second data collection. The first preliminary analyses of the longitudinal inter-relationship between the two dimensions of participation will be done after that. Since we only have data from care providers (proxy ratings) from the first data collection only proxy data will be used to investigate the longitudinal inter-relationships this year. Structured interviews with children have been implemented this year, so mid 2023 we can do the first preliminary analyses of self-reported data on the inter-relationships between the two dimensions of participation based on self reports.

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 increase especially for boys.

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.*

This research question requires longitudinal data to be responded to. A first preliminary analysis of cross-sectional data reveals that:

- The relation between **wellbeing/Cantril** and participation is moderate (.422 frequency and .455 engagement)
- The relation between mental health problems and participation is weak to moderate (**conduct**.19 freq., -.18 eng.; **emot.** -.17, eng. -.20; **hyper. -**.30 freq, -.28 eng,; **peer prob.** -.35 freq, -.38 eng,
- The relation between wellbeing/Cantril and mental health problems is negative and weak to moderate (**conduct.** -31, **emot.** -45, **hyper** -.11, **peer prob**. -37)
- Level of support needed to perform an activity (Independence) has a low negative correlation with wellbeing (-.29) but high with participation **frequency** (.77) and **engagement** (.71)

Our idea that wellbeing has a stronger positive relationship to participation than the strength of the negative relationship to mental health problems is confirmed. Maybe participation interventions can enhance wellbeing and protect from mental health problems? The strong correlation between independence and the participation dimensions is a bit surprising. Is this result partly dependent on proxy- instead of self-ratings?

Regarding the longitudinal trajectories of mental health problems, we have some preliminary data from the systematic review of longitudinal studies of mental health problems in children with disabilities (Danielsson, Imms et al). These preliminary results 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 present 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 levels for adolescents having self-reported NDD. Emotional problems have an increasing trend with difference between groups decreasing. The statistical correlations between participation frequency and importance and mental health (as measured with MHC-SF) are strong while the negative correlations between aspects of participation and mental health problems is low.

3) *To investigate how children and parents perceive that they participate in the different steps of the intervention process and/or group programs*

As a 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). The result indicates that parents are more involved in planning and goal setting decisions (activities usually occurring in the habilitation plan meting) than in decisions and planning regarding how to implement and evaluate decided support/interventions (occurring between planning meetings).

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 child 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.

The 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 was discussed.

Assessment/problem identification	Explain/set goals	Design and implement methods	Evaluate implementation and goal achievement	Family support
Invitation document: • Individualized • Child friendly • Clear aim • Adolescents **Assessment:** • Individualized • Where • Broad questions • Active role in assessment • Adolescents	**Goal vision for child:** • concrete • understand • link goal - intervention	**Help to self-help** • reason • about • when • where • how **Facilitate child involvement** • talking mats • motivate	**Link evaluation, goal, method** • implem. • Indiv. • Explicit **Continuous evaluation** • Start with follow up	**Whole family:** • Informed • Patience • Everyday life

As can be seen in the table the subcategories identified seem to indicate 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 concern clarity and concreteness, understanding why interventions are done and the individualization of information and goals.

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

The work with deciding on which changes interventions aim at, deciding on intervention content and how to evaluate interventions is ongoing 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. Short term goal is to implement intervention late fall 2022.

Appendix 1. Studies related to CHILD-PMH

Doctoral thesis work

Methodological challenges in the measurement of mental health problems and related subjective phenomena in children with developmental disabilities

PhD-student Magnus Ivarsson, main supervisor Henrik Danielsson, co-supervisors Lena Almqvist, Christine Imms, and Lisa Palmqvist

Several methodological challenges are specific to or amplified in the study of mental health problems in children with developmental disabilities due to the specific characteristics of the group. For example, the perspective of the child is often lacking in prior research, which is problematic for both ethical and methodological reasons. Another potential challenge in the field is the overlap between the concepts studied as outcomes (e.g. behavior problems) and aspects of disability (e.g. hyperactivity), often resulting from a lack of clear definitions of key concepts. These and some related questions will be addressed in the present thesis through four studies:

- A systematic review of methodological challenges in studies of longitudinal trajectories of mental health problems in children with developmental disabilities
- A quasi-experimental study 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
- A survey study investigating the type and degree of spontaneous adaptations of material and procedure when interviewing a heterogeneous sample of children with developmental disabilities and the relation of these adaptations to child and interviewer factors
- A study describing the development and validation of a well-being scale adapted to the needs of children with IDD (MHC-SF-NDD)

Factors influencing participation and independence in children with disabilities

PhD student Jennifer Gothilander, main supervisor Lena Almqvist, co-supervisors Camilla Eriksson, Johanna Fritz

Participation is important for physical and mental development and health. Children with disabilities commonly meet restrictions in participation due to both physical and psychological factors and barriers in the environment. There are several cross-sectional studies showing a relationship between participation and mental health. However, to increase knowledge of causal relationships we need to develop and use methods that can handle such complex constructs as participation, as well as study these constructs longitudinally. It is essential to use instruments and methods that are accommodated for children with a broad range of cognitive and functional abilities. The combination of a limited rage of customized instruments for self-rated participation and independence, a simplified view on the participation construct, limitations to research in specific diagnosis groups, small sample sizes and retrospective or cross-sectional studies has led to the knowledge gap of participation and independence trajectories. The overall aim of this doctoral project is to study patterns of factors contributing to independence and participation of children and youth with disabilities in Sweden.

Submitted: *Data quality and reliability of the questionnaire FUNDES-Child-SE measuring participation and independence in children and youths with disability*

Immigrant families of children with disabilities living in Sweden: Parents' and children's experiences of participation, mental health problems and support needs.

PhD student Torun Täljedal, Main supervisor Karin Fängström, Co-supervisors: Mats Granlund, Eva Norén Sellenius, Fatumo Osman

The health and experiences of parents of children with disabilities have been internationally researched from many perspectives. Parents with other cultural or ethnic backgrounds are often excluded from such research, particularly if they are not proficient in the native language of the country of research. Research suggests that there is an increased risk of developmental disabilities such as autism among children in migrant communities. Research focusing particularly on immigrant families of children with disabilities has increased in later years, mainly from English speaking countries. Studies have found that immigrant parents of children with disabilities use services to a lesser extent than native parents, experience isolation, stigma and racial exclusion and difficulty understanding and getting access to services There are few Nordic studies in this field. During recent years there has been a marked increase in immigration to Sweden, from just over 11% of the population born outside Sweden at the beginning of the century, to 19.7% by the end of 2019. Thus, immigrant families of children with disabilities could constitute about one fifth of the Swedish habilitation centres' patients. Some diagnostic groups even seem to be overrepresented among immigrant families. There is a lack of knowledge about the experiences and perspectives of immigrant families of children with disabilities in Sweden. A first step towards adapting services to better suit the needs of this double minority group in Sweden is to investigate the thoughts and experiences of these families. The aim of this thesis is to explore the experiences of participation, mental health problems and the need for support among immigrant parents of children with disabilities in Sweden and the experiences of the children themselves and of their siblings. The first study explores patterns of mental health problems and prosocial behavior in children with disabilities (rated by their parents on the SDQ) and whether parental background and the child's level of comprehension influences these. The second will look at parents' ratings of their parenthood and of the family's involvement in the habilitation through the SSF and the Family Involvement. The third and fourth studies will be qualitative interview studies exploring immigrant parents' perception of their children's disabilities in everyday life and their needs as parents as well as the experiences of children with disabilities and their siblings in families with immigrant parents. Studies three and four will be separate from CHILD-PMH.

Submitted: *Patterns of Mental Health Problems and Prosocial Behaviour in Children with Disabilities*

Assessing the mental health of young people with complex communication needs.

PhD student Jacinta Pennacchia, Main supervisor Christine Imms, Co-supervisors David Coghill & Mats Granlund

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. Current instruments for measuring mental wellbeing and mental health problems may not be appropriate for people with CCN from a physical accessibility perspective and/or from a conceptual/linguistic accessibility perspective. However, having CCN must not preclude people from accessing health services. Valid and reliable instruments are necessary to accurately identify poor mental health or mental health problems, facilitating appropriate treatment to promote positive mental health and mitigate against the consequences of mental health problems. Therefore, the overall research question of this PhD is: *how can poor mental health and mental health problems be validly and reliably identified in young people with CCN?* The PhD will comprise a series of studies. Study 1 will use systematic review methods to identify and evaluate the psychometric properties of mental health screening and assessment tools used with people with CCN. Study 2 aims to a) understand key stakeholders' experiences of communicating about mental health and mental health problems, and b) 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. Finally, Study 3 aims to develop an approach to mental health screening and/or assessment for young people with CCN. Consistent with the larger programs of work, the project will use an integrated knowledge translation approach that embeds stakeholder (consumers and clinicians) involvement throughout.

Children's involvement in the habilitation process
- a staff perspective with a focus on teams and professional level

PhD student Linda Sjödin, main supervisor Lilly Augustine, co-supervisor Frida Lygnegård

In Sweden, there are child and youth habilitations in all regions. The target group and the organization look different in the different regions, but all have the same purpose of being a specialist center for children and young people with permanent disabilities (Habilitering i Sverige, 2020). The habilitation must combine knowledge about the child's development with its disability and their impact on development and living conditions. This is based on the fact that children need support from different skills over time. Based on the mission that habilitation has, they have worked in interprofessional teams. These teams consist of various professions such as occupational therapist, psychologist, physiotherapist, doctor, nurse, counselor and special educator. The teamwork develops a common habilitation knowledge base in collaboration with the child / youth, its family and network. It is knowledge and experiences that are shared to understand the child / adolescent's life situation in order to promote the child's independence and participation. If habilitation staff gets the child and their care providers involved in all stages of habilitation such as mapping / investigation, goal setting, implementation of interventions and evaluation, the probability increases that the child becomes more involved in their everyday life. This is highly relevant in Sweden, given that the Convention on the Rights of the Child became law in Sweden at the turn of the year 2019/2020. The law emphasizes the child's right to express his or her own opinion (UNICEF, 2020). Therefore, it is of the highest interest to study participation in habilitation. Habilitation staff work in teams, therefore it is interesting to study how they work to get children and young people involved at team level and as individuals. Purpose The licentiate dissertation will contain in three sub studies:

The purpose of the first study is to examine the habilitations staff`s perspective of children`s involvement in the habilitation process. The purpose is also to, based on the staff`s own descriptions, identify whether interventions to increase children`s participation in the habilitation process take place on a team or professional basis. The questions are; 1) What are the views of habilitation staff on children`s involvement in assessment, goal setting, intervention and evaluation of habilitation? 2) How do habilitation staff describe interventions that affect children`s participation from the perspective of profession and team? The second study: A literature review with a focus on definitions of interventions to increase children`s and guardians' involvement in the habilitation process based on whether the intervention is developed by profession or team. The questions are; 1) How are interventions to increase children`s participation in the habilitation process described in previous research. 2) Is it possible to discern a difference in interventions to increase children`s participation in the habilitation process from a team or professional perspective, and if so, how? The method is focus groups interview. The third study is to study and describe the habilitation staff's and guardians' experience of children and their families' participation in meetings with habilitation staff. The questions are: 1) How do the habilitation staff assess children's involvement in a habilitation visit, depending in whether the meeting aims at different steps of the habilitation process? 2) How the staff describes factors and circumstances that promote the child's participation in the visit in the PRIME questionnaire. This will be investigated through the free text answers in the PRIME questionnaires.

Children and young people with disabilities and their ability to express their participation in the habilitation process

PhD-student Charlotte Karlsson, main supervisor Karina Huus, co-supervisors Lars-Olov Lundqvist and Anna Karin Andersson

Children with disabilities have a more difficult starting point to be involved in everyday activities, compared to children with typical functioning. Families report higher wellbeing and better child functioning when they have been collaborating with professionals that work in a family centered fashion. Thus, although participation in everyday life is an important outcome, child and parent participation in the intervention process might facilitate such outcomes by establishing the relevance of interventions. Children with disabilities can be involved to a large extent in assessment if methods and instruments used in the intervention process are adapted to the characteristics of children and families. It is particularly important to capture the voices of children and young people who are unable to complete questionnaires, particularly those with communication or intellectual impairments. The aim of this PhD thesis is to describe children's perceptions of their participation in the habilitation process and to evaluate interventions to increase/enhance children's participation through four studies: 1) A systematic literature review, aimed to explore earlier evaluations of interventions focusing on increasing child participation in the habilitation process with outcomes of interventions focusing on child participation, attendance, and involvement, in the habilitation process. 2) Study the usefulness of the instrument Pediatric Rehabilitation Intervention Measure of Engagement (PRIME) for children and adolescents in Swedish habilitation activities through psychometric validation. 3) In a co-production process with children create interventions aiming to increase participation for children in the habilitation process. 4) With a quantitative design evaluate children's involvement in the habilitation process before and after the intervention. Children's estimates of their involvement in meetings whit habilitations professionals will be collected using instrument PRIME.

Studies aimed at validating (or developing) assessment instruments used in the program

Validating Stress och Styrkor i Familjen (SSF) (Family Impact Questionnaire) for use in the longitudinal study (Magnus Ivarsson, Henrik Danielsson, Anna Karin Andersson, Jennifer Gothilander, Mats Granlund)
Based on the Cosmin manual a psychometric validation of the questionnaire SSF/FIQ) has been imålemented focusing on content validity and construct validity. The validation was based on data obtained from the HabQ register as well as data collected at the first wave of data collection in CHILD-PMH Preliminary result confirms original factor structure for capturing stress and strengths in families having children with disabilities. Article submitted.

Validating FUNDES Child-SE (Jennifer Gothilander, Anna Karin Axelsson, Anna Ullenhag, Pia Ödman, Henrik Danielsson)
In collaboration with the Swedish FUNDES group and based on the Cosmin manual a validation of the questionnaire FUNDES Child-SE is done. FUNDES Child-SE is based on the FUNDES measure (Hua-Fang Liao et al) and further developed by the Swedish FUNDES group adding a scale measuring engagement when attending an activity and barriers for participation. Content validity has been investigated and the work in now focused on construct validity. The validation is based on data obtained from the ongoing data collection in CHILD-PMH and a data collection made in another Swedish region. Two articles, one submitted and one accepted.

Validating PRIME (Lars-Olov Lundqvist, Charlotte Karlsson, Linda Sjödin, Anna-Karin Andersson, Karina Huus, Lilly Augustine, Frida Lygnegård)
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.

Studies aimed at developing procedures and methods for involving children and care providers in research as subjects or co-researchers

Methodology for adapting data collection involving children with disabilities (Magnus Ivarsson, Henrik Danielsson. Lena Almqvist, Lisa Palmqvist, Christine Imms), based on data from the longitudinal study and a systematic review of adaptations done in longitudinal studies.

Testing strategies for inclusive research methodology in collaboration with CP-ACHIEVE (Australia) and CAAC (South Africa). (Malin Stensson, Berit Möller Christensen, Juan Bornman) A questionnaire concerning inclusive practices in research is currently being developed and data is currently collected (2022) on all CHILD researchers and international colleges.

Investigating the perceptions and experiences of children, parents and professionals who have participated in CHILDF-PMH as co-researchers – evaluating an inclusive design (Karina Huus, Frida Lygnegård). Members of the reference groups in CHILD-PMH have been involved in forming questions for focus groups, recruiting participants for focus groups, interpreting the results of focus groups interviews and planning interventions aimed at enhancing child and family participation based on the results. This study aims to investigate perceptions of reference group participants with the help of a qualitative interview study using semi structured interviews with data analyzed with a thematic analysis

Studies supporting the further implementation of CHILD-PMH program

Identifying and evaluating instruments measuring mental health in children with disabilities – a scoping review (master student Estrella Torres Cabo (2021), supervisor Mats Granlund) In the review 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 Keye's *Health and care professional's strategies for engaging children in the intervention.*

Strategies used by professionals in pediatric rehabilitation for engaging the child in the intervention process – a scoping review 2022 (Master student Marianna Antoniadou, supervisor Mats Granlund). In the review articles identified to provide data on strategies that professionals use to engage children in the habilitation process were reviewed. Analysis partly deductive based on Self-determination theory and the contextual model of therapeutic change.

Developing and validating an adapted version of MHC-SF (Magnus Ivarsson, Lena Almqvist, Camilla Eriksson, Anna Karin Andersson, Jacinta Pennacchia, Mats Granlund) Based on a scoping review of existing measures for assessing mental health/wellbeing by self-ratings from children with disabilities, no instrument with a broader definition of wellbeing (emotional, psychological, social) was identified. This 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 who will provide input on item content and scale used. Preliminary version will be tested for psychometric validity. Final version is planned to be used in data collection three in CHILD-PMH.

Feasibility of using a web-based zoom and PowerPoint platform for structured interviews with children with intellectual disability (submitted)
(Anna Karin Andersson, Lena Almqvist, Magnus Ivarsson). Because of the Covid pandemic as well as having participants in CHILD-PMH living in rural areas a need for involving children in web-based structured interviews as an alternative to meetings in real life was identified. This project aims to test the feasibility of using a web-based solution to structured interviews with children with cognitive disabilities. The web-based solution use zoom and shared power points. Article is submitted.

Studies aimed at testing program questions using other data than CHILD-PMH

Longitudinal Trends of Participation in Relation to Mental Health in Children with and without Physical Difficulties (Hwang, Chang, Granlund, Imms, Chen, Kang)
Children with physical disabilities (PD) are known to have participation restrictions when in inclusive settings alongside typically developing (TD) children. The restrictions in participation over time may affect their mental health status. This study aimed to investigate the longitudinal relationship between independence in activities (capability) and frequency of attendance in activities, in relation to perceived mental health status 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 may be more important than independence in performing activities for experiencing fewer mental health problems. The findings highlight the need for supporting children's actual attendance in daily activities which may benefit their later mental health.

Trajectories of self-rated Participation, Mental Health and Mental Health Problems in Adolescents with Self-reported Neurodevelopmental Disorders. (Lilly Augustine, Mats Granlund, Frida Lygnegård)
Background: Having a neurodevelopmental disorder (NDD) increases the risk of mental health problems and lower participation. Aim: In this study, we investigated the trajectories of mental health problems and participation in adolescents with self-reported NDD, compared these with peers without NDD, and investigated the relationship between these two phenomena. We also investigated the relationship between participation, mental health and mental health problems. Materials and Method: Data from a Swedish longitudinal research program (LoRDIA) was used and adolescents with and without self-reported NDD were followed from 12/13 years to 17 years of age, in three waves.

Results: Adolescents with self-reported NDD experience more mental health problems than adolescents without NDD. Hyperactivity, a key feature of NDD, remains on a stable high level, while others, such as emotional problems (figure 3) and psychosomatic complaints (figure 4), increase over time for girls, independent of NDD. Participation is stable over time but is more related to mental health status than to NDD or mental health problems. Conclusion: Mental health explains more of the variation in participation than mental health problems and NDD; therefore, participation intervention may enhance mental health. In turn, mental health may decrease mental health problems

The relationship between mental health in adolescents having self-reported neurodevelopmental disorders and sources of parental knowledge: A cross-sectional study (master student Lotte Moes, supervisor Mats Granlund)
The present study aimed to compare adolescents (14-15 years old) having self-reported neurodevelopmental disorders classified as flourishing with those adolescents classified as non- flourishing concerning rated mental health problems and adolescent perceptions of adolescent disclosure and parental control. The study used a cross-sectional design based on a secondary analysis of data collected in the LoRDIA research program. Adolescents having self-reported NDDs in wave 3 were included (n=198). Adolescents rated their mental health using the Mental Health Continuum – Short Form, after which researchers classified them as flourishing, moderate, or languishing based on score. Behavior and emotional symptoms were rated using the conduct problems subscale and emotional symptoms subscale of the self-reported version of the Strength and Difficulties Questionnaire. Adolescents rated their disclosure and parental control using the adolescent disclosure scale and parental control scale. Independent Samples t-Tests, Mann-Whitney U test, and multiple regressions were performed to analyze data. Findings that illustrated those adolescents having self-reported NDDs classified as flourishing report less conduct problems, lower adolescent disclosure, and same levels of parental control compared to those adolescents classified as non-flourishing. Emotional problems seem to be positively related to adolescent disclosure within family interaction patterns, while conduct problems appear to be negatively related to parental control. However, parenting style may be crucial in having few or many conduct- and emotional problems. Thus, adolescent disclosure plays a prominent role in relation to adolescents' mental health, mental health problems, and parent-adolescent interactions, while parental control plays a prominent role in relation to adolescents' mental health problems and parent-adolescent interactions.

Will adolescents with Neurodevelopmental difficulties differ in mental well-being and mental health problems in relation to other disabilities? (master student Nida Rehman, supervisor Lilly Augustine)
Purpose: Neurodevelopmental difficulties are correlated with lower mental well-being and more mental health problems. Issues in social relations such as bullying are a prominent risk factor in a social setting of high school, has also been associated to the status of disability. This thesis investigated the relation between mental health problems, mental well-being, and bullying in adolescents with self-reported neurodevelopmental difficulties and compared these with adolescents with Other disabilities. Materials and methods: Data from a Swedish longitudinal survey study (LoRDIA) was used. Mental health problems were measured through emotional and conduct problems scales of SDQ, mental well-being was measured with MHC-SF, and a bullying questionnaire was used.

Results: Adolescents with NDD experience more bullying victimization and perpetration than adolescents with Other disabilities such as physical disability and autoimmune diseases. Significant association to bullying perpetration was found in NDD adolescents. Adolescents with Other disabilities indicated high mental well-being compared to NDD. While gender predicts high mental well-being, disability and emotional problems have a negative relation with it.

Conclusion: Adolescents with NDD report more bullying victimization and perpetration experiences in comparison to adolescents with Other disabilities. Emotional problems have an inverse relation for predicting high mental well-being for adolescents with NDD and Other disabilities.

Perceptions and Experiences of Social Participation in Physical Activities Among Youths with Physical Disabilities in Greece -a qualitative study 2021 (master student Aikaterini Aranti, Supervisor Elaine McHugh)

How youths with physical disabilities experience social participation in physical activities is a subject that has not been extensively researched in Greece. Asking youths can give a deeper insight of their perceptions related to their social participation and how their contexts contribute to that. The family Participation Related Construct (fPRC) framework was used under the umbrella of the Systems Theory to guide the whole procedure of this study. A qualitative approach was conducted by five in-depth interviews with Greek youths (mean age 23) with physical disabilities using online video-call applications. A deductive content analysis was applied for this study, including four themes: 1) the construct of participation in the context of physical activity, 2) Intrinsic factors that influence social participation, 3) Intrinsic factors that are influenced by social participation, and 4) extrinsic factors that influence social participation. Results showed that youths overall described their social participation as a sense of belongingness and social connection with others. They perceived that attending the physical activities that were meaningful to them strongly influenced their social involvement. They also described that social participation in those specific contexts increased their self-confidence. Admittedly, family and activities were contextual aspects that positively influenced youths' social participation. Results also showed the negative influence of the environment, such as the accessibility, state support and the COVID-19 pandemic, either directly or indirectly influenced youths' social participation. Findings of this study support the need for future practical interventions in the Greek community, considering all aspects of the fPRC framework. Finally, collecting a broader number of perspectives will benefit the presented topic in order to create a more holistic view of what needs to be done to bring balance into the system.

Health care professionals' perceptions about family engagement in rehabilitation process.: A mixed method study. (master student Marios Nikolopoulos, supervisor Mats Granlund, Gillian King)

Background: The fundamental goal of intervention services is to provide help and support families so that they can maximize their children's growth and development. This study explored health care professionals' perceptions of family engagement and ratings in sessions with children in need of special support in different intervention contexts in Greece. Methods: The "Family involvement in habilitation" scale, PRIME questionnaires and interviews were used to explore and analyze the health care professionals' perceptions, the level of child and family engagement in sessions and the strategies the professionals use to engage them. Results: The results indicated moderate to high rating in interventionists' perceptions for family engagement in the different steps of the intervention process, with the professionals leading the interventions and the family having a more supplementary role of making suggestions and giving feedback. The level of family engagement in sessions was moderate to low, while child engagement rating during sessions was higher. The three units of the intervention system related to family engagement were identified and presented as the 3 main themes of interviews: Professionals, Family, Environment (e.g. in-service context) using the Process-Person-Context-Time model of human development (PPCT) as a theoretical lens. The main strategies indicated concerned the "Parents' informing", "Parents' training" and "Parents supporting". Conclusions: Although therapists referred strategies for involving families, there is a need for new ideas and systems to create more family-centered approaches. This study contributed to an understanding of the factors that influence family engagement in health professionals' practice. However, it would be valuable to examine how families perceived their engagement in these interventions as well.

Studies using CHILD-PMH data for other aims related to program aims

The utility of the International Classification of Functioning construct as a statistical tool - operationalizing mental health as an indicator of adolescent participation (Lilly Augustine, Mats Granlund, Frida Lygnegård)
Background: The ICF provides a common scientific language for the study of health and functioning. Adolescent mental health, operationalized as engagement in life situations, is one aspect of functioning. Engagement as mental health has a bi-directional relation with environmental factors. Aim: To test the statistical utility of the International Classification of Functioning (ICF) classification in coding adolescent mental health and mental health problems. Methods: Using data measuring mental health in a representative Swedish sample of 12–13-year-olds linking responses to the classification codes. The internal structure of the classification system constructs was tested using factor analysis. Results: A factorial solution could be found for most chapters indicating that the ICF framework and coding system could be used; however, the variance explained was quite low. Linking worked better at code-level, rather than chapter level. Items measuring risk behavior or risk factors are loaded in separate constructs. Conclusions: When coding items for statistical purposes, code-level rather than chapter level is to be preferred. Also, participation in risk behavior loads in separate factors indicating that these behaviors are separate from other types of participation.

Appendix 2 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. 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*
3. 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*
4. 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*
5. 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

Submitted articles refereed journals

1. Danielsson H. et al (submitted) A systematic Review of Longitudinal Trajectories of Mental Health Problems in Children with Disabilities
2. Gothilander, J. et al (submitted) Data quality and reliability of the questionnaire FUNDES-Child-SE measuring participation and independence in children and youths with disabilities
3. Ivarsson, M. et al (submitted). "Structural Validity of the Strengths and Stressors in Parenting (SSF) Questionnaire in Parents of Children with Intellectual Disability and Other Developmental Disabilities"
4. Andersson A.K. et al (submitted) Feasibility of using a web-based zoom and powerpoint platform for structured interviews with children with intellectual disability
5. Täljedal T., et al (submitted). "Patterns of Mental Health Problems and Prosocial Behaviour in Children with Disabilities"

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
2. Moes, L. (2021) *The relationship between mental health in adolescents having self-reported neurodevelopmental disorders and sources of parental knowledge: A cross-sectional study* (Dissertation). Retrieved from: http://hj.diva-portal.org/smash/get/diva2:1576029/FULLTEXT01.pdf

3. Nikolopolous. M. (2021) *Health care professionals' perceptions about family engagement in rehabilitation process.: A mixed method study*. (Dissertation). Retrieved from: http://hj.diva-portal.org/smash/get/diva2:1583535/FULLTEXT01.pdf
4. Rehman, N. (2021) *Will adolescents with Neurodevelopmental difficulties differ in mental well-being and mental health problems in relation to Other disabilities?* (Dissertation) retrieved from: http://hj.diva-portal.org/smash/get/diva2:1621117/FULLTEXT01.pdf

One year thesis:

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

Manuals and other support material

1. Huus, K., Berglund, I., Stensson, M., Möller Christensen, B., Lygnegård, F. (2020) *Inkluderande forskning med barn och familjer – guider och checklistor.* Jönköping: CHILD, Jönköping University

2. Huus, K., Dada, S., Bornman, J., Imms, C., & Granlund, M. (2020) *Manual Picture my Participation – structured interview material to allow children with ID to self-report participation.* Jönköping and Pretoria; CHILD and CAAC