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

Mats Granlund

INSTITUTET FÖR HANDIKAPPVETENSKAP
SWEDISH INSTITUTE FOR DISABILITY RESEARCH

LINKÖPING UNIVERSITY

JÖNKÖPING UNIVERSITY
School of Health and Welfare

MÄLARDALEN UNIVERSITY SWEDEN

murdoch children's research institute

THE UNIVERSITY OF MELBOURNE

UPPSALA

Bloorview RESEARCH INSTITUTE

CKF
Centrum för klinisk forskning Västerås

Region Gävleborg

Region Jönköpings län

Region Västmanland

Region Örebro län

Region Östergötland

Table of Contents

Purpose and aim 1

  Participation 1

  Mental health, mental health symptoms and mental illness 2

  Relating mental health to the fPRC framework 2

  Participation in the intervention process 2

  Participation as a unifying program construct 3

  Inclusive research 3

Program description 4

Participating researchers 5

  Researchers linked to program 5

Supplementary projects and projects linked to the program 5

  Studies aimed at validating assessment instruments used in the program 5

Studies aimed at developing procedures and methods for involving children and care providers in research as subjects or co-researchers 6

Studies supporting the further implementation of CHILD-PMH program 6

Studies aimed at testing program questions using other data than CHILD-PMH 6

Studies using CHILD-PMH data for other aims related to program aims 6

Design and method of the longitudinal study 7

  Changes following from the Covid pandemic and lock-down 7

  Validation and psychometric properties 10

  Data analyses and statistics 11

Design and method for interventions aimed at increasing child and parent involvement in the intervention process (Aims iii and iv): 12

  Changes following from the Covid pandemic and lock-down 12

  Design and method 12

  Instruments used in the habilitation studies: 13

  Psychometric properties 14

  Data analysis and statistics 14

Appendix 1. Studies related to CHILD-PMH 15

  Doctoral thesis work 15

  Studies aimed at validating assessment instruments used in the program 18

  Studies aimed at developing procedures and methods for involving children and care providers in research as subjects or co-researchers 18

  Studies supporting the further implementation of CHILD-PMH program 18

  Studies aimed at testing program questions using other data than CHILD-PMH 19

  Studies using CHILD-PMH data for other aims related to program aims 19

Appendix 2 Publications in CHILD-PMH 20
  Articles in refereed journals 20
  Manuals and other support material 20

Participation and Mental Health (CHILD - PMH) program update spring 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). The pre-definition bias implies that the certain types of impairment/health condition have a strong influence on everyday functioning and mental health. However, several studies report that if children are clustered in profile groups based on everyday functioning, (i.e. participation pattern or problem behaviours), 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. Knowledge is needed regarding what is specific to certain disability groups, and what is universal to all disability groups when the two perspectives mental health problems and mental health are studied longitudinally and related to participation. Participation is related to wellbeing (Arvidsson et al, 2014) and can be seen as a factor that directly affects mental health and indirectly protects 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 and mental health problems and mental health from children and families recruited through the habilitation services, information about the mental health of children with disabilities with a range of severities and factors hypothesized to affect mental health can be obtained. In this research program the transactional relations between the two dimensions of participation and factors affecting participation with a special focus on mental health and services provided to children with disabilities who have mental health problems are studied.

Participation

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 but do not predict changes in participation patterns as evidenced by the stable levels of participation. However, neither the longitudinal trajectories of mental health or the process specific factors contributing to mental health outcomes are identified in these studies.

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

In this program participation is seen as a positive indicator of functioning related to mental health. Concerning 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. In this program, mental health problems, rather than mental disorders, are in focus since problems that are under the diagnostic threshold can cause difficulties with everyday functioning.

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 behaviour 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 behaviour 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 centred fashion. 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. 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 II-SE based on parent reports of their child's frequency of participation in activities and perceived engagement in activities attended (Axelsson, et al, in prep.) This measure also captures child capacity by ratings of independence in everyday activities. Another tool focus on self-ratings of participation though structured interviews with children Picture My Participation (PMP) (Arvidsson et al, 2019, 2021). By using both tools with 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; Pinsof & Wynne, 2000) and the literature on theory-based program evaluation (Harachi, Abbott, Catalano, Haggerty, & Fleming, 1999; Weiss, 1997)) 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; King et al., 2015). 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.

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 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

This research program is partly based on an inclusive research design. 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 12) care providers and adolescents are paid a small honorarium per hour for their participation. This has been financially supported by Jönköping University.

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

(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.

Time plan and implementation

Program part	2019	2020	2021	2022	2023	2024
Longitudinal study	Ethical approval	Data collection 1	Continue data collection 1 and start 2	Continue data collection 2 and start 3	Continue 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 the 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 have changed.

Participating researchers

Jönköping University, CHILD	Linköping University	Mälardalen University	Region Örebro län	Bloorview Research Institute	Murdoch research Institute, Melbourne University
Mats Granlund Karina Huus Eva Björck Lilly Augustine Anna Karin Andersson Anna Karin Axelsson Frida Lygnegård Karin Bertills Charlotte Karlsson Linda Sjödin	Henrik Danielsson Lisa Palmqvist Magnus Ivarsson Pia Ödman	Lena Almqvist Anna Ullenhag Jennifer Gothilander *Torun Täljedal (at Uppsala University)	Lars-Olov Lundqvist Susann Arnell Eva Resare	Gillian King	Christine Imms

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 5 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.

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)

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)

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

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

The relationship between mental health problems, mental health and participation. Using LoRDIA data (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)

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

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

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

Using the ICF as a common language for statistical analyses of mental health (Lilly Augustine)

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. 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. 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; Augustine et al, submitted)

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

<u>Participants:</u> Participating children and their families for the prospective study was recruited from the two age cohorts (in total appr. 2405 children, see Table 3) in five regional habilitation centres that have consented to participate (Östergötland, Örebro, Västmanland, Jönköping and Gävleborg). All children within the specified age ranges, in 2019, in these centres was used as a basis for recruitment. 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 will participate. Children are asked for assent. The estimated external attrition rate is 75%. Due to the Covid pandemic the initial external attrition was higher than expected. For this reason, among families consenting, we have decided not to collect data directly from the children in the first wave. We rely on only collecting data from care providers with the help of web-based questionnaires or paper versions mailed 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 ruff estimation based on our sample indicate that somewhere in between 30 and 40 % of the population have this background. We have therefore added a second try for recruiting children and care providers to the first wave in which all information material and questionnaires have been translated to Arabic and Somali.

Possible participants for the longitudinal studies at the five sites

Site	Young cohort 4-6 in 2019 Children born 2013-2015	Old cohort 10-12 2019 Children born 2007-2009
Region Jönköpings län	306	197
Region Östergötland	196	196
Region Örebro län	167	376
Region Västmanland	197	349
Region Gävelborg	225	198
TOTAL	**1091**	**1316**

Table 3: Possible participants for the longitudinal studies at the five sites

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 II - 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 web-based questionnaires and/or structured telephone interviews completed by parents. Interpreter service will be arranged for parents that do not speak Swedish. Data from children will be collected with the help of structured face-to-face interviews with parent attendance if necessary, for support. Interviews will be implemented 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).

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 II-SE, SDQ, EQ5D-Y sadness scale).

Questionnaires concerning factors hypothesized to affect participation and mental health problems (predictor variables) collected from families will 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) will be collected. Proxy ratings of children's impairments will be 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. 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 4 for instruments used in the longitudinal study.

Outcome Measures	**Setting/type covered**	**Aspect of construct rated**	**Proxy or self-rating**
FUNDES II - 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	**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 a lot of problems)	**Proxy young cohort, Child self-rating older cohort**
Environmental factors	**Measure/subscale**	**Aspect rated**	**Proxy or self-rated**
FUNDES II - SE[1]	Items about barriers and facilitators 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 • Friend's 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 4 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 II-SE (prospective)	Capability (independence)	Professional/parent
Family demographics		Living, circumstances, education, family composition	Parent information

Table 4: Instruments used in the longitudinal study

---

[1] FUNDES II-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 II - SE - Child (Functioning Scale of the disability evaluation system) based on the CASP (Child and adolescent scale of participation) measure 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 facilitators and barriers have been added after forward and backward translation. Cognitive interviews have been undertaken to begin the validation process. Data currently collected in Sweden is used for test-retest and construct validation (CFA) of a new version (20 items) only using participation questions with a scale. The instrument includes four scales: 1) level of independence in performing activity, 2) frequency of attending activity, 3) engagement in activity and 4) barriers and facilitators for participation. Ethical permission to use and adapt the scale has already been obtained (Dnr 2017/496-31). Data collection is done with the help of the 5 local habilitation centres.

Picture My Participation (PMP) is currently being 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

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, In prep). Analyses further indicate that SDQ is a well-functioning instrument over time, but dependent on sufficient sample sizes in order to detect differences.

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-Sieberer 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 ongoing.

Family involvement 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 four items about involvement in assessment decisions, participation in the assessment procedure, goal setting and intervention. 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-rated reliability (Björck-Åkesson & Granlund, 1995).

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 a multiple study 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).

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. Discussion is ongoing to change instrument to WellSEQ, an instrument based on Keye's flourishing construct.

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 we expect a fair amount of missing data (70%). 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 has however been effects on how the focus groups have been implemented. So far primarily focus groups with professionals and parents have been implemented. The groups have been conducted primarily as zoom meetings. 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

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

Flow chart of research process in habilitation interventions

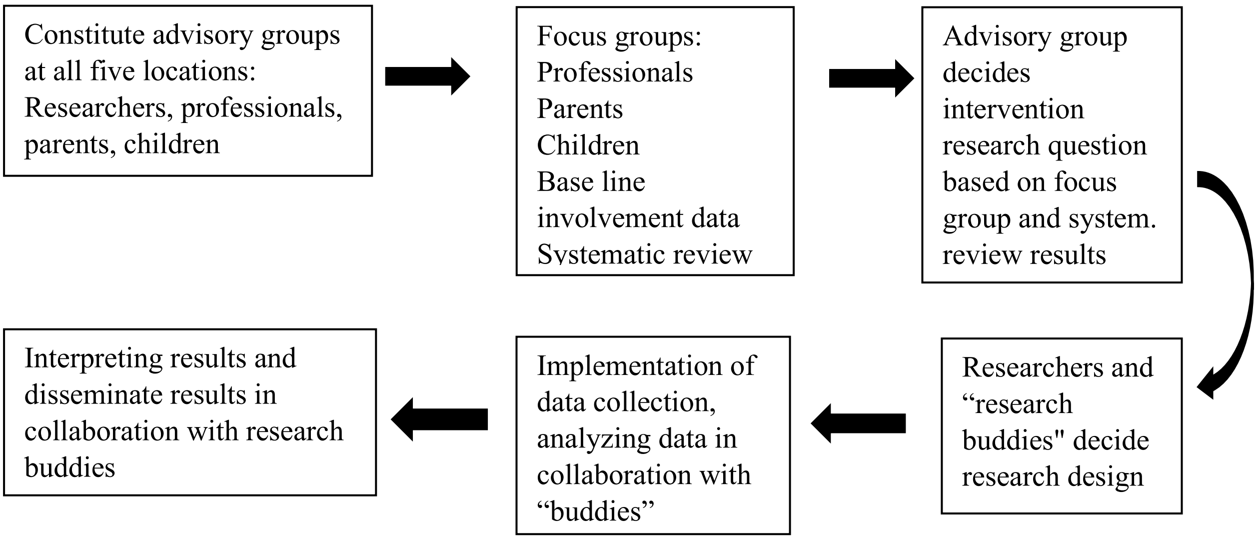

Figure 1: Flow chart of research in habilitation interventions

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

<u>Procedure:</u> Following a co-production inclusive research paradigm, all steps in the research process from defining research questions to disseminating research results include researchers, habilitation professionals, parents and children as co-researchers. Advisory group have been formed at each participating centre (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 five 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 years (fall 2019 - to spring 2021) have been primarily used for 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 is 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 web sites and by having professionals and parents in advisory groups distribute information about focus groups to parents. Children aged 12 years or older are currently asked if they are willing to participate in focus groups. Informed consent from parents and children is required. Content of focus groups is 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) will summarize the discussion and conduct a member check by presenting summaries to participants. Data collected will be analysed 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 will be implemented the following years (2020-2024) locally within the five sites. In addition to focus groups the first and second year will be used to collect base line data on child and family involvement. These data will be collected from child, parent and professionals at each site in conjunction with 10 consecutive encounters per professional. Data will be de-identified - no person information will be collected. Participants will be informed verbally and in text and asked to fill in questionnaires. Filling in the questionnaire implies 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 centre effects, parents' perceptions of "Family involvement in the habilitation process" will be assessed before and after intervention for all involved families. In addition, the coverage rate of the use of the questionnaires included in the HabQ register will be monitored and compared to the habilitation centres not involved in the program activities pre and post program. Since the present coverage rate varies between centres, we will focus primarily on comparing the rate of change between centres participating in the program and centres not participating. See Table 4 for instruments used for baseline measure of involvement before intervention in all sites.

Measures of involvement in the intervention process

Outcome Measure	**Respondent group**	**Aspect of construct rated**	**Proxy or self-rating**
Items from Prime -C	Child	Perceived engagement in one session	Child rates 3 items
Items from Prime - P	Parent	Perceived engagement in one session	Parent rates 3 items
Items from Prime-SP	Professional	Perceived engagement in client in one session	Professional rates 3 items
Perceived family involvement	Parent and professionals	Perceived involvement overall in collaboration with professionals	Parent rates 4 items

Table 5: 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 are currently validated by asking respondent groups to use the instruments in the 5 habilitation centres without any links to personal information. The Perceived 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.

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.

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 a number of related questions will be addressed in the present thesis through five studies: 1) A systematic review of methodological challenges in studies of longitudinal trajectories of mental health problems in children with developmental disabilities, 2) 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, 3) 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, 4) A feasibility and acceptability study of administering Picture my Participation via a video communication application, 5) A study investigating some psychometric properties of SDQ in a diverse sample of children with developmental disabilities.

Factors influencing participation and mental health in children with disabilities

PhD student Jennifer Gothilander, main supervisor Anna Ullenhag, co-supervisors Lena Almqvist, Camilla Eriksson

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 and mental health, as well as study these constructs longitudinally. Children with severe intellectual or physical disability are often excluded from self-report studies of participation and mental health. 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 mental health, 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 mental health trajectories. The overall aim of this doctoral project is to study patterns of factors contributing to participation and mental health of children and youth with disabilities in Sweden.

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 Kent Nilsson, Co-supervisors: Mats Granlund, Eva Norén Sellenius, Karin Fängström

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 will explore immigrant parents' ratings of their disabled children's mental health problems and participation through the SDQ, FUNDES-Child, the "pain and discomfort" and "feeling worried, sad or unhappy" dimensions of the EQ5D-Y and Cantril's life satisfaction ladder. The second will look at these parents' ratings of their parenthood and of the family's involvement in the habilitation through the SSF and the Family Involvement, and in relation to their ratings in the first study. 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. Lotta

Participation in habilitation work – perceptions of professionals and care providers

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 *specialistcenter* 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. Based on the fact that habilitation staff work in teams, 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:
First purpose of the study is to study and describe the habilitation staff's and guardians' experience of children and their families' participation in meetings with habilitation staff. Second purpose of this study is to identify and compare areas of intervention that habilitation staff and care providers identify as possible to increase children's participation in habilitation Third purpose is to study and compare how the habilitation staff and care providers describe the team's role and / or individual professionals 'work regarding children / young people's and guardians' participation in habilitation. The purpose is also to describe obstacles and opportunities based on individual professions and / or the habilitation team in order for children / young people and guardians to participate in habilitation. Methods: Data will be with PRIME (study 1) which measures how staff and parents experience the children's participation in a specific meeting between these parties (King et al, 2017) and perceptions of involvement in the habilitation process (more on team level) (Björck-Åkesson & Granlund). The method in study 2 and 3 is focus group interviews with habilitation staff and guardians from the five regions in CHILD PMH.

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 for to be involved in everyday activities, in comparison to other children. 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 assessment instruments used in the program

Validating Styrkor och Svagheter i Familjen (SSF) (Family Impact Questionnaire) (Magnus) for use in the longitudinal study (Magnus Ivarsson, Henrik Danielsson, Lisa Palmqvist)

Based on the Cosmin manual a psychometric validation of the questionnaire SSF/FIQ) will be implemented focusing on content validity and construct validity. The validation will be based on data obtained from the HabQ register as well as data collected at the first wave of data collection in CHILD-PMH. Aspect focused on in validation are relevance of questions, structural validity, test-retest reliability

Validating FUNDES II - SE (Jennifer Gothilander, Anna Karin Axelsson, Anna Ullenhag, Pia Ödman)

In collaboration with the Swedish FUNDES group and based on the Cosmin manual a psychometric validation of the questionnaire FUNDES II - SE is done. FUNDES II – SE is based on the FUNDES measure (Hua-Fang Liao et al) and further developed by te Swedish FUNDE group adding a scale measuring engagement when attending an activity and facilitators and barriers for participation. Content validity has been investigated and the work in now focused on construct validity. The validation will be based on data obtained from the ongoing data collection in CHILD-PMH and a data collection made in another Swedish region

Validating PRIME (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 will be tested with data being collected at present.

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)

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, supervisor Mats Granlund)

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

Mental health problems, capability and attendance for children with physical impairments. In collaboration with Chang Gung University, (Ai-Wen Hwang, Lin-Ju Kang, Mats Granlund, Christine Imms)

The relationship between mental health problems, mental health and participation. Using LoRDIA data (Lilly Augustine, Mats Granlund, Frida Lygnegård)

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.

Mental health in children with NDD – comparing flourishing and languishing children. Using LoRDIA data (master student Lotte Moes, supervisor Mats Granlund)

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

Professionals' perceptions of care provided and children's engagement in encounters and how they as professionals enhance engagement in clients. Data collected in Greece (master student Marios Nikolopoulos, supervisor Mats Granlund, Gillian King)

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

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

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

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. (accepted). 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*

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

References

Armitage, Samantha, Swallow, Veronica, & Kolehmainen, Niina. (2017). Ingredients and change processes in occupational therapy for children: a grounded theory study. *Scandinavian Journal of Occupational Therapy, 24*(3), 208-213. doi: 10.1080/11038128.2016.1201141

Harachi, Tracy W, Abbott, Robert D, Catalano, Richard F, Haggerty, Kevin P, & Fleming, Charles B. (1999). Opening the black box: using process evaluation measures to assess implementation and theory building. *American journal of community psychology, 27*(5), 711-731.

King, G., Kingsnorth, S., McPherson, A., Jones-Galley, K., Pinto, M., Fellin, M., . . . Savage, D. (2016). Residential immersive life skills programs for youth with disabilities: A pilot study of program opportunities, intervention strategies, and youth experiences. *Research in Developmental Disabilities, 55*, 242-255. doi: 10.1016/j.ridd.2016.04.014

King, G., McPherson, A., Kingsnorth, S., Stewart, D., Glencross-Eimantas, T., Jones-Galley, K., . . . Gorter, J. W. (2015). Residential immersive life skills programs for youth with disabilities: Service providers' perceptions of change processes. *Disability and Rehabilitation, 37*(26), 2418-2428. doi: 10.3109/09638288.2015.1031285

Pinsof, William M., & Wynne, Lyman C. (2000). Toward progress research: Closing the gap between family therapy practice and research. *Journal of Marital and Family Therapy, 26*(1), 1-8.

Weiss, Carol H. (1997). Theory-based evaluation: Past, present, and future. *New Directions for Evaluation, 1997*(76), 41-55. doi: 10.1002/ev.1086