



JÖNKÖPING UNIVERSITY
School of Health and Welfare

Doctoral Thesis

Participation in and outside school

Self-ratings by Swedish adolescents
with and without impairments and
long-term health conditions

Frida Lygnegård

Jönköping University
School of Health and Welfare
Dissertation Series No. 093 • 2018

Studies from the Swedish Institute for Disability Research No.93 • 2018

Doctoral Thesis in Disability Research

Participation in and outside school
Self-ratings by Swedish adolescents with and without impairments and
long-term health conditions

Dissertation Series No. 093 • 2018
Studies from the Swedish Institute for Disability Research No.93 • 2018

© 2018 Frida Lygnegård

Published by
School of Health and Welfare, Jönköping University
P.O. Box 1026
SE-551 11 Jönköping
Tel. +46 36 10 10 00
www.ju.se

Printed by BrandFactory AB 2018

ISSN 1654-3602
ISSN 1650-1128
ISBN 978-91-85835-92-8

“It always seems impossible until it's done.”

Nelson Mandela

Abstract

This thesis in disability research concerns the short-term state of and changes in self-rated participation in domestic life, peer relations and to some extent, school. Participants were adolescents with and without self-reported impairments and long-term health conditions. A functional perspective on adolescents' participation in everyday activities is applied. The thesis is one of several sub-studies in the Swedish research program LoRDIA (Longitudinal Research on Development In Adolescence).

Aim: The aim was to study relationships between individual and environmental factors and participation in a two-time point longitudinal study within the framework of the ICF-CY health classification system. The aim was also to study the impact of environmental and individual factors on self-reported participation in adolescents with and without impairments or long-term health conditions.

Methods: The study designs of the four studies are cross-sectional (studies I and II), and prospective longitudinal (studies III & IV). A combination of person-based (such as cluster analysis in studies II and IV) and variable-based methods (such as ANOVA, multiple regressions, and logistic regressions in studies I, II, III and IV) were used.

Results: When linking items from a questionnaire designed to measure mental health in adolescents to codes in the International Classification of Functioning, Disability and Health, Children and Youth version latent coding is preferred to manifest coding. The focus should be on the underlying meaning of the item and the primary aim of the scale from which the item originated should be taken into consideration. The self-rated experience of participation was stable over time when investigated from a two-time point longitudinal perspective. Results revealed that type of impairment cannot be considered the sole predictor of experience of participation at home, with peers and in school. Factors in the microsystem, e.g., sibling support, and perceived communication within the family, is of greater importance for the level of both participation attendance and the perceived importance of participating in domestic life and peer relations.

At the age of 12 or 13, adolescents with self-reported neurodevelopmental impairments had fewer factors associated with participation in domestic life,

peer relations and school compared to two years later when they were 15 or 16 years of age.

Conclusion: Everyday functioning in adolescents with neurodevelopmental impairments is affected by many of the same factors as for children without neurodevelopmental impairments. However, the effect of neurodevelopmental impairments is particularly evident in school and decreases in importance with age. Factors in the adolescents' environments such as experience of sibling support and communication patterns in the family must be taken into consideration when investigating influences on participation. When measuring participation, both the frequency of attendance dimension as well as the perceived importance of the relevant activity should be included as they seem to be related to partly different influences.

Keywords: participation, adolescents, every-day functioning, ICF-CY, self-ratings, self-reported neurodevelopmental impairment, person-oriented design.

Contents

Original papers	6
Definitions	7
Abbreviations	9
Preface	10
Introduction	11
Background	12
The concept of participation	12
Participation in adolescence	13
The ICF-CY as a conceptual framework	15
The concept of disability; different models	17
Prevalence of disability	18
Neurodevelopmental disorders	19
Mental health and the transition to adolescence	20
Maturity and life role changes during adolescence	21
Theoretical framework	22
Rationale	25
Aim	27
Materials and methods	29
The LoRDIA research program	29
Research design	31
Setting	32
Sample studies I-IV	32
Instruments	33
Linking items to ICF-CY	35
Dependent and independent variables used in the four studies	36
Data collection	42
Data analysis	43
Ethical considerations	45

Results	48
Discussion	52
Changes in maturity and life roles.....	52
Measuring change over time	55
Frequency of attendance and level of involvement; key dimensions in the participation construct	57
A biopsychosocial approach to impairment and disability.....	59
Methodological considerations.....	61
Validity and reliability of the studies	62
Combining variable-based and person-oriented methods	67
Conclusions	68
Theoretical implications	69
Clinical implications.....	71
Future research	72
Summary in Swedish/ Svensk sammanfattning	73
Acknowledgements	77
References	82

Original papers

This thesis is based on the following papers which are referred to by their Roman numerals in the text.

Paper I

Augustine, L., Lyngegård, F., Granlund, M., & Adolfsson, M. (2017). Linking youths' mental, psychosocial, and emotional functioning to ICF-CY: Lessons learned. *Disability and Rehabilitation*, 1-7. doi.org/10.1080/09638288.2017.1334238

Paper II

Lyngegård, F., Almqvist, L., Granlund, M., & Huus, K. (2018). Participation profiles in domestic life and peer relations as experienced by adolescents with and without impairments and long-term health conditions. *Developmental Neurorehabilitation*, 1-12. doi.org/10.1080/17518423.2018.1424266

Paper III

Lyngegård, F., Augustine, L., Granlund, M., Kåreholt, I., & Huus, K. (2018). Factors associated with participation and change over time in domestic life, peer relations, and school for adolescents with and without self-reported neurodevelopmental disorders. A follow-up prospective study. *Frontiers in Education*, 3(28). doi:10.3389/educ.2018.00028

Paper IV

Lyngegård, F., Granlund, M., Kapetanovic, S., Augustine, L., & Huus, K. Short-term longitudinal participation trajectories related to domestic life and peer relations for adolescents with and without self-reported neurodevelopmental impairments.

(In manuscript)

The papers have been reprinted with the kind permission of the respective journals.

Definitions

In this thesis

Activity	The execution of a task or action by an individual (World Health Organization, 2001).
Adolescence	The period in human growth and development that occurs after childhood and before adulthood, from ages 10 to 19 (World Health Organization, 2017a).
Disability	A long-term physical, mental, intellectual, or sensory impairment that in interaction with various barriers may hinder full and effective participation in society on an equal basis with others (United Nations, 2006).
Impairment	Problems in body function or structure such as a significant deviation or loss (World Health Organization, 2001).

Long-term health condition	A condition that it is characterised by three features; the condition should have been there for more than three months, it cannot be resolved spontaneously and is rarely completely cured (van der Lee, Mookink, Grootenhuis, Heymans, & Offringa, 2007).
Mental health	The capacity to achieve and maintain optimal psychological functioning and wellbeing. This capacity is related to the competence one achieves in psychological and social functioning (Gustafsson et al., 2010).
Neurodevelopmental Disorder	A group of conditions characterised by developmental deficits that produce impairments of personal, social, academic, or occupational functioning (American Psychiatric Association, 2013).
Neurodevelopmental impairment	Self-reported impairment within the NDD spectrum that can occur below the threshold criteria required for receiving a diagnosis.
Participation	Participation in this thesis is defined as having two interrelated dimensions; the frequency of attendance dimension, and the perceived involvement dimension (Imms et al., 2017).

Abbreviations

CHILD	Children Health Intervention Learning Development
ICF-CY	International Classification of Functioning, Disability and Health, Version for Children and Youth
	ICF-CY Classification Codes:
<i>b</i>	<i>body functions</i>
<i>s</i>	<i>body structures</i>
<i>d</i>	<i>activities</i>
<i>p</i>	<i>participation</i>
<i>e</i>	<i>environment</i>
LoRDIA	Longitudinal Research on Development In Adolescence
NDD	Neurodevelopmental disorder
NDI	Neurodevelopmental impairment
UN	United Nations
UNCRC	United Nations' Convention on the Rights of the Child
UNCRPWD	United Nation' Convention on the Rights of PersonsIndividuals with Disabilities
WHO	World Health Organization

Preface

My first microsystem consisted for a short time of my biological mother, my identical twin sister and other children and staff at an orphanage in south-western India in the city of Chennai. I spent approximately one year in this orphanage before coming to Sweden. I think that this is why I have always had a special interest in children's rights and living conditions. This interest grew during my time as an occupational therapy student and in particular during my master's education in public health. In 2003, I received a Minor Field Study (MFS) scholarship that I used to collect data in India for my master thesis in public health. The data collection took place in rural parts of India, exploring adolescents' own opinions on attitudes regarding HIV and AIDS. My master's degree in public health provided me with additional knowledge on health-related issues at a populational level. When collecting data in India I made the decision to pursue doctoral studies in the future. I wanted to be able to work as a researcher and shed light on the situation of children in vulnerable situations. Ten years later, in 2013, after working as both an occupational therapist and a university lecturer I was given the opportunity to be part of the CHILD research team working within the longitudinal research program LoRDIA (Longitudinal Research on Development In Adolescence). While working within CHILD and the LoRDIA research program, I learned how to do research with a focus on enhancing the participation of adolescents in three different contexts; at home, with peers and, to some extent, in school. My aim is to continue working for increased participation in everyday activities valuable to children and adolescents as well as to continue promoting the rights of children with and without disabilities nationally and internationally.

Introduction

This thesis in disability research concerns the participation of adolescents with and without self-reported impairments and long-term health conditions. The present state of and short term changes in self-rated participation in domestic life, peer relations and (to some extent) school are studied. The thesis also concerns how individual and environmental factors affect participation. The intention is to contribute towards the existing body of knowledge in Sweden regarding factors that are hypothesised to affect participation over time for adolescents, irrespective of having an impairment or not. The concept of participation has its origin in the macro-setting, where participation can be viewed as an international political objective and a basic human right (United Nations (UN) General Assembly, 1993). A systems perspective (Bronfenbrenner, 1979) is undertaken with special attention to the microsystem (domestic life and relations with peers). In addition, the International Classification of Functioning, Disability and Health, the Child and Youth version (ICF-CY) is used to operationalise the concept of participation. If participation is defined on a macro level, one can argue that all individuals have the right to participate in their own life and that participation is therefore vital for the health and wellbeing of a country's citizens. Participation is however also an individual experience in a close setting (Eriksson, 2006). All data used in the thesis is self-rated. Hence, the users' perspective and the adolescents' own voices are emphasised. The primary aim of this thesis is not to examine the impact of a diagnosis or a specific type of impairment on participation. Rather it is to adopt a perspective on everyday functioning where impairments or long-term health conditions are considered two factors among others which affect functioning. The thesis includes all adolescents in the study population but has a special interest in adolescents with self-reported neurodevelopmental impairments (NDI). Comparisons between groups of adolescents with and without self-reported NDI are made to investigate whether the everyday functioning of adolescents is driven by a combination of common factors rather than primarily by a specific type of impairment or long-term health condition.

Background

The concept of participation

To understand the characteristics of the developing child and the influence of its surrounding environment one of WHO's social classifications is used as a tool to operationalise participation. In order to understand the nature of participation, a sound definition of the concept is essential. Participation can be described as a multi-dimensional concept (Imms, Adair, Keen, Ullenhag, Rosenbaum & Granlund, 2016; Imms, Granlund, Wilson, Steenbergen, Rosenbaum & Gordon 2017). The word participation originates from the Latin word *particeps*, which means part-taking or taking part; and the words *pars + capere* mean to take or to share in (Law, 2002). There are different definitions of participation but common to these are that they focus on both qualitative and quantitative dimensions. The International Classification of Functioning, Disability and Health, launched in 2001 by the World Health Organization (WHO), defines participation as 'involvement in a life situation'. This is the definition of participation that will be used in this thesis. It should be recognised that the participation construct within the ICF-CY only recognised participation in terms of 'being there', defined within the construct as involvement. This definition does not recognise the subject experience of participation. Therefore, as suggested by Granlund et al. (2012), a second dimension, focusing on the experience of involvement while taking part in an activity, supplements this definition.

Participation is stressed in international agreements such as the Standard Rules on the Equalisation of Opportunities for Individuals with Disabilities (United Nations (UN) General Assembly, 1993), the Convention on Rights for Individuals with Disabilities (UNCRPD) (United Nations (UN), 2006) and the Convention on the Rights of the Child (UNICEF, 1989). In these definitions participation is primarily seen in relation to the right to take part in the same activities as others; that is, the attendance aspect of participation is stressed. Taking part in everyday occupations is a vital part of human development and the way we experience life. By participating in everyday activities important life skills and competences are acquired (Law, 2002). Participation can be considered as something positive; an asset, a vital part of a healthy life and therefore, a human right (United Nations (UN) General Assembly, 1993). The involvement part, being engaged while being there, is less investigated (Adair et al., 2018).

To understand the perspective from which the results and conclusions of this thesis are presented, the sub-dimensions of the concept of participation and factors influencing participation will be described below.

Imms et al. (2017) provide a framework of the family of participation related constructs (fPRC) in which participation is presented as being constituted of two separate but interrelated dimensions. The first is the being there dimension, which can be measured as the frequency of attending an activity and the second is involvement i.e. the individual's own experience of participation while attending the activity. The first dimension can be coded within the ICF-CY using the performance qualifier. The frequency of attendance is linked to inclusion and a human rights approach based on equal opportunities and non-discrimination (Maxwell, Alves, & Granlund, 2012). The second dimension cannot be rated in ICF-CY as it relates to the intensity of engagement in an activity, and in this thesis it is operationalised as the importance assigned to the specific activity. The attendance dimension is a prerequisite for the involvement dimension (Imms et al., 2017).

As of today, our existing knowledge on participation in adolescents is primarily based on the attendance dimension (Adair, Ullenhag, Keen, Granlund, & Imms, 2015; Adolfsson, Malmqvist, Pless, & Granlund, 2011; Maxwell, Augustine, & Granlund, 2012) and the involvement dimension is crucial when attempting to increase participation (Imms et al. 2017).

Participation in adolescence

Participating in home, school and community activities has a positive influence on children's health and wellbeing (Law et al., 2013; World Health Organization, 2007). As children with disabilities move into adolescence, participation patterns change, with fewer organised activities occurring outside the home (Brown & Gordon, 1987) while attendance of informal activities outside the home increases. The two ICF-components, domestic life, e.g. cooking food, cleaning the house, and interpersonal interactions and relationships, e.g. relations with relatives, peer relations, are examples of everyday life settings and situations that occur on a regular basis. In these components, differences in participation could arguably be found based on changes resulting from the transition from childhood to adolescence.

For adolescents with disabilities, domestic life activities, such as carrying out household tasks, and taking part in social interactions, constitute valuable everyday life situations in which they can develop skills which are important later in life (Adolfsson, 2011).

Within the home setting, opportunities are provided to participate in various activities including doing household chores and spending time with peers at home. Earlier research has demonstrated that participation in home activities is lower for children and adolescents with disabilities than for their peers without disabilities (G. King, Law, Hurley, Petrenchik, & Schwellnus, 2010). There are several indicators that children with disabilities are at risk of social exclusion. Law, Anaby, Teplicky, Kehtani, Coster and Bedell found that frequency of participation in different activities for children with and without disabilities differs. Children with disabilities tend to take part in both fewer and less complex activities than their peers, and primarily participate in activities with their family members (Law et al., 2013).

There are differences in patterns of participation when comparing adolescent and adults. This is likely due to the influence of developmental changes within the individual, expectations of independence and changes in roles that occur throughout the lifespan (World Health Organization, 2007).

Participation patterns in adolescents with disabilities could, in addition to the conditions for all children vary due to type of impairment and abilities. In addition, personal factors such as the individual's own interest in the activity affect participation (Cardol, Jong, & Ward, 2002). Children and adolescents with and without disabilities often share the same desires and expectations in life, wanting to spend time with peers and share experiences with others. Despite this, having a disability seems to reduce opportunities to interact with peers. It is likely that adolescents with disabilities often need more support from adults in order to participate in leisure activities within and outside the home environment (Cowart, 2004).

The ICF-CY as a conceptual framework

In the present thesis, the Children and Youth version of the International Classification of Functioning, Disability and Health (ICF-CY) is used as a means to describe everyday functioning from a biopsychosocial perspective. This classification was launched in 2007 by the World Health Organization. The purpose of the classification is to provide a common language for understanding health and human functioning in various life situations, with a focus on health and functioning that is specific to the growth and development of children and youth. The ICF-CY is both a universal and multi-dimensional conceptual framework for health, human functioning and disability, and a classification system. According to the ICF-CY,

‘child and youth environments can be viewed in terms of a series of successive systems surrounding them from the most immediate to the most distant, each differing in its influence as a function of the age or stage of the developing child’ (p. xvi).

Given the dependency of the developing child, the physical and social elements of the child’s environment have a significant impact on its functioning. For the last decade, the ICF-CY has been the overarching framework used for defining and describing the concept of participation. The ICF-CY is used as a conceptual framework and therefore the results of this thesis are presented from a bio-psycho-social perspective, where the psychosocial perspective (the adolescents’ self-ratings) is in focus. The biopsychosocial perspective (i.e. combining various levels of reality; body, activity and environment, in relation to participation) has influenced the choice of theoretical framework and the variables studied, as well as the methods employed during data collection and data analysis.

The ICF-CY consists of an interactive health model and a classification system. The interactive model (Figure 1) illustrates the complex relationships between six different dimensions: health conditions (disorder or disease); body functions and body structures (e.g. muscle tone and the structure of a leg); activities (e.g. the ability to walk); participation (the experience of walking and talking while taking a walk with someone); and contextual factors that consist of environmental factors (such as products and technology, natural environment, support and relationships and attitudes); and personal factors (e.g. previous experiences, religion etc.). Environmental factors are referred to as ‘factors that make up the physical, social, and attitudinal environment in which people live and conduct their

lives' (WHO, 2001, p. 197). Personal factors are not classified in the ICF because of the large social and cultural variances associated with them) (Adolfsson, 2011; World Health Organization, 2007). Body functions and body structure components are considered as a single component in the ICF-CY *model*, as illustrated in Figure 1. However, in the ICF-CY *classification system*, they are divided into two parallel components, where body functions and body structures are described separately. In addition, activity and participation are described as *two separate* components in the model but as *one* component in the classification system.

The key construct in the ICF-CY is the neutral term 'participation'. Participation restriction is defined as 'problems an individual may experience in involvement in a life situation' (World Health Organization, 2007, p. 14). This term is intended to replace the previously used term handicap. In this thesis, the ICF-CY is used to operationalise participation. In the ICF-CY manual (Annex 3, pp. 248-251, World Health Organization, 2007), four alternatives are presented for how activity and participation can be separated in the classification system. In this thesis the first option is used. According to this option, distinct sets of activity domains and participation domains are decided by the user of the classification system. The user may decide whether the category refers to either an activity or participation but not both. In this thesis domains 1-5 are defined as activities because they primarily describe actions, while domains 6-9 are defined as participation as they describe life situations. According to the ICF-CY, the definition of participation carries the involvement concept that in the present form of the classification system can only be coded through performance. However, 'the involvement concept is not to be automatically equated with performance' (p. 13). Hence, users who wish to code involvement as a separate part of participation should use the coding guidelines provided in the classification system. Figure 1 provides an illustration of the dynamic interaction between the domains. In this figure, an individual's everyday functioning should be seen as an interaction or complex relationship between their health condition and contextual factors (i.e. environmental and personal factors). Importantly, these interactions work in two directions and the presence of disability may also modify the health condition.

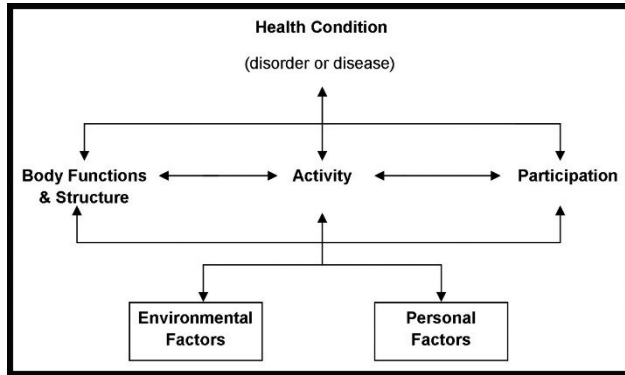


Figure 1. Interactions between components of the ICF-CY (WHO, 2007)

In order to understand the concept of disability, which can be regarded as a multidimensional concept, a selection of disability models are discussed below.

The concept of disability; different models

Disability can be regarded as a multidimensional concept that can be defined from various perspectives. According to Altman (2001), the definition of disability is dependent on the context in which it is being used (Altman, 2001). When participation is defined as a health-related concept and as an indicator for positive functioning it is vital to conceptually relate participation to disability and health (Bickenbach, Chatterji, Badley, & Üstün, 1999). Traditionally, disability research in Sweden has been dominated by the medical model of disability, in which disability is considered an attribute of the person and a deviation from what is considered normal. According to the medical model this deviation is supposed to be rehabilitated, cured or restored. This model does not include social or environmental factors that could be assumed to restrict participation in society. The social model of disability was first established in the United Kingdom during the 1970s and was a reaction against the medical model. With the introduction of the social model there was a shift away from the individual and a focus toward barriers within society. Disability was seen as a social phenomenon without taking impairments into consideration (39).

In the present thesis the biopsychosocial model of disability is applied. This model of disability is a combination of the medical and social models and

aims to merge the two perspectives by applying a multidimensional integrative approach. The biopsychosocial model of disability not only addresses biological aspects but also psychological and social aspects of impairments and disability (World Health Organization, 2007).

In this thesis, adolescents with self-reported long-term health conditions are included. A general definition of a long-term health condition is that it is characterised by three features: the condition should have been there for more than three months; it cannot be resolved spontaneously; and is rarely completely cured (van der Lee et al., 2007). In the United Nations Convention on the Rights of Persons with Disabilities (CRPD), disability is seen as an evolving concept resulting from the interaction between persons with impairments and environmental barriers that hinder full participation in society on an equal basis with others. In Article 1, it is stated that ‘persons with disabilities include those who have long-term physical, mental, intellectual or sensory impairments’ (United Nations, 2006). Therefore, there is an overlap between the definition of impairment and long-term health conditions, and both can be related to disability. In this thesis, the term disability is used for both impairments and long-term health conditions.

Prevalence of disability

According to the World Report on Disability (World Health Organization, 2011) approximately one billion people live with a disability, which is about 15 % of the global population. A global increase of long-term health conditions such as mental health diseases, cancer and diabetes offers some explanation for this increase. Neurodevelopmental disorders are considered the leading cause of disability in all regions worldwide. In Sweden today about 1.5 million people live with a disability (Corell, Augustine, & Löfstedt, 2012). Approximately 15% of all children in Sweden have self-reported that they have a disability or long-term health condition (Idring et al., 2015). In the next section, an outline is given regarding the characteristics of neurodevelopmental disorders, which are a special focus in the thesis.

Neurodevelopmental disorders

Neurodevelopmental disorders (NDD) are listed in the Diagnostic and Statistical Manual of Mental Disorders No. 5 (DSM-5). These disorders represent umbrella terms for several conditions that have an onset in the developmental period. Examples of neurodevelopmental disorders are intellectual disability, attention-deficit/hyperactivity disorders, communication disorders, motor disorders, specific learning disorders, autism spectrum disorders (ASD), and other neurodevelopmental disorders. Dyslexia and dyscalculia are referred to as specific learning disorders and are included in the group of neurodevelopmental disorders. The diagnostic criteria of each specific disorder are unique. However, there is often an overlap and a child can have more than one neurodevelopmental disorder. Development deficiencies vary greatly, ranging from particular impairments on learning and executive functioning to more global limitations on intelligence and social skills.

Common to these disorders is their impact on personal, social and occupational functioning and the fact that they often manifest in early development. In addition, neurodevelopmental disorders often co-occur. This means that a child can have autism spectrum disorder as well as an intellectual disability (intellectual development disorder). Children with attention-deficit/hyperactivity disorder (ADHD) often have additional learning disorders as well (American Psychiatric Association, 2013).

Child and adolescent mental disorders can manifest in several domains and in various ways. A mental illness or disorder is diagnosed after identifying a pattern of signs and symptoms that could be associated with impairment of psychological and social functioning. The criteria for disorders are described in the International Classification of Disease, version 10 (ICD-10, WHO, 2016) or the DSM-5, American Psychiatric Association, 2013), for example. However, children and adolescents may have problems that can be described using criteria for NDD without having symptoms severe enough to prompt a diagnosis, and some individuals do not receive a diagnosis until they reach adulthood (Haller, Cramer, Lauche, Gass, & Dobos, 2014; Shankman et al., 2009). According to a recent systematic review, mental health problems are

increasing in northern Europe (Potrebny, Wiium, & Margrethe Moss - Iversen, 2017). Psychosomatic symptoms are often related to difficulties with everyday functioning. Adolescents with a high rate of psychosomatic complaints are more likely to consume alcohol, for example (Norell-Clarke & Hagquist, 2016). In the present thesis, all adolescents who self-report a neurodevelopmental impairment (NDI) are included in the NDD group, since problems can occur regardless of having a diagnosis or not. By using self-report to define groups it is possible to investigate the life-situation of adolescents based on their own perceptions of their health status.

Mental health and the transition to adolescence

There are many factors that can be considered to have an impact on adolescents' mental health. These factors operate at the individual level of the adolescent, within the family and school setting, as well as at the broader societal level (Morgan et al., 2008). Mental health can be defined as 'a state of well-being in which every individual realizes his or her own potential, can cope with the normal stresses of life, can work productively and fruitfully, and can contribute to her or his community' (World Health Organization, 2014). As can be seen in this definition, there is a strong link between participation and health. Mental health in children and adolescents can be described either as a lack of symptoms or as positive functioning in everyday life activities. Such positive functioning can be operationalised as actively participating in settings that are typical for adolescents to take part in (Law, 2002). Confident and happy adolescents will have greater opportunities to grow into happy and confident adults. In turn, they will then be able to contribute towards the general health and wellbeing within society (Rao, 2001). This has implications for their self-esteem, behaviour and school attendance, educational achievements as well as future health (World Health Organization). Adolescents with impairments and/or long-term health conditions face increased risk of negative life-outcomes such as lower mental health than adolescents without impairments and- or long term health conditions (Statens Folkhälsoinstitut, 2011).

Adolescence is a distinct life phase in which many developmental changes occur (Sawyer et al., 2012). The period of adolescence is considered a healthy part of human life, although many long-term health conditions have their onset during these years (Kessler et al., 2005). WHO defines

adolescence as the period between the ages of 10 and 19. Today, adolescents constitute 1.8 billion people, which is approximately one fourth of the global population (World Health Organization, 2017a). This period in life is characterised by increased autonomy where independent decision-making may influence health and health-related behaviours. Individuals in this age group face many challenges, including alterations to social relationships with family and peers, growing academic expectations, and physical and emotional changes associated with maturation. Behaviours established during this period in life may continue into adulthood and affect issues such as mental health, individual experience of health in general, diet, tobacco use, alcohol use and level of physical activity (Inchley & Currie, 2014).

Maturity and life role changes during adolescence

Adolescence is considered one of the most rapid phases of human development (Roeser, Eccles, & Sameroff, 1998; World Health Organization, 2018). As individuals develop, their life situations change both in number and in complexity (World Health Organization, 2007). Even though biological maturity precedes psychosocial maturity, age is only one of the important characteristics describing this period of development. According to WHO, age can be appropriate to assess and compare biological changes that are universal with changes that are related to social transitions, which vary in relation to the individual's socio-cultural environment. This period in life is a time to learn how to manage emotions and relationships, as well as develop skills and knowledge and acquire abilities which are important during adolescence and when assuming adult roles. Adolescence is characterised by neurodevelopmental changes, such as emotional responses and pleasure seeking, as well as executive functions such as decision-making, impulse control and future planning. Linked to these changes are psychosocial and emotional changes as well as increasing cognitive and intellectual capacities. Changes that occur within the environment both affect and can be affected by these internal changes. External changes concern social values, norms and changing relationship roles, responsibilities and expectations. Changes in adolescence are considered to have health-related consequences, not only during this phase of life but also later over the course of life. Many changes related to adolescence can appear universal. However, their timing and speed can vary among and sometimes even within individuals because of characteristics

within the individual (for example gender) or external factors (such as supportive or non-supportive environments and culture). Hence, the characteristics of the individual as well as the environment should be taken into consideration as both influence changes in adolescence (World Health Organization, 2018).

Theoretical framework

Changes in functioning from a life-time perspective need to be conceptualised with a model that can describe and interrelate changes in the person, context and processes, including the person and context over time. One such model is based on Bronfenbrenner’s bioecological theory and the Process-Person-Context-Time (PPCT) model (Bronfenbrenner & Evans, 2000). This updated version of the bioecological theory has incorporated the PPCT model (Fig. 2)

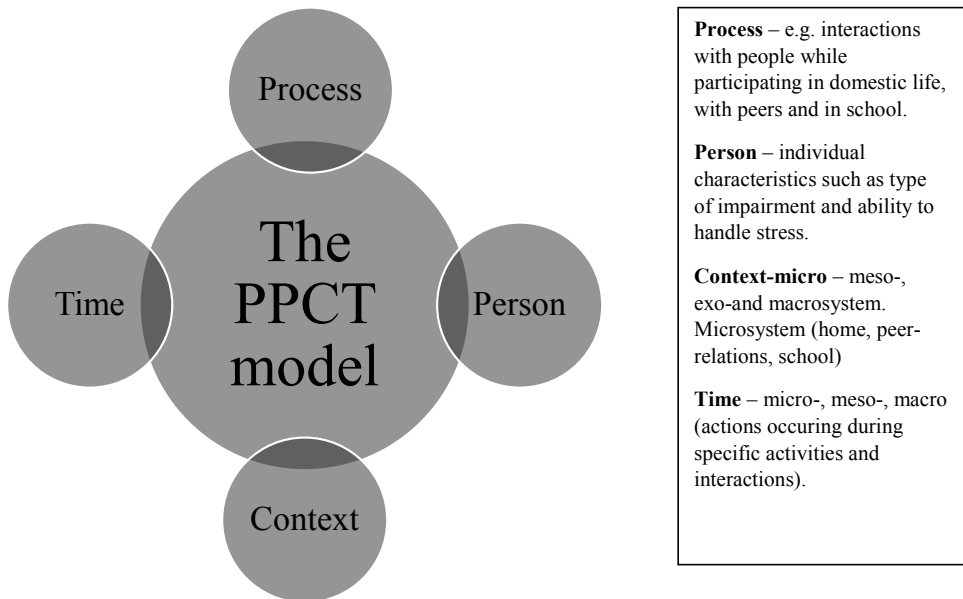


Figure 2. The Process, Person, Context, Time model with examples related to this thesis’s aim and scope (Bronfenbrenner & Morris, 1998; Bronfenbrenner & Evans, 2000).

The central element in the PPCT model is the proximal *processes* involving different forms of interactions between organisms and their surrounding environments, such as interactions between the child and other individuals or objects in the external setting. Examples are interactions between children and children, children and parents, or children and objects. The proximal processes operate over time and are considered the primary engine for human development, as well as for everyday functioning. The degree to which proximal processes influence development and functioning is dependent on the characteristics of the individual, the contexts, immediate as well as remote, and the time at and in which the proximal processes occur (Bronfenbrenner & Morris, 1998). For a child or adolescent to develop and function optimally, taking part in proximal processes is considered a vital prerequisite. Proximal processes are described as transactional and become increasingly complex over time. Proximal processes are important even if a person has a very slow developmental pace. The transactional character of the processes creates context-person interactions where the adolescent and individuals in the environment are mutually reinforced by perceiving each other's engagement (Imms et al., 2017; Sjöman, in prep.) Thus, participation can be described as both a contribution to as well as an outcome of well-functioning proximal processes (Axelsson, 2014). Within the PPCT model, Bronfenbrenner acknowledged the relevance of biological and genetic aspects of *individuals* but paid more attention to the personal characteristics that the individual brings to social situations (Bronfenbrenner & Morris, 1998). Personal characteristics affecting proximal processes can be divided into three types; demand, resource and force. Demand characteristics are those acting as stimuli to other people (such as gender, age and physical appearance) which can influence interactions due to the immediate expectations they generate. In contrast, resource characteristics are not directly apparent and refer partly to mental and emotional resources (such as past experiences and skills) but also to social and material resources. Force characteristics relate to differences in motivation, temperament and persistence, and directly affect other individuals.

Context, or environment in the PPCT model, refers to four interrelated systems. The first is any environment in which a person spends a lot of time in, such as home, peer groups or school; i.e. the microsystems. As individuals develop it is expected that their life roles will change and they will spend time in more than one microsystem. The interrelations between

systems are defined as the mesosystem. Contexts that can affect the individual even when the individual is not present, are referred to as exosystems; for example, the workplace of a caregiver or parent, or parental support. Societal contexts such as cultures, sub-cultures, and social structures, as well as legislations and regulations, are called macrosystems. Macrosystems can influence and be influenced by all the other systems. Finally, *time* is crucial in the PPCT model and is divided into micro-time, meso-time and macro-time. Bronfenbrenner and Morris (1998) write that micro-time is what occurs during a specific activity or interaction, meso-time is the extent to which these interactions or activities occur with some consistency in the person's environment and macro-time (previously defined as the chrono-system) is related to the historical events occurring during a certain time period, e.g. century. Thus, the three time systems occur at different paces, with micro-time having the fastest pace and macro-time the slowest pace. In conclusion, Bronfenbrenner's theory in its developed form addresses the interrelations between the four PPCT concepts described above.

Rationale

Taking part in everyday life situations is an important prerequisite for individual development and functioning. To be able to participate in activities of everyday life, one needs to be able to decide the level of participation and what activities to participate in. Additionally, one needs to be given the opportunity to take part in the desired activities (Eriksson & Granlund, 2004). Participation is considered a vital part of a healthy life and therefore a human right. Adolescents interact in a wider spectrum of close environments than younger children and are thus more susceptible to influences outside the family (Bronfenbrenner & Ceci, 1994). Adolescents with disabilities report lower mental health and are also more exposed to different forms of bullying than their peers without disabilities (Statens Folkhälsoinstitut, 2011). As individuals grow older, natural shifts in environments and contexts occur. Peer relations may be perceived as more important while spending time with parents at home is perceived as less important. Variations in the way participation is perceived in relation to this may be a result of the surrounding environment or maturity changes within the individual. Changes in life roles and maturity mean exposure to a wider set of contexts. This means that higher demands are put on the individual's activity competence to manage life tasks independently of their parents. According to Gustafsson et al. (2010), adolescent mental health is defined as the capacity to achieve and maintain optimal psychological functioning and wellbeing. This capacity is related to the competence one achieves in psychological and social functioning (Gustafsson et al., 2010). The wider set of environments makes it crucial to focus on adolescent participation in specific contexts when promoting participation. Focusing on everyday functioning as situated in the close environment will provide more information on adolescents' health and functioning than merely focusing on the type of impairment or a specific diagnosis (Eriksson, 2006). Longitudinal studies of factors predicting participation are rare (Granlund, 2013; King, 2013). Likewise, longitudinal studies where adolescents with intellectual impairments are invited to participate and where the methods applied are designed to be applicable to adolescents with intellectual impairments are lacking (Alderson & Morrow, 2011). To capture the concept of participation, both frequency of participation, i.e. the attendance dimension, as well as the involvement dimension, i.e. the value one assigns to the activity, should be

included. Studies in which both these dimensions are addressed in relation to participation for adolescents with and without disabilities and/or long-term health conditions are lacking. This project touches on each child's right to voice their opinion, as underlined in the United Nations Convention on the Rights of the Child (UNCRC) (UNICEF, 1989).

Aim

This thesis consists of four interrelated sub-studies that are summarised and discussed in the thesis framework.

The aim was to study the relationships between individual and environmental factors and participation in a two-time point longitudinal study within the framework provided by the health classification system ICF-CY. Another aim was to study the impact of environmental and individual factors on self-rated participation in adolescents with and without self-reported impairments or long-term health conditions.

The following research questions were posed and they form the foundation for the results section of this thesis.

To what extent is the International Classification of Functioning, Disability and Health, Children and Youth Version (ICF-CY), applicable to document and follow the trajectories of participation over time for adolescents with and without self-reported impairments or long-term health conditions? *(Studies I-IV)*

What individual and contextual characteristics are related to self-rated participation at one time point and over time? *(Studies II + III + IV)*

How does self-rated participation change over time for adolescents with and without self-reported impairments or long-term health conditions? *(Studies III + IV)*

The specific objectives of the four sub-studies were:

- Study I To describe methodological challenges experienced when coding variables intended to measure latent constructs and capture mental health phenomena, e.g. emotions and relations, into the ICF-CY.
- Study II To identify how individual factors (related to body function and activity performance) and factors within the family environment relate to self-reported participation cluster profiles of attendance and perceived importance in domestic life and interpersonal interactions and relations (peer relations) as defined by the ICF-CY.
- Study III To investigate predictors of change in participation, operationalised as frequency of attendance, and perceived importance in domestic life activities, peer-related activities and school activities as experienced by adolescents with and without self-reported neurodevelopmental disorders.
- Study IV To investigate trajectories across clusters based on self-rated participation patterns in frequency of attendance and perceived importance of domestic life and peer-related activities for adolescents with and without self-reported neurodevelopmental impairments.

Materials and methods

The LoRDIA research program

This thesis is one of several sub-studies being done as part of the on-going Swedish research program LoRDIA (Longitudinal Research on Development in Adolescence). The program uses a longitudinal prospective design and primarily aims to study developmental pathways leading to alcohol and drug use as well as the mental health in a population of Swedish adolescents between the ages of 12-18. LoRDIA is a collaboration between the School of Health and Welfare, Jönköping University and the University of Gothenburg, Sweden. The research program is multidisciplinary and covers the fields of disability research, social work and psychology. The author's and co-researchers' combined knowledge have been useful in attempting to create inter-disciplinary methods by developing appropriate methods for data collection involving adolescents with intellectual disabilities.

The total population of 2108 adolescents in 6th and 7th grade, aged 12-14, in 4 municipalities in the south and southwest of Sweden were invited to participate in the LoRDIA research program. In this thesis, data from the first wave of data collection that took place in 2013 is used along with data from the third wave of data collection, which took place in 2015. The first wave is referred to as time 1 and the third wave as time 2 (Figure 3). Items from the second wave of data collection are not used as some of the variables used at time 1 were removed from the questionnaire used at time 2 and the aim was to have a short-term longitudinal perspective in the studies.

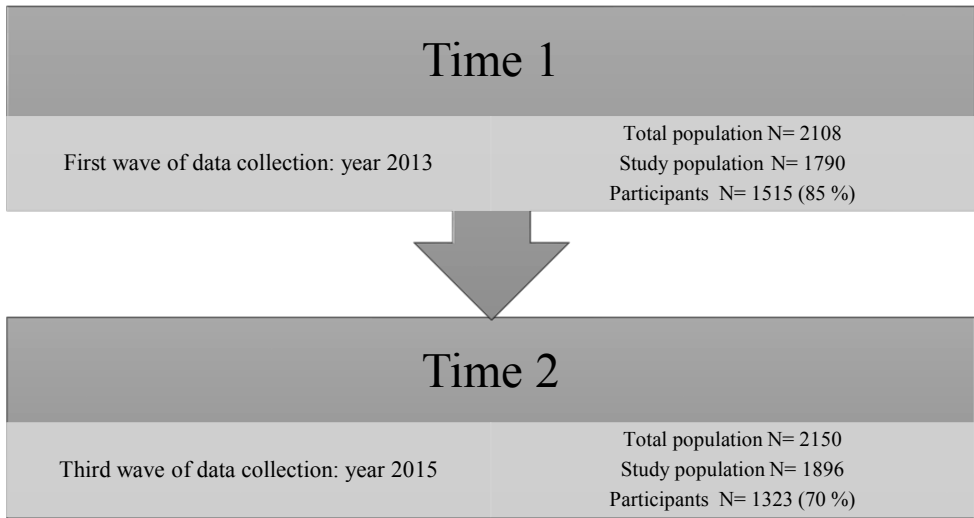


Figure 3. Flow-chart of time points and participants.

Note: Total population: All adolescents invited at the start of the LoRDIA research program in 2013. Study population: those who agreed to participate. Participants: those who chose to fill in the questionnaire. N=1515 is the total population of the four sub-studies in this thesis.

Research design

Both cross-sectional as well as longitudinal designs are used in this thesis, with a combination of variable-based and person-oriented approaches. In Table 1, an overview of the studies presented in this thesis is provided.

Table 1. Overview of the studies in the thesis

Study	Design	Sample	Data collection	Data analyses
I	Conceptual and cross-sectional	1515 adolescents	LoRDIA wave I (time 1) Data collected in 2013	Cohen's kappa, descriptive statistics
II	Cross-sectional, Person-based	1349 adolescents	LoRDIA wave I (time 1) Data collected in 2013	Descriptive statistics, Principal Component Analysis, K-means cluster analysis, One-way ANOVA
III	Prospective longitudinal, variable-based	916 adolescents	LoRDIA wave I+ III (time 1+2) Data collected in 2015	Multiple logistic regression + independent samples T-test
IV	Prospective person-based, longitudinal	916 adolescents	LoRDIA wave I+ III (time 1+2) Data collected in 2015	K-means longitudinal cluster analysis, Multinomial logistic regression

Note: all studies are based on the same cohort based on self-rated data obtained from the LoRDIA research program.

Setting

The four municipalities in which data was collected for studies I-IV have between 9,000-36,000 inhabitants and are relatively near to each other. They represent variations in rural/urban density. Two of the municipalities were chosen as a linked pair, as they had a relatively high degree of internal school migration, i.e. adolescents from the minor municipality usually attend senior high school in the somewhat larger municipality. Two of the municipalities are industrial and relatively small. One is somewhat larger and close to Sweden's second largest city, while the other is relatively small and more rural (Gerdner, Falkhe, Granlund, & Skårner, 2013).

Sample studies I-IV

At time 1, the questionnaire included a question that made it possible to identify students who perceived themselves to have an impairment. The question was phrased: 'Do you have an impairment?' This item was then followed by the following information: 'Impairment, in this case, means that you, for example, have a physical disability, dyslexia, visual and/or hearing impairments. It could also be that you have ADHD, epilepsy or diabetes.' This statement was followed by a list which gave examples of impairments. In the studies the participants were grouped into: those who self-reported as having no impairment, those who reported physical impairments and those who reported neurodevelopmental impairments. The selection of impairments belonging to the group of neurodevelopmental disorders was made with reference to the Diagnostic and Statistical Manual of Mental Disorders (DSM-5) (American Psychiatric Association, 2013).

In study I the sample was based on all participants who filled in the questionnaire at time 1. In study II the sample consisted of 1349 adolescents. In studies III and IV only adolescents participating at both time 1 and 2 *and* who answered the items in the outcome variables at both time points were included. The sample in studies III-IV were therefore n=916. Adolescents with self-reported NDI were n=154 and adolescents without self-reported NDI were n= 762. Girls with NDI were n= 75 and boys with NDI were n= 79.

Table 2 gives an overview of the sample populations who participated in studies I-IV.

Table 2. Demographic data of analytical samples used in studies I-IV

Study	I	II	III	IV
Total number	1515	1349	916	916
Female	766	708	504	504
Male	749	641	412	412
Age (<i>M</i> / <i>SD</i>)	<i>M</i> 13.01 <i>SD</i> 0.60	<i>M</i> 13.03 <i>SD</i> 0.59	<i>T</i> 1 13.09 <i>SD</i> 0.59 <i>T</i> 2 14.34 <i>SD</i> 0.64	<i>T</i> 1 13.09 <i>SD</i> 0.59 <i>T</i> 2 14.34 <i>SD</i> 0.64
Ethnicity (other than Swedish)	337	252	168	168

Note: in the published version of study II, the total number of participants who filled in the questionnaire is stated as 1520. The correct number is 1515.

Instruments

The questionnaire used in the first wave of data collection in 2013 (referred to in the thesis as time 1) contained questions concerning the identity of the individual, perceptions of self, body and puberty, leisure time activities, peer network and quality of peer relations, family relations and parenting models, sibling relations, school behaviours and relations to teachers, experiences of harassment, use of tobacco, alcohol and drugs. At time 2, which occurred during 2015, the questionnaire consisted of partly differing items compared to time 1. Some of the scales were created for the LoRDIA research program and some are based on instruments that have been validated internationally or have been used in previous Swedish studies concerning adolescents. For more information regarding the variables used in the studies please see the section on dependent and independent variables and Table 3.

A total of five pilot studies were performed during early summer and autumn 2013. Three of the pilots aimed to test the original questionnaire used in the

first wave of data collection. Two pilots were performed to test and adapt the questionnaire and the procedures that were used in the compulsory schools for adolescents with intellectual disabilities. The adapted version consisted of the same questions except one that was removed following the pilot studies due to its complexity, and was assumed (and confirmed in the pilot testing) to be too abstract for the adolescents enrolled at the compulsory school for adolescents with intellectual impairments:

'How do your parents behave towards you in general'

1. *V33b 'You mostly know how she/he will react if you have done something that she/he doesn't agree with'*
2. *V33m 'It's impossible to know how she/he will react; one day she/he behaves in one way and the other day in another way'.*

The language in the adapted version was formulated somewhat more concretely and the response options were reduced from five to three. The following question is an example of a question involving a time dimension, requiring the respondent to think back in time.

Example: V41b 'If you think about how you have felt in the last six months, have you had sleeping difficulties?'

This question was rephrased as:

'If you think about how you have felt since the summer holidays, have you had sleeping difficulties?'

Several tests concerning the psychometric properties of the questionnaires (the original version and the adapted version) were performed and the results showed that the psychometric properties of the questionnaires were satisfactory, with Cronbach alpha-values of around 0.7 and 0.8 (Gerdner et al., 2013). Of the total study population at wave 1, 1378 used the original form of the questionnaire and 142 adolescents used the adapted version. At time 2, all adolescents answered the same version of the questionnaire and a three to four-point scale was used. The questionnaire used at time 2 was designed with the same requirements as the adapted version and the same questionnaire was therefore used for all students.

Linking items to ICF-CY

To facilitate international comparisons with other studies focused on adolescents with impairments using partly differing questionnaires, a common language for describing functioning is required. Therefore, items in the questionnaire have been linked to the ICF-CY codes which are considered to be a common language for describing function. This linking process and the challenges encountered are described in study I (Augustine, Lyngegård, Granlund and Adolfsson, 2017). Internationally established linking rules were used as a guidance tool in the linking process (Cieza et al., 2002; A. Cieza et al., 2005). The following abbreviations were used, as instructed in the ICF-CY classification (World Health Organization, 2007), to refer to the different components of the classification: body functions (*b*), body structures (*s*) (although not applicable in this thesis since none of the items in the questionnaire referred to this component), activities (*d*), participation (*p*) and environmental factors (*e*). Personal factors are abbreviated as *pf*. Table 3 gives an overview of the ICF-CY components and the chapters referred to in study I. Note that not all chapters were represented by codes following the linking process.

Table 3. Overview of ICF-CY components and related chapters referred to in study I.

Components	Chapters
b Body functions	b1 Mental functions
d Activities and participation	d1 Learning and applying knowledge
	d2 General tasks and demands
	d3 Communication
	d4 Mobility
	d5 Self-care
	d6 Domestic life
	d7 Interpersonal interactions and relationships
	d8 Major life areas
	d9 Social life
e Environmental factors	e1 Products and technology
	e3 Support and relationships
	e4 Attitudes

Dependent and independent variables used in the four studies

The linking procedure in study I led to the creation of indices in study II. To study the relation between individual and environmental factors that might influence self-rated participation, codes representing body functions and environmental factors were separated from codes representing participation. The separation of activities and participation was made according to the first alternative in ICF-CY, annex 3. According to this first alternative, chapters 5-9 in the activity/participation component can be considered measuring participation while codes from chapter 1-4 represent activity.

Based on earlier studies concerning the relation between mental health and functioning in adolescents, two indices were chosen to measure participation in domestic life and interpersonal interactions and relationships (World Health Organization, 2007). In this thesis the indices are referred to as *domestic life* (ICF-CY chapter 6) and *peer relations* (ICF-CY chapter 7). For each of these chapters two indices were used. First an index representing frequency of attendance (items answering *how often* one spends time in different activities). Second, an index representing involvement (items answering the question of the *importance* one assigns to a certain activity).

These indices were used as the *dependent* variables representing participation in studies II-IV. The *independent* variables in studies II-IV (thought to influence participation) were indices related to individual factors such as body functions (experiences of self- and time functions), the execution of a task or action, referred to in the activity component of the ICF-CY. The environment component was represented by an index called atmosphere in the family/family communication and another index labelled support from siblings. Indices representing self-rated frequency of attending school and perceived importance of school were used as dependent variables in study III. In study IV, where the aim was to study participation outside school, self-rated participation in school was used as an independent variable that might affect participation outside school. The process of creating indices for body function, activity, participation and environmental factors is illustrated in Figure 4.

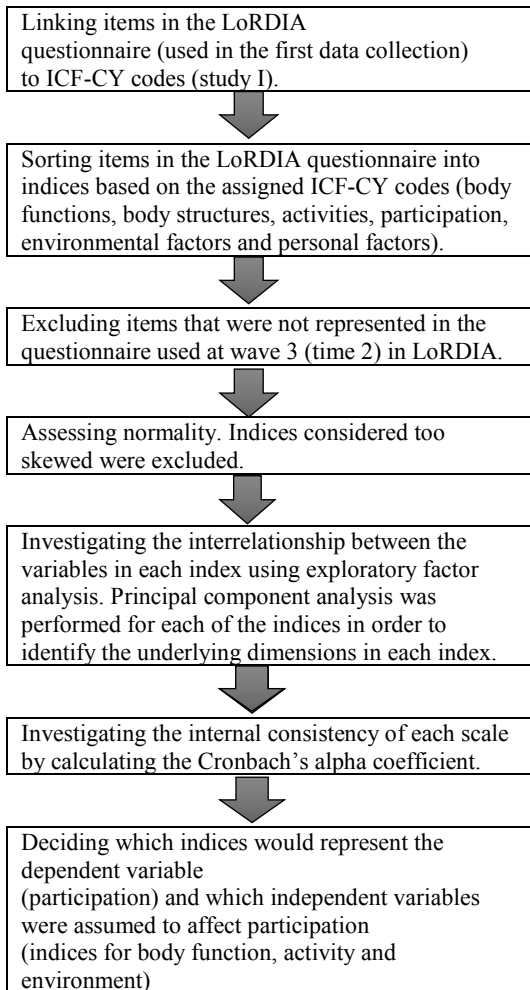


Figure 4. Illustration of the process by which new indices/scales for body functions, activity, participation and environment were created (used in studies II-IV).

Indices that were used in studies II-IV were selected based on several analyses. Principal component analysis was performed for each of the indices based on items linked to ICF in order to find the optimal number of variables for each index. After this step the normality was assessed and overly skewed indices were removed. Next the internal consistency of each index/scale was investigated by calculating the Cronbach's alpha coefficient. Finally, correlations between the indices were investigated. After this, a comparison between the questionnaire used at time 1 and time 2 was made

and items used in study II that had been removed at time 2 to make room for other items in the LoRDIA questionnaire had to be removed from analysis in studies III and IV. For example, the index regarding discussion was not included in the questionnaire at time 2 and therefore it was only possible to use this index in study II, which was based on data from time 1. In another study based on the LoRDIA-sample, investigating participation in school for adolescents with self-reported NDI, results revealed that these adolescents had an increased risk of experiencing participation restrictions, especially in school, compared to their peers without self-reported NDI (Carlberg & Granlund, 2018). Therefore, variables representing frequency of participation in school and perceived involvement in school were added as dependent variables in study III. In study IV, these variables were instead used as independent variables to investigate whether these school variables together with the other variables representing body, activity and environment, could predict typical and atypical participation trajectories for frequency and perceived involvement in domestic life and in peer relations. Table 4 gives a description of the variables used in the thesis and Table 5 provides an overview of how the dependent and independent variables were applied in the studies.

Table 4. Variables used in the thesis

Dependent variables Indicies representing:	Items included	Response scale
<i>Frequency of attendance in domestic life¹</i>	<i>How often do you:</i> -help out at home? -do grocery shopping? -prepare a meal? -wash your clothes? -clean your room?	Three-point Likert scale: 1=never 2= sometimes 3= often
<i>Perceived importance of domestic life²</i>	<i>How important is it to?</i> -help out at home? -do grocery shopping? -prepare a meal? -wash your clothes? -clean your room?	Three-point Likert scale: 1= no 2= not really 3= yes
<i>Frequency of attendance in peer relations³</i>	<i>How often do you:</i> -make new friends? -get along with friends? -spend time with a girl- or boyfriend?	Three-point Likert scale: 1= never 2= sometimes 3= often
<i>Perceived importance of peer relations²</i>	<i>How important is it to?</i> -make new friends? -get along with friends? -spend time with a girl- or boyfriend?	Three-point Likert scale: 1= no 2= not really 3= yes
<i>Frequency of attendance in school⁴</i>	Have you been truant a full day from school this term?	Three-point Likert scale: 1= no, not once, 2= sometimes, 3= many times
<i>Perceived importance of school</i>	Are you satisfied with your performance at school? Do you try to do your best at school? How do you like school?	Four-point scale: 1= often, 2= sometimes, 3= occasionally, 4= almost never (reversed) 1= often, 2= sometimes, 3= occasionally, 4= almost never (reversed) 1= very much, 2= it's ok, 3= not so much, 4= not at all (reversed)

Table 4. cont.		
Independent variables <i>Experience of time and self</i> ³	Compared to peers of the same age, I feel: My friends treat me as if I were: Compared to most people my age, I look:	Three-point Likert scale: 1= younger 2= about the same age 3= older
<i>Stress</i> ²	How often do you feel under [time] pressure?	Three-point Likert scale: 1= never 2= sometimes 3= often
<i>Discussion</i> ²	How often do you participate in a discussion (reasoning, small talk etc.)? How important do you consider it to be to participate in a discussion?	Three-point Likert scale: 1= never 2= sometimes 3= often
<i>Support from siblings</i> ²	My sibling supports me if I get into conflicts with others If I argue with my parents, my sibling supports me. If I get into trouble, I can expect help from my sibling. My sibling is like a close friend I can usually trust my sibling	Four-point Likert scale: 1= I don't agree at all 2= I partly agree 3= I mainly agree 4= I entirely agree
<i>Atmosphere in the family</i> ⁴ (In study IV referred to as family communication).	Items related to parental control ¹ and parental solicitation ² and child disclosure ³ : How often do your parents ask you to tell them about things going on in your leisure time? Do your parents always demand to know where you are in the evenings, who you meet with and what you do together?	Three-point Likert scale: 1= mostly 2= sometimes 3= seldom or never

¹ Scale created for LoRDIA except the first item 'how often do you help out at home', which originates from a scale used in the Swedish study 'Barn-ULF' 2009-2011. ² Scale created for LoRDIA. ³ Scale from 'Barn-ULF' 2009-2011. ⁴ Scale from (Kerr & Stattin, 2000). ⁵ Scale originally from 'Adolescents' subjective age: An indicator of perceived maturity'. (Galambos, Kolaric, Sears, & Maggs, 1999).

Table 5. Overview of which studies the variables were used in (with ICF-CY components and related chapters)

Dependent variables	Study II	Study III	Study IV	Alpha
<i>Participation</i>				
Frequency of attendance in domestic life (d6)	X	X	X	.54
Perceived importance of domestic life (d6)	X	X	X	.62
Frequency of attendance in peer relations (d7)	X	X	X	.35
Perceived importance of peer relations (d7)	X	X	X	.31/ Time 2: .33
Frequency of attendance in school (measuring self-rated truancy) (d8)		X		Only one item
Perceived importance of school (d8)		X		.62
<i>Independent variables</i>				
<i>Body functions</i>				
Experience of self- and time functions (b180)	X	X		.70
<i>Activity</i>				
Handling stress and psychological demands (d240)	X	X		.44
Discussion (d355)	X			.67
<i>Environment</i>				
Support from siblings (e3)	X	X		.86
Atmosphere in the family (e4) is referred to in study IV as family communication	X	X		.79
<i>Participation</i>				
Frequency of attendance in school (self-rated truancy) (d8)			X	Only one item
Perceived importance of school			X	.62

Data collection

To get access to the schools within the four municipalities, written consent was obtained from the head principals in each municipality. Prior to the data collection, all schools in the four municipalities (with adolescents enrolled in grade 6 or 7) were informed about the project. A letter of information was sent out to the caregivers and to the teachers with information about the Research Program LoRDIA, as well as a letter addressed to the adolescents themselves. In the information letter to the caregivers they were given the opportunity to decline their child's participation in the study. At the time of the data collection, the researchers explained the nature of the study as well as the voluntary nature of participation and that the answers would be handled confidentially. The questionnaire took 60-90 minutes to complete. For some of the adolescents with intellectual disabilities, or adolescents who spoke another language at home, additional time (approximately 30 minutes) was required. The participants filled in the questionnaires in their classrooms at their desks and could ask questions (e.g. regarding the meaning of words). They were also able to take at least one break and were offered refreshments while completing the form. A few exceptions for adolescents with intellectual disabilities were made; for example where a staff member of the research team made a home visit to make it possible for one student to fill in the questionnaire at home because of an agreement between the LoRDIA researchers and the student's caregiver.

A manual, which had been piloted, was used to ensure the data collection procedure. When in the classrooms the adolescents received written and oral information regarding the procedure from the research team staff. Those adolescents who required it received extra assistance primarily from the researchers. The students in the compulsory school for adolescents with intellectual disabilities were offered the opportunity to be interviewed when considered necessary. The adapted version of the questionnaire as well as the adapted procedures were used when necessary in the compulsory school as well; for example with adolescents who had reading difficulties for various reasons (e.g. dyslexia or having recently immigrated to Sweden). The data collection was performed in the same way at both times 1 and 2. At time 2, some of the items from the questionnaire used at time 1 were removed and hence, only items used at both times 1 and 2 were included in the analysis for studies III and IV.

Data analysis

Before carrying out statistical analyses with time 1 data the original version and the adapted version of the questionnaire were merged into one data file where all five-point Likert scales in the original version of the questionnaire were collapsed into a three- or four-point Likert scale where the median value was kept unchanged. The values below or above the median were replaced by one lower and one higher value respectively. An example is provided below.

Response options in the original questionnaire:

<i>Never</i>	<i>Seldom</i>	<i>Sometimes</i>	<i>Often</i>	<i>Always</i>
1	2	3	4	5

Response options in the adapted questionnaire:

<i>Seldom</i>	<i>Sometimes</i>	<i>Often</i>
<i>Never (1) +seldom (2)</i>	3	<i>Often (4) +always (5)</i>

Study I aimed to describe the methodological challenges that occurred when linking latent constructs to the ICF-CY. The linking procedure was performed by two independent coders (Frida Lyngegård (FL) and Lilly Augustine (LA), who had previous knowledge of the ICF-CY. Two experienced ICF-CY researchers (MA and MG) provided back-up in case of uncertainty. The linking procedure was done in seven steps. In the first step there was an initial discussion regarding the purpose of the linking procedure as well as the purpose of the instruments that were to be linked to ICF-CY codes. In the second step, meaningful concepts were identified. In the third step, the meaningful concept(s) and the underlying meaning were considered independently by the main coders. Step four included an independent decision on which concept represented the item. Step five included a decision on which was the most precise code to link to the item. In the sixth step, iterative discussions between the two main coders were held and in the seventh and final step, all linked items were inspected by one of the main coders (FL) to make sure that they as far as possible reflected the essence of the assigned code.

In this study the inter-rater reliability of the assignment of codes was tested by calculating Cohen's kappa. Descriptive statistics were used as well as Principal Component Analysis (PCA) to investigate the underlying dimensions within the indices created in the linking procedure in study I.

In study II, prior to the main analyses, the internal consistency of the dependent as well as the independent indices (the indices for body function, activity and environment) was investigated by calculating the Cronbach's alpha coefficient. Correlations between the dependent and independent variables were investigated. The main analysis consisted of a K-means Cluster analysis (Wards method) (Bergman, Magnusson, & El Khouri, 2003). The cluster analysis was performed to find patterns of participation related to participation in domestic life and peer interactions. One-way ANOVAs were performed, followed by a post-hoc test (Scheffés) to establish whether there were differences between the groups identified in the cluster analysis and between what groups these differences occurred. The cluster analysis was performed in SLEIPNER (Bergman et al., 2003) and the subsequent analyses in SPSS 21.0. The critical p-value was set to 0.05 for all the analyses.

In study III multiple regression analysis was performed in which interaction terms were included to investigate whether the associations between the dependent and independent variables differed over time. Logistic regressions as well as independent sample t-tests were used to investigate similarities and differences between groups.

In study IV a hierarchal longitudinal cluster analysis (Wards method) was used to investigate changes in participation patterns as well as trajectories of subjects between time 1 and 2 cluster groups. These analyses were performed using the statistical software ROPstat (Vargha, Torma, & Bergman, 2015) and generated groups of subjects with typical trajectories between cluster groups at time 1 and time 2. For the identified typical trajectory groups multinomial regression analysis was performed to investigate associations between the independent variables for body function, activity and environment and membership in typical trajectory groups. The additional analyses were made in SPSS version 25.

Ethical considerations

Extra consideration is necessary when children and youths without full autonomy are included in research (Hill, 2005). With regard to this, several ethical questions were considered as this thesis involves young people (Alderson & Morrow, 2011). The principle of justice (Swedish Research Council, 2007) was considered as the aim was to include all adolescents in a compulsory school and all pupils in a compulsory school for adolescents with learning disabilities. Within the LoRDIA research program, a so-called passive consent method was used. One reason for this was that the research program aims to investigate mental health and drug misuse. Therefore, it was of high importance to include adolescents coming from families where the parents themselves might not prioritise participation in this kind of research, perhaps because of a problematic home situation. Asking for active consent from caregivers with low socioeconomic status was therefore assumed to put the participation of adolescents who would be able to provide valuable information in line with the aim and scope of the research program at risk. All caregivers were informed via mail about the study, both in Swedish and their native language, and were specifically asked to inform the research group if they did not give consent for their child to participate. It was explained that not giving notice meant giving consent for their child to participate.

Written information regarding the research program and provided by the researchers was also given to the adolescents before the data collection. The written information was developed to be as concrete and easy to understand as possible, a procedure necessary when involving individuals with learning disabilities (Kalman, 2012). The adolescents themselves were given the opportunity to agree or decline to participate in the study at the time of data collection. On the first page of the questionnaire they were asked to fill in their names and consent to participate in the study. Those adolescents who had caregivers who had declined their child's participation were provided with other tasks by their teacher; as was agreed on before the time of the data collection.

By giving the adolescents the opportunity to agree or disagree to participate, the principle of autonomy was taken into consideration. This is however a complex issue as the adolescents may have felt obliged to participate in

order to support their teachers and the researchers. Therefore, the researchers began each data collection by stressing the voluntary nature of participation. The data was collected in the classrooms and all data was handled with strict confidentiality. Only the authorised researchers had or will have access to the collected data and this was also stressed in the oral information to the adolescents at the time of each wave of data collection.

The principle of no maleficence should be addressed (Swedish Research Council, 2007). It will not be possible to use any data taken from the participating individuals to track to any individual. The questionnaires contain questions of sensitive character and special consideration has been taken regarding how to handle the data to protect the adolescents' and the caregivers' integrity.

The procedure for data collection in the compulsory school for adolescents with intellectual disabilities was tested prior to the first wave of data collection. Two pilot studies were performed in a compulsory school for pupils with learning disabilities. The lesson learned was that practical preparations were important since some of the adolescents needed to read aloud to themselves, some needed to have the questions read aloud to them, and some needed to be interviewed due to their impairment (cognitive, visual etc.). Taking this into consideration, separate rooms to respect the adolescents' integrity were required. Another aspect to consider was the complexity of collecting data from the same sample in separate ways. For example, the adolescents who were interviewed might have felt a greater need to answer questions in a 'correct' way (Barron, 1999).

The principles of beneficence (Beauchamp & Childress, 2001) have been addressed since children themselves are often excluded from research. In addition, for protective motives, researchers tend to exclude children with learning difficulties (Alderson & Morrow, 2011). One of the major advantages of this project is that the adolescents at the compulsory school for adolescents with intellectual disabilities are included, which is rare for longitudinal studies in Sweden.

In conclusion, there are several important ethical reflections to make when performing this kind of research. The overall assessment, however, is that this thesis can provide valuable new knowledge that could benefit the population, and that the benefits outweigh the risks. Ethical reflections are

important during the entire research process, however. Ethical permission for the research program was granted by the Regional Research Ethics Board in Gothenburg 2013 (No. 362-13; 2013-09-25), with additional approvals for wave II 2014-05-20 (T446-14) and wave III 2015-07-31 (T553-15). The ethical application approval concerned both the aim of the main study and the aim to investigate participation in adolescents with self-reported impairments or long-term health conditions.

Results

In this section, the results and conclusions of the four sub-studies will be presented in relation to the three overarching research questions posed in the thesis.

To what extent is the International Classification of Functioning, Disability and Health, Children and Youth Version, applicable to document and follow the trajectories of participation over time for adolescents with and without self-reported impairments or long-term health conditions? (Studies I-IV)

The first study aims to describe challenges encountered during the linking process in which the 375 items within the LoRDIA questionnaire were linked to ICF-CY codes. The linking process was guided by the linking rules established by Cieza et al. (Cieza et al., 2002; A. Cieza et al., 2005). Linking items to ICF-CY classification demonstrated relatively good inter-rater reliability with an agreement percentage of 76.7 and a Cohen's kappa value of 73.4% (.734). The need to be very specific in the intended use of the data was established as being in line with the recently published refinements of linking rules by Cieza et al. (2016). In study I, many chapters were represented, yet not all of these were used in the following studies (II-IV). This is due to several factors, for example that the questionnaires used in time 1 and time 2 differed, and only items represented at both times could be used. Therefore, not all aspects of participation identified in study I were possible to follow over time. When using the LoRDIA questionnaire to link the items to ICF-CY codes it was evident that not all domains in the components within the ICF-CY were covered; domains such as interpersonal relationships (d7) were well represented, whereas other domains within body structures and body functions (b, s) and the activity/participation component were less covered e.g. domain learning and applying knowledge (d1). This is most likely related to the original aim of the scales in the LORDIA questionnaire focusing on mental health and risk factors for substance use in relation to mental health, school adaption and social networking.

Several challenges arose during the linking process. The main challenges were related to assigning codes to items intended to measure latent constructs (i.e. items with an underlying meaning represented by several items), for example items regarding time spent following the news (reported

on television or radio). If the linking procedure had been done manifestly (i.e. coding only what is described and not the underlying meaning) this item could have concerned functions such as listening and acquiring knowledge. As the coding was focusing on the underlying latent meaning of the items, the decision was to assign this item a code concerning political life and citizenship (d950). In sum, the code chosen included both aspects to do with the aim behind a specific question and the underlying meaning of the question. Another challenge encountered was when there were several meanings within one item, for example: ‘When you come home from school, do you talk about your school day (what you did, your relations to teachers and so forth)?’. Here, the decision was to assign this item a code concerning conversation (d350).

Another challenge concerned whether an item could be considered to measure frequency of attendance or involvement in activity. The solution was: If the item included a question such as ‘how often’ then it measured frequency of attending an activity. If the question included the question ‘how important’ the item measured involvement with reference to earlier studies by for example (Granlund, 2013; Granlund et al., 2012). The conclusion from the first study was that latent coding is preferable when linking items with a latent content, such as mental health. In 2016, Cieza et al. published refinements of their previous linking rules (Cieza, Fayed, Bickenbach, & Prodinger, 2016) and results from study I confirm the relevance of these refinements, for example, the necessity of deciding from what perspective the linking will take place (manifest or latent) before initiating a linking procedure.

Studies II and IV indicate that it is possible to construct participation clusters based on ICF-CY codes that describe patterns of functioning rather than by using an approach focusing on single variables as summary scores for this purpose. This is in line with suggestions from Simeonsson et al. arguing that ICF-CY allows for describing functioning as a multidimensional construct describing aspects of functioning rather than providing a diagnosis where a single diagnosis/label is used to describe a person (Simeonsson et al., 2003). Therefore, the use of ICF-CY supports a non-categorical approach to disability research. Using the ICF-CY to create participation patterns belonging to the group of adolescents with self-reported NDI did not predict cluster membership.

What individual and contextual characteristics are related to self-rated participation at one time point and over time? (studies II + III + IV)

Study II concerned how individual body factors, factors related to activity, and factors in the environment, affect self-rated participation in domestic life and in peer relations. A nine-cluster solution revealed that the clusters were all different from each other in terms of patterns of participation in home activities and peer relations. Adolescents with impairments and long-term health conditions were represented in all clusters. Adolescents perceived peer relations as more important than participation in domestic life. The experience of time and self (the body function index) did not significantly affect the self-rated experience of participation in domestic life and peer relations.

Taking part in discussions was related to participation for adolescents in several clusters, as were environmental factors, i.e. family atmosphere/family communication and perceived support from siblings. Hence, the results indicate that less parental control and more solicitation were associated with being more active in discussions at home and with more support from siblings. Both the frequency of attendance and level of perceived importance of peer relations were related to high ratings of discussion, sibling support, and the communication pattern in the family. Social interactions with friends and family could therefore be considered important for the experience of participation. Additionally, the fact that several factors were related to perceived participation can be interpreted as an indicator of the importance of the aggregated effect of several factors in the home environment on participation.

In study III results demonstrated that the patterns of predictors for participation differed from time 1 to time 2 for adolescents with and without self-reported NDI. For adolescents with self-reported NDI, more associations were found between participation in domestic life and peer relations at time 2 (age 15/16) and body, activity and environmental factors. At time 2, stronger associations were found between frequency of attendance in domestic life and stress, support from siblings, atmosphere in the family/family communication, and gender. At time 1 (age 12/13), no associations were found between the independent variables and the frequency of attendance and perceived importance of school. At time 2, however, the experience of time and self, stress, support from siblings and

family communication were all associated with the perceived importance of school. Stress was associated with participation both for adolescents with and without NDI and this association appeared to increase over time.

Results from study IV illustrated that the more mature one perceives oneself in relation to others (experience of time and self), the less time was spent on domestic life activities (frequency of attendance in domestic life). Typical trajectories where the perceived importance of peer relations was rated high were associated with high ratings of perceived importance of school as well as with high levels of sibling support and positively perceived family communication. An increase in the rating of perceived importance of domestic life was associated with sibling support for one of the typical trajectories. Adolescents with NDI were not overrepresented in any of the typical trajectories. In sum, environmental factors were important in predicting typical trajectories and the importance of sibling support should be emphasised. Self-reported NDI did not predict any of the typical trajectories, which parallels findings from study II.

How does self-rated participation change over time for adolescents with and without self-reported impairments or long-term health-conditions? (Studies III + IV)

The indices measuring participation were stable over time with few indicators of increasing or decreasing values. Study III investigated predictors of change over time for participation in terms of frequency and perceived importance of participation in domestic life, peer relations and school for adolescents with and without self-reported NDI. Partly different factors seemed to affect participation when adolescents were 12 and 13 years of age in comparison to two years later. At time 2, the factors related to participation profiles of adolescents with NDI seemed to occur in patterns that were more similar to those of adolescents without NDI. Study IV indicated that level of participation was relatively stable over time in both home and peer relations when measured at the two time points.

Discussion

The thesis involves young people entering early adolescence, a period in life that is characterised by rapid changes in the individual but also in the surrounding contexts and environments (World Health Organization, 2017b). Within life-course theories, there is a strong emphasis on the importance of continuous alterations between different contexts as individuals move into adulthood. In life-course models of adults, the inability to separate the individual from its context is stressed and this provides a motivation to consider the developmental context of younger individuals as well. However, a child is not a stable unity and any model depicting an individual should also include psychological and underlying biological changes (Sameroff, 2010). Based on the results of this thesis, the following section the main findings of the four sub-studies will be discussed in relation to two hypotheses related to changes in maturity and life roles.

Changes in maturity and life roles

The underlying challenge of adolescence is to handle changes in maturity and changes in life roles (World Health Organization, 2001). Two hypotheses are therefore presented in the following section.

- 1) As individuals grow older natural shifts in environments and contexts occur in which peer relations may be perceived as more important and spending time with parents at home as less important. Variations in the way participation is perceived in relation to these natural shifts, can be considered as a result of the surrounding environment or as maturity changes within the individual.*

When using Bronfenbrenner's bioecological theory, all four elements of the PPCT model must be in focus (Tudge et al., 2016). The power of the proximal processes to influence development 'varies substantially as a function if the characteristics of the person, the immediate and remote contexts and the time periods in which the processes occur' (Nobre, Coutinho, & Valentini, 2014). The proximal processes studied in this thesis are interactions at home, with peers and at school. Since there are only two measurement occasions from which data was collected, it is rather snapshots

of proximal processes that have been studied. These snapshots are indicators of proximal processes but the results of the current thesis do not explicitly reveal whether the proximal processes become more complex with time.

Results from this thesis indicate that type of impairment or long-term health condition do not solely determine the frequency of participation in domestic life or peer relations, or involvement in school to any significant extent. Frequency of participation in dialogues and family communication seemed to affect participation profiles more than factors related to body functions (experience of time and self) and the existence of an impairment (Studies II and IV). In addition, study IV demonstrated that the impairment itself did not predict patterns of participation at a specific time point nor typical trajectories when comparing participation between two measurement occasions. Factors based on perceived communication in the family were more prominent in predicting trajectories in participation in domestic life and peer relations.

- 2) *Changes in life roles and maturity generally mean a shift, where individuals spend time in and have prolonged exposure to several contexts outside the family. In addition, expectations about what tasks adolescents should perform at home change where higher demands are put on the individual's activity competence to manage life tasks independently of their parents.*

Study III indicates that the factors influencing participation change with chronological age, a result that from an ecological perspective probably also indicates changes in life roles. When removing the influence of specific impairments on functioning from the analysis, other factors become visible as important influences on participation. That fact that fewer factors seem to influence participation for adolescents with NDI at time 1 may indicate that a NDI is a factor that partly 'drives functioning' in early childhood, especially in school, but with increasing age or changes in life roles it becomes less influential on participation (Carlberg & Granlund, 2018). However, changes in life roles may be delayed in adolescents with impairments. This delay may have consequences for the 'rhythm' of change, which could differ between adolescents with impairments and adolescents with typical functioning. At the second measurement occasion in study III, there was an increased number of factors affecting participation in school

and a larger similarity in patterns of factors related to participation with the group without self-reported NDI. These results may indicate that with experience and increased skills such as increased ability to communicate (probably obtained in the family) adolescents can manage their school situation and activities involving peers in a more functional manner, dependent on the level of support provided by their family.

One could argue that the changes between time points in associations between participation and the atmosphere in the family for adolescents without self-reported NDI observed in study III is an indication of maturity or changes in life roles. Both family relations and support from siblings are perceived as being less important when one gets older, whereas peers and the influence of peers is more prominent.

In study IV, however, this was not as obvious for adolescents with NDI. Family communication was associated with participation only at the second measurement occasion and support from siblings was less associated with participation. Perhaps, the process of changing contexts of participation from family activities to peer activities is slower for children with NDI; thus they are dependent on family support for a longer time.

Results from study IV indicate that the more mature one feels, the higher the probability of belonging to the trajectory group labelled lower frequency of participation in domestic life, which is somewhat surprising given the assumption that the more mature one perceives oneself, the more frequently one take part in domestic life activities. The result may rather indicate that adolescents who perceive themselves as more mature spend more time with peers and less time at home, a result that supports an interaction between biological maturity and life role changes. Biological maturity may affect the onset of life role changes and thus the timing of more pronounced changes in functioning.

Measuring change over time

Within the PPCT-model, time is one of the four central elements that simultaneously influence development (Bronfenbrenner & Evans, 2000).

The results from studies III and IV indicated stable trajectories of functioning both in domestic activities and peer interactions when measuring participation based on ICF-CY indices. This stability is somewhat surprising considering the changes in life roles towards more emphasis on peer relations and less emphasis on family activities indicated by the results. This may indicate problems related to measuring/scaling level of functioning using qualifiers. In this thesis the scales used had either four (as in the suggested qualifiers for ICF-CY) or three response alternatives based on the questionnaire layout, rather than being based on the qualifiers suggested in the ICF-CY manual. However, the ICF-CY manual contained no information on how changes in functioning should be conceptualised and measured. Further research needs to focus both on investigating the use of ICF-CY qualifiers and how change can be conceptualised in the ICF-CY system.

The indices measuring participation were stable over time across a two year period (a meso-time perspective). One reason for this might be that participation as a phenomenon is relatively stable over time, but it could also be due to the type of response scale used. At time 1 the three-point Likert scale was used. This scale was chosen in line with recommendations for individuals with a mild intellectual disability (Hartley & MacLean, 2006; Nilsson, Buchholz, & Thunberg, 2012). By using this kind of scale, nuances might be missed that would have been identified if several response options had been included.

Another reason could be that the time between the measurement occasions (approximately two years) was relatively brief when considering a meso-time perspective; although two years is also a long time period when measuring participation from a micro-time perspective. The questions were partly phrased according to a micro-time perspective. A consequence might be that adolescents perceive and self-rate participation in their specific niches related to the present situation or context. This is in line with Bronfenbrenner and Morris's (1998) suggestion of dividing time into sub-elements, where micro-time concerns what occurs during a specific activity

or interaction. Since adolescents' self-reports in the current thesis are based on their opinions regarding activities post hoc but from a micro-time perspective, perhaps this is one reason why no significant change occurred despite assumed life role changes. It could therefore be argued that perceived participation is always related to the present context or situation from a micro-time perspective. A person can perceive participation to be stable, even if the actual contexts have changed because of changes in life roles, e.g. from a meso-time perspective. Bronfenbrenner and Morris further argue that macro-time constitutes historical events and changes that occur during particular time periods. According to the PPTC-model, when testing the level of influence on the proximal processes in focus, a developmental study should be longitudinal (Tudge et al., 2016). It is probably best to decide whether to use a micro- or meso-time perspective before starting to analyse data.

A longitudinal study aiming to investigate questions related to change over time should include a minimum of three measurement occasions for each outcome variable. This is required to facilitate studies on the form or trajectory of change (Ployhart & Vandenberg, 2010). Because this study only measures variables at two occasions, due to a lack of transactional data, the results from this thesis cannot explicitly determine changes in the level of complexity of proximal processes. (Imms & Adair, 2017) argue that

‘given the relative stability of participation trajectories identified in children with typical development, studies that follow participants longitudinally over several years are required to enhance our understanding of participation outcomes’ (p. 175).

Studies III and IV, however, indicate that participation is relatively stable over time when measuring at two time points. When measuring engagement, the level of engagement could be argued not to change from a meso-time perspective if considered separate from factors such as the complexity of the activities attended. Engagement itself is more related to life roles within a micro-time perspective, which in turn are affected by attitudes in the present environment, for example.

If a normative life role change does not mirror typical development this may cause problems if external expectations are based on what can be required of a typically developing person. This is illustrated by the changes in patterns of relations between participation and other factors seen for children with NDI in study III, with increasing associations at time 2. This reasoning emphasises the importance of a supportive family atmosphere for adolescents with self-reported NDI, as demonstrated in studies III-IV, including later in adolescence when the influence of the family decreases for adolescents with typical functioning.

Frequency of attendance and level of involvement; key dimensions in the participation construct

When linking items with a latent construct, the ‘being there’ dimension needs to be separated from the subjective perceived involvement dimension (study I). This reflects current research on the participation concept done by Imms et al. (2016). They argue in their proposed family of Participation Related Constructs-model (fPRC) that the frequency of attending an activity and the perceived involvement (which might include elements such as motivation, persistence and level of affect) are embedded constructs and that attendance is a necessary but insufficient requirement for involvement.

The fPRC framework can be applied when describing relations between factors within the individual that are influenced by past experiences of participation as well as influencing future participation. Participation is further described as being applied both as an outcome and as a process (Imms et al., 2017). In this thesis, participation is applied as an outcome and the focus is both on the frequency of attending dimension as well as the level of perceived involvement dimension. Within the fPRC framework, preferences are defined as interests or activities that hold meaning or value. One result regarding peer interaction in this thesis is that perceived involvement was mostly rated higher than frequency of attending. Establishing friendships during adolescence is associated with positive development and higher levels of psychological wellbeing (Masten et al., 1995). According to Imms et al. (2017) preferences are established for example via interactions in social groups that share common beliefs. The items related to participation in domestic life are expressed as ‘how often do

you' for example prepare food, clean your room etc. Perhaps this wording implies that this is something that is supposed to be done alone and therefore is not rated as highly as peer relations. Or, more likely, given the age of the adolescents, and life-role changes, hanging out with friends is more appealing than doing chores at home.

According to the present ICF-CY classification, as mentioned previously, it is not possible to measure the subjective experience of participation. Perhaps this is because measuring this aspect of participation was not the original intention behind the development of the ICF (Granlund et al., 2012). The ICF has currently been more applied at the micro level and individuals rather than to groups, and children in need of special support are often identified by assessing body functions. Therefore, supplementary models that also measure engagement in activities, such as the FPRC, are desirable. If operationalised as perceived involvement, measures of engagement such as those applied in this thesis might be applicable, but the question of to what extent one can really measure the subjective experience of participation remains. Within this thesis, there is a notion that participation is positive. One should however acknowledge that there might be situations in which it could be considered undesirable to participate e.g. risk situations. This is, however, not taken into account in any of the thesis's four sub-studies.

A biopsychosocial approach to impairment and disability

The biopsychosocial approach used in the thesis, in accordance with Bickenbach et al. (1999), is a synthesis of the medical and the social model of disability, combining the biological aspects as well as psychological and social aspects of impairment. This thesis has a specific focus on adolescents who have self-reported an impairment. Within this thesis, the term impairment is used as a description of a deviation or loss in either a body function or body structure. This is in agreement with the ICF-CY. However, the adolescents themselves self-report the impairment. Therefore it might be under the threshold for what is required for a diagnosis. Still the impairment, in interaction with the environment, can have an impact on functioning in everyday life. By including all adolescents that self-report impairment such sub-threshold problems could be detected.

Where the medical model searches for normality and deviations from normality the biopsychosocial model strives to focus on functioning and the surrounding environment is considered to be as important for functioning as biological aspects (World Health Organization, 2001). Results from this thesis imply that it is not appropriate to focus solely on a diagnosis or impairment when measuring factors influencing participation. It is however important to recognise that the context, referred to as the nodal point between the person and the activity, can vary substantially even when two individuals engage in the same activity. The context is influenced by both individual subject characteristics and environmental characteristics. Thus, the large individual variations in the perceived experience of participation found in this thesis are most likely due to its close connection to individually specific contexts. These results are consistent with the findings presented by Castro and Pinto, who argue that a functional approach to disability should be supported, emphasising the importance of level of engagement and environmental factors when determining functioning in children with disabilities (Castro & Pinto, 2015).

Previous research has focused on the environment within the components/boxes of the ICF-CY model, where environment has been viewed as either a facilitator or barrier. Context, as the nodal point between

the person and the environment, cannot be classified. In their paper, Imms and Granlund et al. (2016) focus on the interrelations between the body, activity and environmental components of the ICF-CY when discussing factors related to participation. They thereby challenge the view that increased participation is mainly to be considered as an effect of rehabilitation focused on the body function or body structure level. Instead they emphasise participation as the entry point for changes within the activity and body function or structure component.

The results of this thesis can be interpreted in the light of an interdisciplinary approach. If we are to focus on everyday functioning in children and youth, avoiding focusing solely on type of impairment or long-term health condition, interventions aiming to enhance participation should be preceded by an interdisciplinary assessment which takes both personal characteristics and the influence of environments into consideration. In this kind of assessment an interdisciplinary approach could inform decisions, drawing on expertise from different professions. While making such decisions, the impairment should be considered in relation to which everyday functions are desired by the individual person.

Methodological considerations

Theoretical limitations

This thesis has its theoretical base in the developed version of Bronfenbrenner's bioecological model, with a particular focus on the proximal processes and the interrelations between the concepts of process, person, context and time (the PPCT-model). To understand these concepts, an operational design where all four concepts should be included. Tudge et al. (2016) state that using the bioecological theory as a foundation should mean testing the theory using the data gathered. With this in mind, the concept of time should be given some attention. Only two points of time with approximately 2 years in between them are used and therefore, one could argue that only a short-term longitudinal design is applied, focusing on meso-time. To assess the process concept within the PPCT-model, both resource and force person characteristics as well as several related microsystems (both shared and non-shared environments), and measures of interactions should be taken into consideration. Proximal processes are often studied with questions phrased on a micro-time level (current functioning) although the time frame for data collection points might be meso-level (in this dissertation two years). Using this combination of item content and time points for collecting data participation is stable. Changes in participation with items phrased within a micro-time perspective might 'average out' when the time points for self-ratings are distributed from a meso-time perspective. A longer timespan (micro-time) with many more measurement points might have revealed additional variable trajectories. A study by Maxwell et al. (2012) in which level of engagement was self-rated five times a day at school for one week revealed large variations in level of engagement. In contrast, the results of this thesis indicate that changes occur on a meso-time level related to changes in maturity and in life roles that are not visible in the stable trajectories based on micro-time items. Perhaps studying proximal processes on a meso-time level requires other kinds of outcome variables that are more related to changes in life roles. Probably, studying proximal processes on the level of macro-time might even require the comparison of participation self-ratings of different generations.

Validity and reliability of the studies

All data used in the four sub-studies within this thesis was collected via paper-based self-rated questionnaires administered within schools. The use of self-ratings needs to be discussed in relation to validity and reliability, both in terms of how the target group has been defined and the usefulness of self-ratings. Concerning the target group, data used in the thesis is based on adolescents' own perceptions of having an impairment or not. It should be emphasised that it was not possible to determine whether adolescents had been diagnosed with a neurodevelopmental disorder or not. This should be taken into consideration when interpreting results and conclusions in relation to children diagnosed with e.g. ASD or ADHD. Earlier research has emphasised that children's knowledge of health and illness becomes more accurate and sophisticated with increased age (Myant & Williams, 2005). Asking youth to self-report problems within the neurodevelopmental spectrum can also be considered a strength of the thesis. The use of self-ratings makes it possible to investigate the everyday situation of adolescents who perceive that they have problems within this area, independent of having a diagnosis or not. Individuals reporting subthreshold problems (under the threshold of diagnostic criteria) may experience problems that affect every day functioning (Shankman et al., 2009). Therefore, self-ratings are preferable when it comes to identifying perceived disability. It is rare that studies ask adolescents themselves about their opinions on a wide range of areas across everyday life, and when exploring participation restrictions, a combination of the attendance measure and the perceived involvement measure is essential (Arvidsson, 2013). In the present thesis the involvement aspect of participation is operationalised as the perceived importance, a subjective measure that reflects the motivation to perform an action (Maxwell, Augustine, et al., 2012; Nordenfelt, 2003; J. Simeonsson, Carlson, Huntington, Sturtz McMillen, & Lytle Brent, 2001). It is difficult for other individuals (proxies) to rate the perceived importance of different activities. Proxy-ratings can be useful as supplements but the individual's own perspective should still be in focus. A relatively high correspondence with proxy-ratings of attendance (being there) has been reported by Arvidsson (2013) but correspondence of ratings of importance was lower. Thus, self-ratings are preferred in order to capture the subjective dimension of participation.

This study is part of the research program LoRDIA's sub-studies aiming to include the total population of adolescents aged 12-13 within four Swedish municipalities. This meant that all adolescents of these ages were invited to participate, including those following the syllabus for children with intellectual disabilities. Several methodological adaptations were therefore necessary for all participants to be able to answer the questionnaire. Consequently, this had some implications regarding validity that should be addressed. The adapted version of the questionnaire was not only beneficial and used for the adolescents following the syllabus for children with intellectual disabilities, it was also recommended by the teachers for several adolescents with reading and writing difficulties as well as for adolescents who had recently immigrated to Sweden. This adapted version was used as a template for further changes to the whole questionnaire package.

The questions within the LoRDIA questionnaire were not originally designed to measure participation. This could be considered a threat to the *construct validity* that occurs when inadequate or weak definitions and measures of variables are used (Creswell, 2014). A clear definition on the construct of participation is an ultimate criterion for drawing valid conclusions. Several studies have addressed the methodological challenges in measuring the complex concept of participation (Coster et al., 2011; Granlund et al., 2012). According to King (2013), participation is not a global construct or single variable, and it can therefore be conceptualised in a variety of ways (King, 2013). Several of the scales used in the questionnaires were based on validated instruments (Gerdner et al., 2013), which could be considered as a preventive measure, taken to avoid drawing invalid assumptions (Kazdin, 2010). However, extra attention should be given to this issue since new scales were derived from the ICF-CY linking procedure described in study I. Therefore, the definition of the construct must refer to other studies examining the construct of ICF-CY and participation (for example, King, 2013; Granlund, 2012; and Coster, 2008). Principal Component analysis, PCA was performed for both the original scales as well as the new scales to investigate the pattern of correlations between the variables and to obtain an empirical summary of the indices and what items to keep in the new scale.

Internal validity refers to what extent the relation found is causal from the operational variable (Kazdin, 2010). This means that one can draw the conclusion that the dependent variable was caused by the independent variable and not any other variable. There are different potential threats to internal validity (Creswell, 2014; Kazdin, 2010). The greatest threat to internal validity is non-random sampling since there might be differences between groups that are not controlled for. Non-random sampling was not applied in this study since the aim was to include all adolescents in the four communities and hence, there was no risk of selection bias. Maturation is another possible threat to the internal validity and concerns changes over time (such as growing older). One way to decrease maturational threats is to ensure that the data collection is performed in the same way at each data collection procedure. As mentioned in the data collection section, a written manual was developed to ensure as far as possible that data was collected in the same way each time. In addition, a measure of how mature one perceives oneself in relation to others (referred to in the thesis as the experience of time and self, with the ICF-Cy code b180), has been included in studies II, III and IV. Therefore, one could argue that this aspect has been addressed.

External validity refers to the extent to which the conclusions from the study can be generalised to other populations and circumstances (Kazdin, 2002). In this thesis the question is to what degree the results can be generalised in a Swedish context. Concerning sample characteristics (raising the question of whether results from one group could be transferred to another), the response rate at time 1 was 85% and at time 2, 70% of all adolescents in the investigated age range within the four communities. Given these numbers, some generalisations can be drawn (e.g. the sample consists of both small and larger schools in the countryside as well as in cities and towns of various size) when it comes to the adolescents at the compulsory schools. On the other hand, there was a significantly lower number of adolescents attending the compulsory school for children with learning disabilities, which might make it more difficult to generalise the findings if this group is considered in isolation. However, in the sub-studies of the present thesis, adolescents with intellectual disabilities were included in the group with self-reported NDI, comprising a relatively large proportion of the population. Thus, some generalisations can be made about the group of students with self-reported NDI. Hence the conclusion was that the study population was representative of those who were invited to participate.

Regarding attrition, there were significantly more boys than girls who did not participate in study II, III and IV which should be taken into consideration when interpreting the results since this might affect generalizability. Regarding internal attrition for the dependent and independent variables, there was no substantial differences and it can be argued that the representativeness is relatively good.

In the sections below, some specific considerations in relation to studies I-IV are discussed.

Study I

The first study aimed to describe the challenges that occurred in the process of linking all items within the student questionnaire that was used at the first wave of data collection in the LoRDIA research program. The linking procedure was guided by previously established international linking rules (A. Cieza et al., 2016; A. Cieza et al., 2005) and experts within the field of ICF-CY research were consulted when disagreements on the linking procedure occurred. The inter-rater reliability was calculated as 76.7, which can be interpreted as moderate (Cooper et al., 2012). The coding procedure of the questionnaire resulted in new scales/indices that were assumed to measure participation (World Health Organization, 2007). The indices regarding body functions, activity and the environment were also created through the process of assigning ICF-CY codes to the items. Previous research has debated whether to separate the activity and participation components or not (Granlund, 2013; Granlund et al., 2012; Maxwell, Alves, et al., 2012). Today the concepts of activity and participation are treated as two different concepts in the ICF-CY model but not in the classification system, as mentioned earlier in this thesis. This has resulted in indices that in some cases were represented by few items or low internal consistency (the peer relation index). This could be a result of the content of the Activity and Participation chapters of the ICF-CY classification. These chapters were developed to describe important aspects of everyday life situations for children and youths and therefore the areas included in each chapter are not homogenous, as neither are life situations. A clinimetric approach has been considered in which one could argue that these indices can be kept since the aim of this approach is to measure clinical phenomenon that includes several but not always related important characteristics of the phenomenon that is in

focus. Due to using a clinimetric approach, compromises regarding psychometric criteria are sometimes necessary. For example, fewer items that are considered important for the phenomenon in focus can be prioritised over a large number of possibly related items (Arvidsson, 2013; Ullenhag, 2012). Additionally, Granlund et al. (2016) argues for a functional approach since participation can be considered both the entry point and the outcome of an intervention. This means for example, that it may in some cases be more relevant to focus on matters for adolescents within a life course, for example asking whether a child can engage with friends rather than to ask to what extent a child can construct a short sentence to initiate a conversation which would be harder to generalize and taken out of context. The indices with low Cronbach's alpha values were also kept since they were found theoretically interesting to examine further since earlier studies have demonstrated that the ICF-CY has been useful in reducing large data materials (Lee, 2011; Norderyd, Lillvist, Klingberg, Faulks, & Granlund, 2015).

Study II

The second study had a cross-sectional design. The purpose of a cross-sectional study is to investigate key and associated characteristics of the population that will be studied, and this type of design is useful when identifying correlations and associated features. In addition, a cross-sectional study is often used when one wants to make comparisons between groups at a certain time (Kazdin, 2010). The second study will not be able to provide explanations of causes. However, it can provide key factors to study further since existing knowledge (within Swedish research) on the self-rated experience of participation is limited.

Studies III and IV

Study III is a prospective short-term longitudinal cohort study comparing adolescents with and without NDI. Study I also has a prospective short-term longitudinal person-based design. In study III, the total number of adolescents who self-reported a NDI was low (145) in relation to the total sample (n=1135). This might be one of the explanations as to why fewer associations were found for adolescents with NDI in relation to the participation outcomes at home, with peers and at school. This should be taken into consideration when interpreting results from the third study but

also results from the thesis since the same population is studied in study IV. In study III the main outcome participation variables did not change significantly over time. One explanation for this might be the relatively brief time that elapsed between time 1 and time 2 (approximately 2 years). Adding more measurement occasions would have enhanced the statistical power and added to the reliability of the study (Ployhart & Wandenberg, 2010).

Combining variable-based and person-oriented methods

In the ICF-CY (2007), the use of a profile approach to functioning over different areas of functioning on body, activity and participation level is recommended (World Health Organization, 2007). However, changes over time in functioning are difficult to capture using the ICF-CY system. One possible solution is to use a person-centred longitudinal approach to try to understand adolescents' experiences of participation in a holistic, interrelated, and dynamic manner. Person-centred approaches allow analyses of variability in functioning profiles among individuals (e.g. examining 'what' for 'whom'), whereas variable-centred approaches consider one variable at a time (Bergman, Magnusson, & El Khouri, 2003). In this thesis, adolescents with and without impairments were included. The main outcome, self-reported participation in specific types of activities, was examined as participation profiles where patterns of adolescent participation in several types of activities were examined simultaneously. The person-oriented method was applied in studies II and IV. Results from these studies revealed that when using an analysis that has a person in focus rather than specific variables, there are several factors that affect the self-rated experience of participation, of which impairment is only one. Hence, this kind of analysis probably mirrors the complexity of everyday functioning more than variable-based methods. The latter was used in study III where the type of impairment was deliberately not considered as an independent variable. However, this study demonstrated differences for adolescents with and without self-reported NDI in patterns of predictors for participation in domestic life activities, with peers and at school. In sum, a combination of these two methods will broaden our understanding of how participation patterns are experienced by adolescents with and without impairments and long-term health conditions.

Conclusions

- Addressing several different aspects of reality simultaneously is crucial to enhancing participation for adolescents. For example, the influence of family and peers should be studied simultaneously with health conditions or impairments as factors influencing participation.
- Both the frequency of attendance and the involvement dimension of participation should be addressed in interventions aiming to enhance participation since they are dependent on partly differing influencing factors.
- Patterns of participation differ for adolescents with and without self-reported NDI when investigated between groups and in relation to changes over time. Fewer factors are associated with participation outcomes at the first time point where adolescents with NDI were 12 and 13 years of age. At time 2, this difference decreases.
- The effect of NDIs seems to be less evident as adolescents grow older and other factors related to body, activity and environment seem to be of increased importance with regard to self-rated participation.
- Everyday functioning in adolescents with NDI is affected by partly the same factors as for adolescents without NDI, but the effect of NDIs seems to be more evident in school.
- The impact of the atmosphere in the family, i.e. communication within the family, on acquiring social skills to facilitate participation in different contexts is important.
- When investigating participation trajectories, self-reported NDI was not associated with any of the typical trajectories. It is probable that environmental factors such as support from siblings and communication within the family have a strong impact on typical trajectories between participation profiles at different time points.

Theoretical implications

The following implications are made in relation to the overall theoretical framework, the PPCT model.

- Regarding *processes*, on a meso-time level, participation is a stable phenomenon with few changes over time, probably because ratings of participation are based on perceptions of participation in relation to the present context (micro-time). The results instead indicate that individuals tend to rate their micro-time perceptions of participation similarly over time. Changes occurring on a meso-time level relate to changes in maturity and in life roles and are indicated by changes in relational patterns between participation and other factors with an increase in the strength of correlations between peer interaction and participation. Studying proximal processes on a meso-time level requires outcome variables that are related to changes in life roles.
- Regarding the *individual*, biological aspects do not seem to be key factors in predicting the level of frequency of attendance and perceived involvement in domestic life activities, in peer relations or in school. Frequency of participation in dialogues and family communication seems to affect participation profiles more than factors related to body functions and the existence of an impairment. Participation restrictions related to self-reported NDIs are more prominent in school but the everyday functioning for these adolescents mainly seem to be driven by the same factors as for all adolescents.
- Regarding *context*, family atmosphere and perceived communication in the family matter in relation to degree of participation in discussions as well as perceived sibling support. For adolescents with self-reported NDI, no factors to do with body, activity or environment were related to frequency of attending and perceived involvement in school when they were 12-13 years of age. Two years later, factors related to body, activity and environment were associated with perceived involvement in school for adolescents with NDI. Professionals working with adolescents with NDIs need

to be aware that their development relates to maturity and changes in life roles tend to occur later than for their peers without self-reported NDIs. Hence, interventions in school aiming to support difficulties experienced with functioning are crucial in supporting participation of adolescents with NDIs.

- Regarding *time*: studying changes in participation using only two measurement occasions gives a snapshot of the proximal processes taking place in domestic life, in peer relations and at school. However, using only two time points provides no information on whether or not the proximal processes become more complex. Adolescents' self-reports in the current thesis are based on their opinions regarding activities post hoc but in a micro-time perspective. Perceived participation could therefore be argued to be related to the present context or situation within a micro-time perspective. Hence, a person can perceive participation to be about the same at two time points, even if the actual contexts have changed because of changes in life roles.

Clinical implications

- The bio-psycho-social approach applied in this thesis to investigate factors at body, activity and environment level, implicates that an interdisciplinary approach in interventions aiming to enhance participation for adolescents is crucial. Fusing knowledge from different disciplines improves the possibility of enhancing participation and avoiding participation restrictions for adolescents with and without impairments or long-term health conditions.
- Interventions aiming to enhance participation should be preceded by an interdisciplinary assessment, taking both personal characteristics as well as the influence of the adolescents' close environments into consideration.
- The ICF-CY can be considered a useful tool in documenting adolescents' mental health in various life domains.
- Users of the ICF-CY can capture a broad range of life areas relevant to participation and everyday functioning in adolescents with mental health problems by mapping latent constructs onto the classification.
- Interventions addressing participation in domestic life, peer relations and in school need to focus on the participation attendance and involvement dimension separately i.e. which activities does the adolescent take part in and which activities do they actually value?
- The impact of neurodevelopmental impairments seems to be more prominent at school. Given the relation between school, learning and mental health, interventions encouraging adolescents' everyday functioning in school should be emphasised.
- Enhancing adolescence participation requires a holistic view of the individual, including the perceived communication pattern in the family as well as the perceived support from siblings.

Future research

This thesis focuses on patterns of participation for adolescents with and without impairments and long-term health conditions in a Swedish context. Predictors for frequency of attendance and perceived involvement in domestic life activities, peer relations and school might be very different in a context where a child is expected to for example take care of other family members as part of their daily life. Hence, more research on participation, preferably based on children and youths' own opinions, where these issues are investigated in a variety of countries, would broaden our understanding of the concept of participation. The use of qualitative methods would add value to the design of the studies in this thesis. Applying qualitative methods would deepen our knowledge of the barriers and facilitators affecting adolescent participation in domestic life activities as well as activities with peers and at school. This thesis has demonstrated the importance of sibling support and this could be further explored by the use of qualitative methods. The use of interviews or focus groups for adolescents with self-reported NDI, for example, would also give a broader understanding of the factors affecting participation in and outside school. Further research could also investigate predictors of negative/deviant participation, in situations harmful for children and adolescents with and without impairments and/or long-term health conditions.

Summary in Swedish/ Svensk sammanfattning

Denna avhandling är en delstudie inom forskningsprogrammet LoRDIA (Longitudinal Research in Development in Adolescence). Avhandlingsprojektet är knutet till forskningsmiljön CHILD och Avdelningen för beteendevetenskap och socialt arbete vid Jönköping University samt Göteborgs universitet och avdelningen för Socialt arbete. Forskningsprogrammet LoRDIA syftar till att följa ungdomar i fyra kommuner genom tonåren och avser belysa ungdomars sociala nätverk, missbruk, psykiska hälsa och skolanpassning.

Barn och ungdomar med utvecklingsrelaterade funktionsnedsättningar såsom intellektuella funktionsnedsättningar eller funktionsnedsättningar inom autismspektrumet upplever ofta delaktighetsbegränsningar i vardagliga aktiviteter. Det finns idag få långtidsstudier som rör delaktighet och hälsa där ungdomar med funktionsnedsättningar själva inkluderats och där de själva fått svara på frågor. Denna studie handlar om den i sitt slag första svenska långtidsstudien av vardagsfungerande, hälsa och delaktighet som inkluderar ungdomar med funktionsnedsättningar, inklusive de ungdomar som följer grundsärskolans läroplan. För att möjliggöra deltagande för ungdomarna med intellektuella funktionsnedsättningar har metoder för såväl datainsamling som utformande av elevenkäter anpassats.

Syfte och övergripande frågeställningar

Syftet med avhandlingen är att över tid studera relationer mellan individuella och miljömässiga faktorer mätt vid två tidpunkter inom ramen för den internationella klassifikationen av funktionstillstånd, funktionshinder och hälsa, barn och ungdomsversion (ICF-CY). Syftet var också att studera hur individ- och miljöfaktorer påverkar självrapporterad delaktighet i vardagen hos ungdomar med och utan självrapporterade funktionsnedsättningar och långvariga hälsotillstånd.

Följande frågeställningar adresserades:

- I vilken utsträckning är den internationella klassifikationen av funktionstillstånd, funktionshinder och hälsa-barn och ungdomsversion (ICF-CY) användbar för att dokumentera och följa utvecklingen av delaktighet över tid för ungdomar med och utan självrapporterade funktionsnedsättningar och långvariga hälsotillstånd?
- Vilka individ och miljöfaktorer påverkar ungdomars självrapporterade delaktighet vid ett specifikt tillfälle och över tid?
- Hur förändras självrapporterad delaktighet över tid för ungdomar med och utan självrapporterade funktionsnedsättningar och långvariga hälsotillstånd?

Bakgrund

Delaktighet i vardagen är avhandlingens huvudtema. Delaktighet kan ses som en indikator på god hälsa. För att teoretiskt definiera delaktighet används den Internationella Klassifikationen av funktionstillstånd, funktionshinder och delaktighet – barn och ungdomsversion (ICF-CY) (World Health Organization, 2007) där delaktighet definieras utifrån hur en person agerar och fungerar i olika livssituationer och där delaktighet yttrycks som involvering i en livssituation. Delaktighetsbegreppet består av två dimensioner där engagemang är den ena och frekvens- närvaro eller tid i en aktivitet är den andra dimensionen (Coster, Bedell et al. 2011, Granlund, Arvidsson et al. 2012). En persons delaktighet kan ses som en konsekvens av kroppsliga funktioner, aktivitetsutförande och omgivningens utformning. Att använda ICF-CY som tankemodell vid datainsamling ger en möjlighet till att systematiskt samla information om hur exempelvis kroppsliga funktioner influerar olika aktiviteter.

Metoder

Avhandlingen består av fyra delstudier. De metoder som använts för dataanalys är kvantitativa. Detta innebär att den data som samlats in har analyserats med hjälp av olika statistiska metoder såsom deskriptiv statistik, faktoranalyser, klusteranalyser, variansanalys och olika former av

regressionsanalyser. Studie I och II baseras på den första datainsamlingen (i avhandlingen benämnd som tidpunkt 1) i LoRDIA och studie III och IV på den tredje datainsamlingen (i avhandlingen benämnd som tidpunkt 2). I studie III och IV består urvalet av de elever som deltog och svarade på frågor vid båda tidpunkterna. Vid tidpunkt 1 deltog totalt 1515 ungdomar i LoRDIA varav mer än hälften självrapporterat en funktionsnedsättning eller långvarig sjukdom. I studierna har ungdomarna som självrapporterat funktionsnedsättning/långvarig sjukdom delats in i grupperna fysiska funktionsnedsättningar (t. ex astma, diabetes, motoriska svårigheter) och utvecklingsrelaterade funktionsnedsättningar (t. ex ADHD eller utvecklingsstörning).

Resultat

Resultatet visade bland annat att det vid överkodning av frågeformulär som är avsedda att mäta mental ohälsa krävs att hänsyn tas till den underliggande betydelsen av varje enskild fråga. När det gäller vilka faktorer som är av betydelse för den självskattade betydelsen av delaktighet visar resultaten att tillbringa tid tillsammans med kompisar och kunna hantera konflikter med kompisar skattas som mer viktigt än hur ofta och hur mycket man deltar i vardagsaktiviteter i hemmet. Resultaten visar också att typ av funktionsnedsättning inte kan ses som en enskilt avgörande faktor som påverkar upplevelsen av delaktighet hemma och bland kompisar eller i skolan. De ungdomar som är delaktiga i kamratrelationer upplever mer stöd av syskon och är mer delaktiga i samtal och diskussioner i hemmet samt upplever mindre kontroll av föräldrar. Resultaten visade också att delaktighet verkar vara stabilt över tid mätt vid två tillfällen. Färre faktorer kunde relateras till delaktighet hemma, med kompisar och i skolan för ungdomar utvecklingsrelaterade funktionsnedsättningar (såsom intellektuell funktionsnedsättning, adhd, autism) vid tidpunkt 1 när ungdomarna var 12/13 år. Resultatet visar att två år senare är det fler faktorer som verkar påverka den självskattade upplevelsen av delaktighet för ungdomar med självskattade utvecklingsrelaterade funktionsnedsättningar.

Slutsatser och rekommendationer

Delaktighet mätt vid två tidpunkter är relativt stabilt över tid. Typ av funktionsnedsättning predicerar inte den självskattade upplevelsen av delaktighet hemma, med kompisar och i skolan. Vardagsfungerande för ungdomar med utvecklingsrelaterade funktionsnedsättningar påverkas delvis av samma faktorer som för typiskt utvecklade ungdomar men effekten av funktionsnedsättningen blir mer framträdande i skolan. Denna effekt förefaller också minska med ålder. Åtgärder som syftar till ökad delaktighet hemma, med kompisar och i skolan bör ta faktorer i miljön i beaktande såsom stöd av syskon och upplevt kommunikationsklimat i familjen. Både frekvens/närvaro och upplevd betydelse av aktiviteten bör tas i beaktande vid bedömning av delaktighet i vardagliga aktiviteter för ungdomar med och utan självrapporterade funktionsnedsättningar.

Acknowledgements

The work with this thesis was made possible by the financial support to LoRDIA from the Swedish Research Council (VR), the Swedish Research Council for Health, Working Life and Welfare (FORTE), Sweden's Innovation Agency (VINNOVA), and the Swedish Research Council for Environment, Agricultural Sciences and Spatial Planning (FORMAS) (studies I and II).

Additional funding for studies III and IV was received from the Sunnerdahl Foundation, the Sävstaholm Foundation, Futurum, Region Jönköping County, the Swedish Institute for Disability Research (SIDR) and the School of Health and Welfare, Jönköping University.

I would like to gratefully acknowledge **all the adolescents and their families** as well as the **school staff** who participated in the LoRDIA research program. Thank you for lending your time and energy and sharing your opinions on many different areas of life.

In addition, my sincere gratitude goes to the following people, who have contributed towards the progression of this thesis.

Karina Huus, main supervisor for always being there with critical reasoning and your knowledge on administrative matters important for a doctoral student. I really appreciate the time you took to read and give feedback even when I know you had a lot to do. Thank you also for including me in the research collaboration 'Picture My Participation' (PmP) with colleagues at the University of Pretoria, South Africa.

Mats Granlund, previous main supervisor, co-supervisor and head of the research environment CHILD. You have always challenged me to think beyond my comfort zone. I admire your expertise in research and for always giving fast and valuable feedback. Thank you also for the many opportunities you have given me by inviting me to be a member of the CHILD research environment.

Lilly Augustine, co-supervisor for your hawk-eye for details and for challenging me with difficult questions. Thank you also for the statistical expertise that has been of value to me.

Many thanks to the reviewers at the half-time seminar, **Stephen Widén, Disa Bergnehr and Bodil Monwell, and Mats Eriksson, Dido Green and Karin Bertills** at the final seminar for providing valuable feedback.

Thanks to co-authors **Margareta Adolfsson** (study I) and **Lena Almqvist** (study II) and Ingemar ‘**Pingo**’ Kåreholt (study III) (study IV). Your methodological skills and input in the studies are much appreciated. Special thanks to Lena for taking the time to guide me in using the statistical software SLEIPNER and ROPstat and to Pingo for the amount of time you have put into helping me with the statistics.

This project was initiated in 2013 and some people who made important contributions to the pilot studies which took place prior to the first wave of data collection should be mentioned. My friend and colleague **Paula Bergman** for helping me find participants to the first think-loud interview to pilot the questionnaire. **Susanne Törnvall, Fredrik and Cinna and Eva Sveen** at Barnarpsskolan. Staff at the compulsory school for students with intellectual disabilities at Rosenlund, in particular **Kerstin Ottosson**.

Thanks to **Carola Glitrén** for her assistance in the data collection within LoRDIA. Thanks also for helping out with the data collection at the compulsory school for students with intellectual disabilities while I was on maternity leave.

Doctoral students, past and present at the Research School of Health and Welfare. *Former* doctoral students, **Ulrika Börjesson, Martina Boström, Anna-Karin Axelsson, Lena Olsson, Inger Ahlstrand, Tomas Dalteg, Åsa Söderqvist, Christina Peterson, Johanna Norderyd, Ingalill Gimbler Berglund, and Birgitta Ander**.

Present doctoral students, **Louise Rundqvist and Saffran Möller, Paula Bergman, Magdalena Stadin, Elin Ekström, Andrea Tompa and Hanna Ahonen** for important support and ‘fika’-breaks. Much appreciated! I wish you and our new colleagues at the Research School all the best in your work on your theses.

Past and present doctoral students within the Swedish Institute for Disability Studies (SIDR). In particular **Ulrika Englund, Jennie Hjalldahl and Karin Bertills** for happy times and good talks during the Foundation courses.

CHILD coordinator **Cecilia Allergriind** and SIDR coordinator **Maria-Hugo Lindén** for valuable assistance during my time as a doctoral student.

LoRDIA coordinators **Thorbjörn Ahlgren** and **Timo Mäntylä Liffner** for your assistance and logistical skills during the data collection. I know that many hours of work were required by you before we could visit schools and do data collection.

Present LoRDIA research coordinator **Helena Engkvist** for your logistical administration skills and for being eager to help when needed.

Sabina Kapetanovic for collaboration in LoRDIA and co-authoring study IV. I look forward to future collaborations!

Gunilla Brushammar, Stefan Carlstein and Elisabeth Nylander librarians at the Jönköping University library for your professional and friendly service and support.

Kajsa Linnarsson for always being helpful with a positive attitude. It has meant more than you know. Also, thanks for the time you took to review the layout of the final version of this thesis. I don't know anyone else with your attention to details. I wish you the best of luck in your future adventures!

Karolina Boberg for your friendly assistance in finalising the thesis.

Susanne Einarsson, thank you for your positive attitude and for always encouraging me. Your support means a lot. I wish you all the best in your 'new life'.

Members of the research environment **CHILD**, for many inspiring discussions, happy memories and fruitful collaborations. I look forward to continuing working with you!

Juan Bornman, Shakila Dada and Colleagues at the Centre for Augmentative and Alternative Communication at the University of Pretoria, South Africa. You are such skilled researchers and I highly appreciate our collaboration within CHILD. Special thanks to my friend **Alecia Samuels** for your critical and friendly discussions. I always laugh and learn with you. Let's do more of that in the future!

Patrik Arvidsson for sharing many reflections on work and different aspects of life. I am glad that in the final phase of the thesis work I got to know a bit more of the person behind the reference "Arvidsson, 2013". I look forward to future collaborations!

Ann Johansson and **Irène Linddahl** for your support during my first years as a university lecturer. Without you I am not sure that I have continued along this road. *Irène*, I miss you! I have never met anyone with such a warm heart and positive thinking combined with firm leadership. A unique combination that I will always remember. *Ann*, thank you for your crystal-clear communication, along with your support and friendship. You are a role model to me as a parent and I am grateful to have you as my friend. I look forward to more years of work together and many more years of friendship.

Eva-Lotta Martinsson for your support and professional advice when unexpected circumstances in my doctoral studies demanded the most out of me. Thank you also for the love and support you give me and my family.

Anneli ‘Loppan’ Olsson for your never ending encouragement during this journey. It is very highly appreciated. We have shared many adventures and I look forward to new adventures together!

Louise Baek Larsen for your Excel-lent-expertise and knowledge on how to create nice-looking tables and figures. But most of all, thanks for your unconditional support including many hours of valuable talks on life as doctoral students and parents. I value our friendship highly and I am grateful for having shared this journey with you.


To my parents **Susanna and Tomas Lygnegård** for support and for inspiring me to continue with post-graduate studies. Also, thanks for introducing the meaning and value of books at an early age. I have made sure to pass this onto my own children.

My parents-in-law, **Anita and Ingemar Persson**. Thank you for all your support. It means so much!

My brother **Gustav Lygnegård** and sister-in-law **Matilda Wulf** for support. For sharing experiences in combining thesis work with parenting. I look forward to sharing new life adventures with you and your wonderful children Sigrid and Idun to whom I am a very proud aunt :)

My sister, **Kristin Borneling**. Thank you for always supporting me and for being critical with your questions. I really admire your work and what you and your husband **Richard** along with your family invest in others to make them feel visible and valuable. You and I started our life journey together and I am forever grateful that we now share it again. Special thanks also to **Jonathan, JohannaLouise** and **Emil** for being the fantastic people you are. To be your aunt is a privilege. Also, thanks to **Mahdi** for letting me be your aunt as well. I wish you all the best in life.

Finally, my warmest thanks to my fantastic family for being a constant reminder of what I value the most. To **Fredrik** for your never-ending support along with your opinion that something is worth it if I believe in it. Happiness and sorrow are best shared, and I am fortunate to share life with you by my side. With you, it feels like the impossible can be done.

Gabriel and Loni. This thesis is dedicated to you. I am so proud of you for who you are and to be your mother. I love you 

Jönköping, August, 2018

Frida Lygnegård

References

- Adair, Ullenhag, A., Keen, D., Granlund, M., & Imms, C. (2015). The effect of interventions aimed at improving participation outcomes for children with disabilities: A systematic review. *Developmental Medicine and Child Neurology.*, 57(12), 1093-1104.
- Adair, Ullenhag, A., Rosenbaum, P., Granlund, M., Keen, D., & Imms, C. (2018). Measures used to quantify participation in childhood disability and their alignment with the family of participation-related constructs: A systematic review. *Developmental Medicine and Child Neurology.*
- Adolfsson. (2011). *Applying the ICF-CY to identify everyday life situations of children and youth with disabilities [Elektronisk resurs]*. School of Education and Communication, Jönköping. Retrieved from <http://urn.kb.se/resolve?urn=urn:nbn:se:hj:diva-16195>
- Adolfsson, Malmqvist, J., Pless, M., & Granlund, M. (2011). Identifying child functioning from an ICF-CY perspective: Everyday life situations explored in measures of participation. *Disability and Rehabilitation.*, 33(13-14), 1230-1244.
doi:10.3109/09638288.2010.526163
- Alderson, P., & Morrow, V. (2011). *The ethics of research with children and young people. A practical handbook*. Los Angeles: Sage Publications Ltd
- Altman, B. M. (2001). Definitions of disability and their operationalization, and measurement in survey data: An update. In *Exploring theories and expanding methodologies: Where we are and where we need to go* (pp. 77-100). Amsterdam: Emerald Group Publishing Limited.
- American Psychiatric Association. (2013). Neurodevelopmental disorders. Retrieved April 20, 2018 from <http://dsm.psychiatryonline.org/doi/abs/10.1176/appi.books.9780890425596.dsm01>
- Arvidsson, P. (2013). *Assessment of participation in people with a mild intellectual disability*. Örebro, Örebro Universitet.
- Axelsson, A. K. (2014). *Children with profound intellectual and multiple disabilities and their participation in family activities*. Göteborg, School of Health Sciences.

- Barron, K. (1999). Ethics in qualitative social research on marginalized groups. *Scandinavian Journal of Disability Research*, 1(1), 38-49.
- Beauchamp, T. L., & Childress, J. F. (2001). *Principles of biomedical ethics*. New York: Oxford University Press
- Bergman, L. R., Magnusson, D., & El Khouri, B. M. (2003). *Studying individual development in an interindividual context: A person-oriented approach*. London and New York: Psychology Press
- Bickenbach, J. E., Chatterji, S., Badley, E. M., & Üstün, T. B. (1999). Models of disablement, universalism and the international classification of impairments, disabilities and handicaps. *Soc. Sci. Med.*, 48(9), 1173-1187.
- Bronfenbrenner, U. (1979). *The ecology of human development. Experiments by nature and design*. Cambridge: Harvard university press
- Bronfenbrenner, U., & Ceci, S. J. (1994). Nature-nurture reconceptualized in developmental perspective: A bioecological model. *Psychological Review.*, 101(4), 568-586.
- Bronfenbrenner, U., & Evans, G. W. (2000). Developmental science in the 21st century: Emerging questions, theoretical models, research designs and empirical findings. *Social Development*, 9(1), 115-125. doi:10.1111/1467-9507.00114
- Bronfenbrenner, U., & Morris, P. A. (1998). The ecology of developmental processes. In W. Damon & R.M. Lerner (Eds.), *Handbook of child psychology: Theoretical models of human development* (pp.993-1028). New York: Wiley.
- Brown, M., & Gordon, W. A. (1987). Impact of impairment on activity patterns of children. *Archives of Physical Medicine and Rehabilitation.*, 68(12), 828-832.
- Cardol, M., Jong, B. D., & Ward, C. D. (2002). On autonomy and participation in rehabilitation. *Disability and Rehabilitation.*, 24(18), 970-974.
- Carlberg, L., & Granlund, M. (2018). Achievement and participation in schools for young adolescents with self-reported neuropsychiatric disabilities: A cross-sectional study from the southern part of Sweden. *Scandinavian Journal of Public Health*. doi:10.1177/1403494818788415

- Castro, S., & Pinto, A. (2015). Matrix for assessment of activities and participation: Measuring functioning beyond diagnosis in young children with disabilities. *Developmental Neurorehabilitation*, 18(3), 177-189. doi:10.3109/17518423.2013.806963
- Cieza A, Brockow, T., Ewert, T., Amman, E., Kollerits, B., Chatterji, S., & Stucki, G. (2002). Linking Health-Status Measurements to the International Classification of Functioning, Disability and Health. *Journal of Rehabilitation Medicine (Taylor & Francis Ltd)*, 34(5), 205-210. doi:10.1080/165019702760279189
- Cieza, A., Fayed, N., Bickenbach, J., & Prodinger, B. (2016). Refinements of the ICF linking rules to strengthen their potential for establishing comparability of health information. *Disability and Rehabilitation*, 1-10. doi:10.3109/09638288.2016.1145258
- Cieza, A., Geyh, S., Chatterji, S., Kostanjsek, N., Ustun, B., & Stucki, G. (2005). ICF linking rules: an update based on lessons learned. *Journal of Rehabilitation Medicine*, 37(4), 212-218. doi:10.1080/16501970510040263
- Cooper, H. E., Camic, P. M., Long, D. L., Panter, A., Rindskopf, D. E., & Sher, K. J. (2012). *APA handbook of research methods in psychology, Vol 1: Foundations, planning, measures, and psychometrics*. Washington: American Psychological Association
- Corell, M., Augustine, L., & Löfstedt, P. (2012). Hälsa och välfärd hos barn och unga med funktionsnedsättning. In: Statens folkhälsoinstitut, A 2012:02.
- Coster, W., Bedell, G., Law, M., Khetani, M. A., Teplicky, R., Liljenquist, K., Kao, Y. C. (2011). Psychometric evaluation of the Participation and Environment Measure for Children and Youth. *Developmental Medicine and Child Neurology*, 53(11), 1030-1037. doi:10.1111/j.1469-8749.2011.04094.x
- Cowart, B., Saylor, C., Dingle, A., & Mainor, M. (2004). Social skills and recreational preferences of children with and without autism. *North American Journal of Psychology*, 6, 27-42.
- Eriksson, L. (2006). *Participation and disability: A study of participation in school for children and youth with disabilities*. Stockholm: Karolinska Institutet

- Eriksson, L., & Granlund, M. (2004). Perceived participation. A comparison of students with disabilities and students without disabilities. *Scandinavian Journal of Disability Research*, 6(3), 206-224. doi:10.1080/15017410409512653
- Galambos, N. L., Kolaric, G. C., Sears, H. A., & Maggs, J. L. (1999). Adolescents' subjective age: An indicator of perceived maturity. *Journal of Research on Adolescence*, 9(3), 309-337.
- Gerdner, A., Falkhe, C., Granlund, M., & Skårner, A. (2013). *Longitudinal Research on Development In Adolescence (LoRDIA)- A programme to study teenagers' social network, substance misuse, psychological health and school adjustment. Research Project Plan*. Retrieved from School of Health Sciences, Jönköping University and Departments of Psychology and Social Work, Gothenburg University.
- Granlund, M. (2013). Participation - challenges in conceptualization, measurement and intervention. *Child: Care, Health and Development*, 39(4), 470-473. doi:10.1111/Cch.12080
- Granlund, M., Arvidsson, P., Niiä, A., Björck-Akesson, E., Simeonsson, R., Maxwell, G., Pless, M. (2012). Differentiating activity and participation of Children and Youth with Disability in Sweden: A third qualifier in the International classification of functioning, disability, and health for children and Youth? *American Journal of Physical Medicine & Rehabilitation.*, 91(2), S84-S96. doi:10.1097/Phm.0b013e31823d5376
- Gustafsson, J.-E., Allodi Westling, M., Åkerman, A., Eriksson, C., Eriksson, L., Fischbein, S., & Ogden, T. (2010). *School, learning and mental health: A systematic review*. Stockholm: Kungl. Vetenskapsakademien.
- Haller, H., Cramer, H., Lauche, R., Gass, F., & Dobos, G. J. (2014). The prevalence and burden of subthreshold generalized anxiety disorder: A systematic review. *BMC Psychiatry.*, 14(1), 128. doi:10.1186/1471-244X-14-128
- Hartley, S. L., & MacLean, W. E. (2006). A review of the reliability and validity of Likert-type scales for people with intellectual disability. *Journal of Intellectual Disability Research.*, 50(11), 813-827. doi:10.1111/j.1365-2788.2006.00844.x

- Hill, M. (2005). Ethical considerations in researching children's experiences. In *Researching Children's Experience*. London: SAGE Publications Ltd.
- Idring, S., Lundberg, M., Sturm, H., Dalman, C., Gumpert, C., Rai, D., Magnusson, C. (2015). Changes in prevalence of autism spectrum disorders in 2001–2011: Findings from the Stockholm Youth Cohort. *Journal of Autism and Developmental Disorders.*, 45(6), 1766-1773. doi:10.1007/s10803-014-2336-y
- Imms, & Adair, B. (2017). Participation trajectories: impact of school transitions on children and adolescents with cerebral palsy. *Developmental Medicine and Child Neurology.*, 59(2), 174-182. doi:10.1111/dmcn.13229
- Imms, C., Adair, B., Keen, D., Ullenhag, A., Rosenbaum, P., & Granlund, M. (2016). 'Participation': A systematic review of language, definitions, and constructs used in intervention research with children with disabilities. *Developmental Medicine and Child Neurology.*, 58(1), 29-38. doi:10.1111/dmcn.12932
- Imms, C., Granlund, M., Wilson, P. H., Steenbergen, B., Rosenbaum, P. L., & Gordon, A. M. (2017). Participation, both a means and an end: a conceptual analysis of processes and outcomes in childhood disability. *Developmental Medicine and Child Neurology* 59 (1), 16-25
- Inchley, J., & Currie, D. (2014). *Growing up unequal: gender and socioeconomic differences in young people's health and well-being*. Retrieved from http://www.euro.who.int/__data/assets/pdf_file/0014/303440/HSBC-No.7-Growing-up-unequal-PART-1.pdf?ua=1
- Kalman, H. (2012). Etik i forskning och etiska dilemman—en introduktion. Kalman, Hildur & Lövgren, Veronica (red.), I Etiska dilemman—forskningsdeltagande, samtycke och utsatthet. Malmö: Gleerups.
- Kazdin, A. E. (2010). *Research design in clinical psychology*. Boston: MA: Allyn and Bacon
- Kerr, M., & Stattin, H. (2000). What parents know, how they know it, and several forms of adolescent adjustment: Further support for a reinterpretation of monitoring. *Developmental Psychology.*, 36(3), 366-80

- Kessler, R. C., Berglund, P., Demler, O., Jin, R., Merikangas, K. R., & Walters, E. E. (2005). Lifetime prevalence and age-of-onset distributions of DSM-IV disorders in the National Comorbidity Survey Replication. *Archives of General Psychiatry*, 62(6), 593-602. doi:10.1001/archpsyc.62.6.593
- King, G. (2013). Perspectives on measuring participation: Going forward. *Child: Care, Health and Development*, 39(4), 466-469. doi:Doi 10.1111/Cch.12083
- King, G., Law, M., Hurley, P., Petrenchik, T., & Schwellnus, H. (2010). A developmental comparison of the out-of-school recreation and leisure activity participation of boys and girls with and without physical disabilities. *International Journal of Disability, Development and Education*, 57(1), 77-107.
- Law, M. (2002). Participation in the occupations of everyday life. *American Journal of Occupational Therapy*, 56(6), 640-649.
- Law, M., Anaby, D., Teplicky, R., Khetani, M. A., Coster, W., & Bedell, G. (2013). Participation in the home environment among children and youth with and without disabilities. *The British Journal of Occupational Therapy*, 76(2), 58-66.
- Lee, A. M. (2011). Using the ICF-CY to organise characteristics of children's functioning. *Disability and Rehabilitation*, 33(7), 605-616.
- Masten, A. S., Coatsworth, J. D., Neemann, J., Gest, S. D., Tellegen, A., & Garmezy, N. (1995). The structure and coherence of competence from childhood through adolescence. *Child Development*, 66(6), 1635-1659.
- Maxwell, G., Alves, I., & Granlund, M. (2012). Participation and environmental aspects in education and the ICF and the ICF-CY: Findings from a systematic literature review. *Developmental Neurorehabilitation*, 15(1), 63-78. doi:10.3109/17518423.2011.633108
- Maxwell, G., Augustine, L., & Granlund, M. (2012). Does thinking and doing the same thing amount to involved participation? Empirical explorations for finding a measure of intensity for a third ICF-CY qualifier. *Developmental Neurorehabilitation*, 15(4), 274-283.

- Morgan, A., Currie, C., Due, P., Gabhain, S. N., Rasmussen, M., Samdal, O., & Smith, R. (2008). Mental well-being in school-aged children in Europe: Associations with social cohesion and socioeconomic circumstances. In *Social cohesion for mental well-being among adolescents*. Copenhagen: World Health Organization
- Myant, K. A., & Williams, J. M. (2005). Children's concepts of health and illness: Understanding of contagious illnesses, non-contagious illnesses and injuries. *Journal of Health Psychology*, *10*(6), 805-819.
- Nilsson, S., Buchholz, M., & Thunberg, G. (2012). Assessing children's anxiety using the modified short state-trait anxiety inventory and talking mats: A pilot study. *Nursing Research and Practice*, *2012*.
- Nobre, F. S. S., Coutinho, M. T. C., & Valentini, N. C. (2014). The ecology of motor development in coastal school children of Brazil northeast. *Journal of Human Growth and Development*, *24*(3), 263-273.
- Nordenfelt, L. (2003). Action theory, disability and ICF. *Disability and Rehabilitation*, *25*(18), 1075-1079.
- Norderyd, J., Lillvist, A., Klingberg, G., Faulks, D., & Granlund, M. (2015). Oral health, medical diagnoses, and functioning profiles in children with disabilities receiving paediatric specialist dental care—A study using the ICF-CY. *Disability and Rehabilitation*, *37*(16), 1431-1438.
- Norell-Clarke, A., & Hagquist, C. (2017). Changes in sleep habits between 1985 and 2013 among children and adolescents in Sweden. *Scandinavian Journal of Public Health*, *45*(8), 869-877. doi:10.1177/1403494817732269
- Ployhart, R. E., & Vandenberg, R. J. (2010). Longitudinal research: The theory, design, and analysis of change. *Journal of Management*, *36*(1), 94-120.
- Potrebny, T., Wiium, N., & Margrethe Moss - Iversen, L. (2017). Temporal trends in adolescents' self-reported psychosomatic health complaints from 1980-2016: A systematic review and meta-analysis. *PloS one*, *12*(11), e0188374
- Rao, M. (2001). Book Review. Promoting children's emotional well-being. By Ann Buchanan and Barbara Hudson. *Journal of Public Health*, *23*(2), 168-169. doi:10.1093/pubmed/23.2.168

- Roeser, R. W., Eccles, J. S., & Sameroff, A. J. (1998). Academic and emotional functioning in early adolescence: Longitudinal relations, patterns, and prediction by experience in middle school. *Development and Psychopathology*, *10*(2), 321-352.
- Sameroff, A. (2010). A unified theory of development: A dialectic integration of nature and nurture. *Child Development*, *81*(1), 6-22. doi:10.1111/j.1467-8624.2009.01378.x
- Sawyer, S. M., Afifi, R. A., Bearinger, L. H., Blakemore, S.-J., Dick, B., Ezech, A. C., & Patton, G. C. (2012). Adolescence: A foundation for future health. *The Lancet*, *379*(9826), 1630-1640.
- Shankman, S. A., Lewinsohn, P. M., Klein, D. N., Small, J. W., Seeley, J. R., & Altman, S. E. (2009). Subthreshold conditions as precursors for full syndrome disorders: A 15-year longitudinal study of multiple diagnostic classes. *Journal of Child Psychology and Psychiatry*, *50*(12), 1485-1494.
- Simeonsson, J., Carlson, D., Huntington, G. S., Sturtz McMillen, J., & Lytle Brent, J. (2001). Students with disabilities: A national survey of participation in school activities. *Disability and Rehabilitation*, *23*(2), 49-63.
- Simeonsson, R. J., Leonardi, M., Lollar, D., Bjorck-Akesson, E., Hollenweger, J., & Martinuzzi, A. (2003). Applying the International Classification of Functioning, Disability and Health (ICF) to measure childhood disability. *Disability and Rehabilitation*, *25*(11-12), 602-610. doi:10.1080/0963828031000137117
- Statens Folkhälsoinstitut. (2011). *Hälsan hos barn och ungdomar med funktionsnedsättning*. Östersund: Statens Folkhälsoinstitut
- Swedish Research Council. (2007). *Forskningsetiska principer inom humanistisk-samhällsvetenskaplig forskning*. Retrieved from <http://www.codex.vr.se/texts/HSFR.pdf>
- Tudge, J. R. H., Payir, A., Merçon-Vargas, E., Cao, H., Liang, Y., Li, J., & Brien, L. (2016). Still misused after all these years? A reevaluation of the uses of Bronfenbrenner's bioecological theory of human development. *Journal of Family Theory & Review*, *8*(4), 427-445. doi:10.1111/jftr.12165

- Ullenhag, A. (2012). Participation in leisure activities of children and youths with and without disabilities. Stockholm: Karolinska Institutet
- UNICEF. (1989). Convention on the Rights of the Child. Retrieved February 12, 2018 from <https://www.unicef.org/crc/>
- United Nations (UN). (2006). Convention on the Rights of Persons with Disabilities. Retrieved from <http://www.un.org/disabilities/documents/convention/convoptprot-e.pdf>
- United Nations (UN) General Assembly. (1993). *The Standard Rules on the Equalization of Opportunities for Persons with Disabilities*: Retrieved August 17, 2018 from <http://gtnc.org/wp-content/uploads/2017/04/UN-Standard-Rules.-Equalization-of-Opps-for-PLWD.pdf>
- van der Lee, J. H., Mokkink, L. B., Grootenhuis, M. A., Heymans, H. S., & Offringa, M. (2007). Definitions and measurement of chronic health conditions in childhood: A systematic review. *JAMA*, 297(24), 2741-2751.
- Vargha, A., Torma, B., & Bergman, L. R. (2015). ROPstat: A general statistical package useful for conducting person-oriented analyses. *Journal of Person-Oriented Research*, 1(1-2), 87-97.
- World Health Organization (WHO). (2001). *International Classification of Functioning, Disability and Health (ICF)*. Geneva, World Health Organization. Retrieved from <http://www.who.int/classifications/icf/en/>
- World Health Organization (WHO). (2007). International Classification of Functioning, Disability and Health: Children and Youth Version: ICF-CY. Geneva, World Health Organization.
- World Health Organization (WHO). (2011). *World report on disability*. Retrieved from http://www.who.int/disabilities/world_report/2011/en/
- World Health Organization (WHO). (2014). Mental health: a state of well-being. Retrieved from http://www.who.int/features/factfiles/mental_health/en/

- World Health Organization (WHO). (2015). Adolescent mental health: mapping actions of nongovernmental organizations and other international development organizations Retrieved March 20, 2018, from:http://apps.who.int/iris/bitstream/handle/10665/44875/9789241503648_eng.pdf;jsessionid=6B677A8956CFBC47E938BF742C31AA61?sequence=1
- World Health Organization (WHO). (2016). International Statistical Classification of Diseases and Related Health Problems, 10th revision (ICD-10). Retrieved April 8, 2018 from <http://apps.who.int/classifications/icd10/browse/2016/en>
- World Health Organization (WHO). (2017a). Adolescence development. Retrieved from http://www.who.int/maternal_child_adolescent/topics/adolescence/dev/en/
- World Health Organization (WHO). (2017b) Adolescent health. Retrieved March 14, 2017 from http://www.who.int/topics/adolescent_health/en/