Bringing more to participation

Participation in school activities of persons with
disability within the framework of the International
Classification of Functioning, Disability and Health for
Children and Youth (ICF-CY)

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ABSTRACT

As societies the world over move towards defining inclusive and effective education systems this presents the educator with the new challenge of providing an equal and democratic education environment for all students. With children the nature of functioning and environmental settings varies greatly in comparison with adults and assessing children's involvement in activities is of particular importance to ensure effective and inclusive society building through education. Building on the existing and previous participation research this thesis specifically aims to provide a means to theorize participation from two perspectives (frequency of attending and intensity of involvement) and put in to operation using five dimensions of the environment: availability, accessibility, affordability, accommodability, and acceptability. Contextually this has been done by investigating children in need of additional support (including children with disabilities) at school. Results indicate that while research and theory take a holistic and balanced approach by using participation based on two perspectives, this has yet to filter down to practice. A new approach to measuring inclusive education using social capital, the five environmental dimensions, and the ICF-CY is proposed and tested. However, while the ICF-CY provides a consistent descriptive framework, no clear connections between social capital and inclusive education policy could be drawn and the five environmental dimensions – especially the involvement-related ones – need further development. The final paper presents evidence from the individual perspective for a third ICF-CY activities and participation qualifier to represent the subjective experience of involvement. Participation can thus be regarded as

a multi-dimensional phenomenon with two main conceptual roots: sociology and developmental psychology.

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Gregor Maxwell

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Results and descriptions of the project have been presented at conferences, for example the European Conference on Educational Research, the Nordic Network on Disability Research bi-annual conference, and the European Association for Research in to Learning and Instruction junior conference, and published in peer-reviewed journals. The outcome from this thesis will also be incorporated as material for courses on children's educational development and disability in children.

Last but not least I need to thank my family for always providing me with support, joy, fulfilment, and love. Relaxing with Kate, our children Matilda and Samuel, and our dog Rhuaridh has been a welcome and necessary distraction from my studies.

My first two children were also born during my time as a doctoral student and while teaching me to better focus my work (and sleep!) time they have also truly taught me what valuable assets children are.

For children.

LIST OF STUDIES

This doctoral thesis is based on the following studies:

I. Maxwell, G., Alves, I. F., & Granlund, M. (2012). Participation and environmental aspects in education and the ICF and the ICF-CY, findings from a systematic literature review: can we get there and what can we do once there? *Developmental Neurorehabilitation, 15(1)*, 63-78. doi: 10.3109/17518423.2011.633108

II. Maxwell, G., & Granlund, M. (2011). How are conditions for participation expressed in education policy documents? A review of documents in Scotland and Sweden. *European Journal of Special Needs Education, 26(2)*, 251-272. doi: 10.1080/08856257.2011.563610

III. Maxwell, G., & Koutsogeorgou, E. (2012). Using social capital to construct a conceptual ICF-CY-based framework for stronger inclusive education policies in Europe *American Journal of Physical Medicine & Rehabilitation, 91(13)*, supplement 1, S118-S123. doi: 10.1097/PHM.0b013e31823d4b92.

IV. Koutsogeorgou, E., Maxwell, G., Moretti, M., Aluas, M., & Quintas, R. (submitted). Evaluating social capital indicators and national inclusive education policies in six European countries using the ICF-CY. *Educational Evaluation and Policy Analysis*.

V. Maxwell, G., Eriksson-Augustine, L., & Granlund, M. (accepted). 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*.

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CONTENTS

Studies

CHAPTER I

INTRODUCTION

As we globally move towards defining an inclusive and effective education system this presents the educator with the new challenge of providing an equal and democratic education environment for all students. Higher degrees of participation will lead to increased independence, academic achievement and social inclusion for students with disabilities (Simeonsson, Carlson, Huntington, McMillen, & Brent, 2001). This thesis specifically looks to provide more clarity on the operationalization of participation and provide suggestions for its improvement as currently its vague definition is open to interpretations which can be adapted to suit a need. Within a school setting theoretical aspects of participation are still found to lack the necessary complexity which is required to understand all aspects of childhood disability (Egilson & Traustadóttir, 2009). What remains to be explored is how activity and participation in school activities are conceptualized, measured and operationalized. This

work explores participation from both the perspectives of the frequency of attending and the intensity of involvement.

Participation can be regarded as a multi-dimensional phenomenon and can be defined as "involvement in a life situation" (Björck-Åkesson, Granlund, & Simeonsson, 2005; WHO, 2007). However, the need to provide clarity on the participation construct is currently well debated in the literature with a number of studies discussing how to measure participation (Badley, 2008; Coster & Khetani, 2008; McConachie, Colver, Forsyth, Jarvis, & Parkinson, 2006). While definitions of participation may vary, from previous studies it has been shown that differences in participation are context-specific (Eriksson, Welander, & Granlund, 2007) for both children with and children without disabilities. Participation patterns over activities and students' concepts of participation are not strongly dependent on type or degree of disability (Almqvist & Granlund, 2005; Eriksson & Granlund, 2004a, 2004b; Granlund, Eriksson, & Ylvén, 2004) with students' conceptions of participation being more age-dependent (Eriksson & Granlund, 2004a). Similarly, environmental factors are also seen as influential in these studies. One of the proposals by Badley (2008) to enhance the conceptual clarity of participation is that there is a reciprocal relationship between contextual factors acting as 'scene-setters' as well as facilitators/barriers, and participation seen as societal involvement, and performing tasks and acts.

The work presented here is participation-focused and is practically influenced by the World Health Organization's International Classification of Functioning, Disability and Health (ICF, WHO, 2001) and the child and youth version, the ICF-CY (WHO, 2007) as the ICF/ICF-CY framework is used extensively as a methodological tool in the studies. As a person-based social model, as opposed to a deficit-based medical model, the ICF was devised by the World Health Organization (WHO) as a universal standardized framework to describe health and health-

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related states (WHO, 2001) and is a member of the WHO family of international classifications. The ICF takes the assumption that disability is a normal occurrence and experience of living and not necessarily comparable to an illness. The Child and Youth version, the ICF-CY (WHO, 2007), has been further produced to address problems surrounding the considerable changes in development, behaviour and contexts for functioning which take place in the first two decades of a person's life. Both the ICF and the ICF-CY use codes to categorize the functioning of an individual and there are four main areas (called domains) of classification: body functions, body structures, activities and participation, and environmental factors.

A forerunner to the ICF/ICF-CY, the ICIDH (WHO, 1980), contained a linear connection between disability and functional impairments which served to re-enforce the medical components or physiological consequences of disability. There was thus resistance to taking disability as a rights issue and this delayed the connecting of the environment as a contributing factor to disability; this also led to services and policies becoming impairment-driven rather than rights or needs-based (Hurst, 2003). The lack of a rights-approach to disability or any societal components in the ICIDH naturally over-shadowed the ICF, however the WHO did recognize that disability was a rights issue during the revisions of the ICIDH and as a result the ICF now has an interactive model of disability (Hurst, 2003). In the case of children, as a pre-cursor to the ICF-CY, there were also calls to use the ICF as a universal standard to realize the rights of children with disabilities under the UN Convention of the Rights of the Child (Simeonsson et al., 2003). Of specific relevance to this thesis, the ICF/ICF-CY considers disability to be a term "encompassing impairment, activity limitations and participation restrictions."(WHO, 2007, p. xviii). This is further emphasized by Leonardi, Bickenbach, Üstün, Kostanjsek, and Chatterji (2006, p. 1220)

who propose "Disability is a difficulty in functioning at the body, person or societal levels, in one or more life domains, as experienced by an individual with a health condition in interaction with contextual factors."

CHAPTER 2

AIMS

This thesis aims to theorize and put in to operation participation from two perspectives – the frequency of attending the activity, and the intensity of involvement. New knowledge on how participation is conceptualized and operationalized is presented and this will have implications for the ICF-CY framework (WHO, 2007). Practically, the objectives have been explored by engaging across the following areas:

a. How is participation expressed in research within the field of education? A thorough systematic search and review of the existing literature addressed this by comparing how participation is theorized and put into operation within educational research.

b. How is participation on an individual level expressed within a societal participation framework? Are legislation, policy and practices related to education for children and youth needing additional support inter-related in terms of participation? Is par-

ticipation expressed as opportunities for participation and/or as a concrete goal in terms of involvement? This has be done by investigating the correspondence between policy documents on national, regional and local level from Sweden and Scotland. Data were collected through case studies. Elements of the United Nations Convention on the Rights of the Child, the United Nations Convention on the Rights of Persons with Disabilities, and the ICF-CY were used to clarify whether the policy definition of participation matches the definition as expressed in ICF-CY.

c. How does social capital influence inclusive education practice and policy? This conceptual paper proposes the International Classification of Functioning, Disability and Health Children and Youth Version (the ICF-CY) as a bridge to link social capital and inclusive education and thus provide a way to measure inclusion with social capital. A macro-level measure for participation based on inclusive education policy and social capital is proposed which will add to existing conceptual frameworks for inclusive education policy development and health equity while Europe is building national identities through education (Horenczyk, 1996).

d. Can a practical tool be constructed to measure inclusive education by using social capital? The aim of this article is not only to provide a sociological overview of the issue of inclusion in education, but also to show practical ways of strengthening social capital building within inclusive education environments. This has been attempted through a comparative analysis of the level of social capital – for Germany, Greece, Romania, Spain, Sweden, and United Kingdom – in relation to the level of the quality of the most recent inclusive education policies for children with disabilities within these countries.

e. Can a measure of the subjective experience of involvement be practically constructed? This article investigated the intensity of participation in school activities of school-aged children with disabilities in an educational setting within the ICF-CY framework. The ICF-CY only measures doing something using the capacity and performance qualifiers, a dimension measuring the experience is needed; a third qualifier. It was hypothesized that the experienced involvement of pupils in school activities is higher when thinking and doing coincided. Thus a measure of the subjective experience of involvement could be constructed.

The outcomes of (a) to (e) have produced a better understanding of the construction and operationalization of participation and form the basis of this doctoral thesis.

CHAPTER 3

THE CONSTRUCT OF PARTICIPATION

The need to provide clarity on the participation construct is currently well debated in the literature with a number of studies discussing how to measure participation (Badley, 2008; Coster & Khetani, 2008; Coster et al., 2012; McConachie, et al., 2006). Participation can be focused on the right to be in the same activities as other children in school or/and the level of engagement when being in a school activity (Granlund et al., 2012); these two perspectives of participation have two conceptual roots, both of which relate to functioning within a context: sociology and developmental psychology (Granlund, 2006). Participation based on the sociological root focuses on the availability of and access to everyday activities and describes participation as equal to frequency of attending the same activities as others. Participation based on the psychological root focuses on the child's intensity of involvement or engagement

within an activity and whether the environment is accommodated to the child and accepted by the child.

Building on the conceptual re-working of participation is the recent model developed by Granlund and Simeonsson (Granlund, 2009, see figure 1; Simeonsson, et al., 2001) in which the two aspects of participation (frequency of attending and intensity of involvement or engagement) exist as a spectrum of participation related to five environmental dimensions of conditions for participation. The dimensions were originally proposed by Simeonsson et al. (1999) as dimensions of access based on a model of access to health (Penchansky & Thomas, 1981).

Frequency of attending

Is it possible to act?
Can I access the context?
Is it worth it in terms of time and money?
Can the situation be adapted to my
way of functioning?
Am I accepted in this situation?

Availability
Accessibility
Affordability
Accommodability
Acceptability

Intensity of involvement
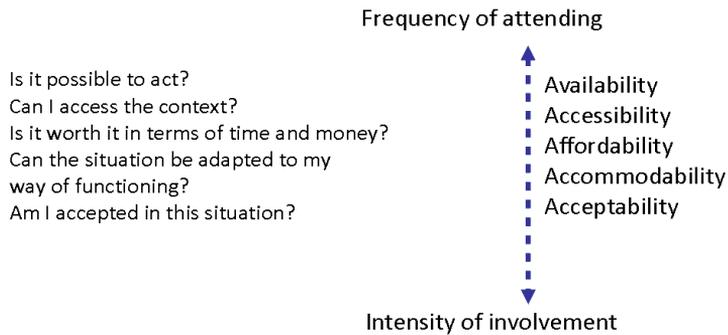
Figure 1. Environment dimensions of opportunity as a proposed measure of participation.

The model outlined in figure one contains five central dimensions concerning the environment: Availability describes the objective possibility

to engage in a situation. In terms of services it refers to the objective provision of facilities or resources. Accessibility describes whether you can, or perceive that you can, access the context for the situation. Affordability covers not only financial constraints but also whether the amount of effort in both time and energy expenditure is worth the return to engage in the situation. Accommodability describes whether a situation can be adapted. Acceptability covers people's acceptance of a person's presence in a situation. If there is an expression of values or common beliefs which are of a subjective nature then this is also acceptability. These five dimensions represent environmental or 'scene setting' (Badley, 2008) factors which directly influence participating in an activity and represent the intrinsic link between participation and the context, the way they interact is represented in figure two which shows Badley's (2008) model with the five environmental dimensions of opportunity over-laid.
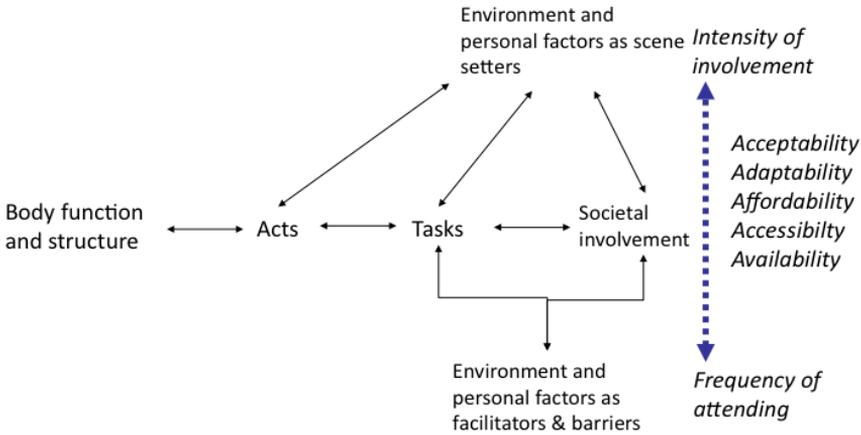
Figure 2. Badley's (2008) enhanced disability model with the frequency-intensity model overlaid (shown in italics).

The environment itself is an intrinsic part of the participation experience in both these dimensions as it acts as a pre-requisite and 'scene-setter' (Badley, 2008) as well as a context that facilitates or hinders participation. Although involvement is referred to within a psychology context, it is not related to a medical perspective as it consists of a subjective experience of participation, which includes the child's perception of the situation. Badley's (2008) enhanced disability model presents a relationship between contextual factors as scene-setters, contextual factors as facilitators and barriers, societal involvement, tasks, and acts (see figure 2); this is an extension of the model which underlies the ICF/ICF-CY's activities and participation and environment components.

The five dimensions outlined in figures one and two represent environmental or 'scene setting' (Badley, 2008) factors which directly influence participating in an activity and represent the intrinsic link between participation and the context. It is argued here that it is important to represent participation from both a frequency of attending and an intensity of involvement perspective to avoid any reductionist issues related to focussing on only one. This new way of looking at participation provides a more balanced way of representing the construct and brings in involvement, which has previously not been successfully done.

PARTICIPATION AS FREQUENCY OF PERFORMING AN ACTIVITY

Societal barriers can be a risk factor for children with disabilities having restrictions in their frequency of participation in activities. A number of studies indicate that children and youths with disabilities have a lower frequency of participation in unstructured school activities than their peers but for structured, teacher-led activities differences are less pronounced (Eriksson & Granlund, 2004b; Eriksson, et al., 2007; Skär, 2003; Tamm & Skär, 2000). Older children with disabilities have less

variation in the type of activities they participate in, especially in social activities (Law et al., 2006); they frequently play alone (Brown & Gordon, 1987; Tamm & Skär, 2000) and have a less rich play experience than their peers (Howard, 1996). In the home context children with disabilities spend more time in self-care and passive activities (Brown & Gordon, 1987; Buttimer & Tierney, 2005; Law, et al., 2006), and in school they are more frequently engaged in on-looking activities than their same age peers (Hestenes & Carroll, 2000), and are more frequently excluded during breaks than in teacher lead structured activities (Schenker, Coster, & Parush, 2005). Loneliness is often a problem for children with disabilities; and it is one of the reasons mentioned, by children leaving regular school for special school, as something negative about regular school (Eriksson, et al., 2007; Szönyi, 2005).

Having a disability is negatively related to frequency of participation, but the diagnostic category does not seem to affect frequency and diversity of participation in different activities (Almqvist & Granlund, 2005; Brown & Gordon, 1987; Law, et al., 2006). Simeonsson et al (2001) found, in their US national survey, that teachers rated children with more severe disabilities as participating less frequently than students with mild disabilities. In a study of frequency of participation in leisure activities of children with motor disabilities Imms (2008) reports that children with severe motor impairments participate less frequent than children with mild to moderate impairments. There is some consequence related to whether a child's limitations are physical or psychosocial with Egilson and Hemmingsson (2009) finding that children with physical limitations have their needs met to a more satisfactory extent. Several other factors than impairment are related to frequency of participation. Eriksson and Granlund (2004b) found that frequency of participation is more strongly related to personal factors, such as autonomy, to skills in interacting with significant others, such as peers and teachers,

than to general environmental factors. In school specific environmental factors such as availability and specific support have a stronger relationship to frequency of participation than general school environment (Eriksson, 2005).

PARTICIPATION AS THE SUBJECTIVE EXPERIENCE OF INVOLVEMENT

Measures of performance do not give the child's own perspective or give a measure of the subjective experience of involvement. Skinner and Simmer-Gembeck (1998) report that post-hoc self-ratings of intensity of engagement in school activities, i.e. a measure of intensity in participation, is related to achievement. Also being included (Finn & Cox, 1992) and having support from teachers and peers have been reported to facilitate achievements, and create a feeling of belonging and competence (Bear, Minke, Griffin, & Deemer, 1998; Goodwin & Watkinson, 2000).

Feelings and perceptions concerning the relationship between the person and the activity, such as control perceptions, should be included when constructing the subjective experiences of involvement. Relating to perceptions of control, one measure of the intensity in participation can be achieved from reports of post-hoc self-ratings of intensity of engagement in school activities (Skinner & Simmer-Gembeck, 1998). Also related to perceptions of control is self-efficacy, defined as "beliefs in one's capabilities to organize and execute the courses of action required to manage prospective situations" (Bandura, 1998). Clarke et al. (2011) also report that children with severe communication disabilities that rate their self-efficacy higher also report higher participation in school activities. Autonomy is also another required concept related to control perceptions and is the primary causal agent in one's live relating to self-determination (Wehmeyer & Schwartz, 1997).

For a person to perceive full participation they need to feel motivated thus a measure of involvement should also focus on the subjective experiences of self in relation to the activity. The prerequisites of an activity, e.g. whether the activity is self-selected/chosen or compulsory, are also factors related to the subjective experience of involvement rather than an expression for the subjective experience of participating in the activity. Therefore, whether an activity is self-chosen or not should not be strongly related to the subjective experience of involvement.

Attention is also has a significant influence and can be regarded as either a top-down process where it is active and controlled by the individual, or as a bottom-up process where it is a passive process being controlled by external stimuli. The focus in this thesis was on the subjective, and thus personal, experience of involvement, so attention was considered active and a top-down process.

In this thesis it is proposed that the subjective experience of involvement can be represented by the psychological constructs of involvement, control, motivation, and attention as experienced in the here and now moment. In addition, a positive emotional state is more frequently reported when having a subjective experience of involvement but is not a part of the experience itself. Whether an activity is self-chosen or not is related to participation, but this is a factor affecting participation rather than a part of the experience itself. School activities are structured and this will remove some of the self-chosen aspect, but not the sense of control over whether or not to do the activity.

CHAPTER 4

APPROACHES TO DISABILITY

Perspectives on theorizing childhood disability can be taken from general theories on disability. Participation is a central issue for those occupied with disability issues in childhood (Egilson & Traustadóttir, 2009) and occurs in models of disability both explicitly (WHO, 2007) and implicitly such as is seen in a number of the disability models outline in the following sections. Ways to theorize disability have traditionally been classified as either medical or social in their nature. Children with disabilities are also not a single or homogeneous group so require a variety of approaches. These will be outlined in this section along with child and childhood-specific aspects.

THE MEDICAL APPROACH TO DISABILITY

The need to classify people as disabled or non-disabled arose from the needs of health professionals and the welfare system (Söder, 2005); this,

historically, has led to a societal dependence on medical diagnosis labels which do not necessarily give an accurate description of needs such as is seen in education (Davis & Florian, 2004). The idea that the existence of a disability was caused by the body being deviant led to the conceptualizing of the medical model of disablement. However, evidence for the actual existence of this 'medical model' is scarce (Kelly & Field, 1994, p. 35, cited in; Shakespeare, 2006, p. 19) and its existence could merely be a component of the conceptualization of disability that some – the social-model proponents particularly – use to enhance their standpoint and arguments. What does exist however is the field of Medical Sociology. Carol Thomas (Thomas, 2004), coming from Great Britain, argues that while there is a distinct division between the fields of medical sociology and disability studies/the social model of disability, there is also common ground. She highlights that disability studies forms its theoretical basis on the idea that disability comes from social oppression, inequality, and exclusion (Thomas, 2004, p. 570):

"Disability is a form of social oppression on a par with other forms of oppression in our society associated with gender, race, class, and sexuality." (Thomas, 2004, p. 581).

In comparison, medical sociology forms its theoretical base for disability on the premise that illness and impairment cause suffering and social disadvantage and so disability occurs. Thomas concludes her review by highlighting the need to revive a 'social rational understanding of disability' (Thomas, 2004, p. 581). This is an example of Gustavsson's (2004) relative interactionist perspective of disability and is similar to Tom Shakespeare's 'social theory of embodiment' (Shakespeare, 2004) and shares much in common with the Nordic Relational approach (see following section) also.

THE SOCIAL APPROACHES TO DISABILITY THEORY

A social approach to disability places the 'blame' or reason for disability on society, or, more specifically, on factors which are external to the individual and in its most extreme form rejects that the body has any inputting factors. Social approaches have their roots in de-institutionalization and normalization practices which have been seen across Europe and the United States of America, the minority-group model (also dominant in US disability politics), treating disability as a right-based issue, and the emancipation of persons with disabilities as equal members of society.

DISABILITY STUDIES/THE SOCIAL MODEL

Emerging in parallel with other social movements relating to gender and race equality during the 1950s and 1960s the most marked development of a social approach to disability emerged in both the United Kingdom and North America. While North American theorists and activists have taken a social approach to defining disability they have not gone as far as their UK colleagues in defining it as social oppression (Shakespeare, 2006). Oppression can be expanded further to include the concepts of recognition and re-distribution (Fraser & Honneth, 2003). Fraser (1999) describes a theory of re-distribution and recognition which leads to the removal of barriers and thus equal societal participation for oppressed groups. Recognition leads to cultural equality, which on a personal level equates to social status, and a removal of any degradation and lack of respect. Re-distribution needs to occur to alleviate socio-economic ine-qualities which can lead to exploitation and marginalization. Danermark and Gellerstedt (2004) have proposed that Fraser's theory of re-distribution and recognition can be linked to disability from a critical realist philosophical perspective (Williams, 1999, also makes this pro-

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posal but from the perspective of re-introducing the body to the strong social model). When linked to disability Fraser's theory of re-distribution and recognition can explain that there is still some way to go in terms of recognizing cultural equality; on a personal level this equates to social status and is seen in the effect that labelling (e.g. disability category 'intellectual disability') can have in terms of personal identify – e.g. individuals with the label resist its application because they are seen or perceived to describe their personal competencies (Björnsdóttir, 2010). Similarly, the removal of any degradation and lack of respect is still ongoing as a study with teenagers with ADHD (Hallberg, Klingberg, Setsaa, & Möller, 2010) showed that the teenagers were likely to want to conceal parts of themselves (e.g. medical treatment), and were especially concerned about being different and wanting to be like everyone else. Re-distribution needs to occur to alleviate these socio-economic inequalities which can lead to exploitation and marginalization.

From a theoretical perspective two generations of the British/American 'social model' can be described: the first stressing calls for changes in societal structures and the second replacing this materialistic perspective with a more constructionist-based theory (Gustavsson, 2004). There have been calls to abandon the circular reasoning of the first generation of social model, where an assumption about what disability and impairment are is made (Shakespeare, 2006), and to bring the body back in with the alternative philosophical standpoint of critical realism (Williams, 1999). There is also the point that the strong UK social model is not unique and is only one of a number of social-contextual models (Gustavsson, 2004). These various social models for disability can collectively be called a social theory which is starting to emerge from the field and can be seen in reviews of the literature (Gustavsson, 2004; Gustavsson & Söder, 1990), and from theoretical papers making this

argument, such as Tom Shakespeare's 'social theory of embodiment' (Shakespeare, 2004).

THE NORDIC RELATIONAL APPROACH

In the Nordic countries there also emerged a social approach to disability, often referred to as the 'Nordic relational approach'. It should be noted that this is not an alternative to the social model, but another type of social model (Shakespeare, 2004). The Nordic relational approach represents disability as situational and takes an interactive understanding of the environment (Gustavsson, 2004; Tøssebro, 2004) with the relative situational aspects being seen when there is a discrepancy between individual functioning and societal or situational demands. The Nordic relational approach has its roots in the political and philosophical ideals which underpin the key values of the Nordic countries' welfare states; these are values of equality of all, full participation in society, and citizenship. De-institutionalization and normalization were also predominant in the Nordic countries as pre-cursors to today's Nordic relational approach (Gustavsson, Tøssebro, & Traustadóttir, 2005) and have contributed to the evolution of the Nordic relational approach to disability seen today and described above. Research also tends to be carried out by non-disabled researchers which means there is not the close connection between disability research and disability activism as is seen in British and North American disability studies (Shakespeare, 2006).

THE LIFE COURSE APPROACH

The recent development of a life course approach to disability (Priestley, 2003) allows society to organize the relationship between disability and the life course. It addresses how life course transitions are organized at the collective level and about the generational significance of disability-related issues as they affect people of difference ages. The specific ad-

justing of factors for age makes this approach of particular interest to anyone working with children as the approach involves investigating how disabled lives are understood, organized, and governed within societies, from birth until death.

THE ICF'S APPROACH TO DISABILITY

It must be stressed that the WHO's ICF does not offer any theory in its own right, but merely a framework and language for health and health-related states around which existing theoretical approaches can be applied.
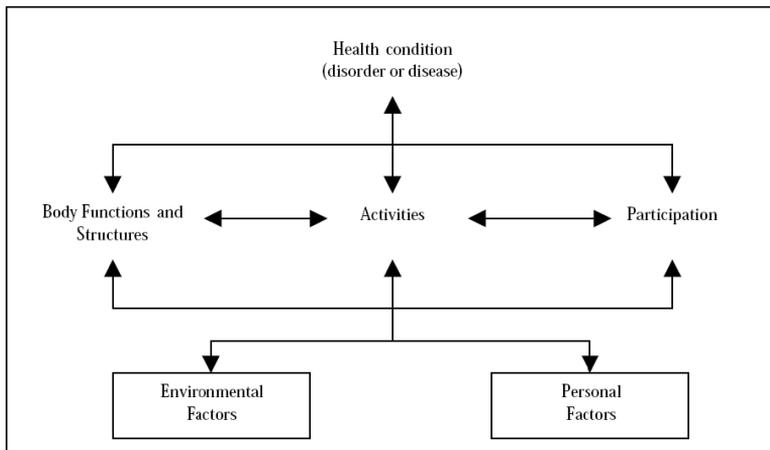
Figure 3. Interaction between the components of ICF (WHO, 2007, p. 17)

There are, however, some guidelines as to how language and concepts should be used with the ICF and the manual defines disability as "an umbrella term for impairments, activity limitations or participation restrictions." (WHO, 2007, p. 3). This presents disability as a multi-dimensional construct which is influenced by all of the components shown in figure three above; this approach can be compared quite close-

ly with the Nordic Relational approach which similarly takes an interactive understanding of disability as being related to a discrepancy between an individual's functioning and the surroundings. The ICF-CY, and the preceding ICF, also takes a human rights approach to disability by stating in its aims (WHO, 2007, p32) that it is intended to be a suitable framework in which to implement the mandate of international human rights legislation, such as the UN convention on the Rights of Persons with Disabilities (United Nations, 2006) and the UN convention of the Rights of the Child (United Nations, 1989).

A BALANCED RELATIONAL APPROACH: RELATIVE INTERACTIONISM

Placing the blame solely on society for constructing disability or only on biology for creating an impairment does not give a balanced or holistic approach to defining and conceptualizing disability; aspects of biology, psychology, and functioning in the environment (which includes social aspects) and how the environment itself inhibits or promotes functioning should all be considered with equal merit. Taking this holistic approach is beneficial as it allows these competing factions to interact without conflicting or predominating. In terms of disability identity, we should also take a universal stand point and start with the assumption that disability is a normal occurrence and experience of living, can occur to anyone at any point in their life, and is not necessarily comparable to an illness. Disability itself can thus be defined as a functional limitation or hindrance imposed by biological, psychological, social, or environmental influencing factors, which has a restrictive influence on participating in activities; none of this should be considered special or unique nor give the individual themselves undue (positive or negative) attention, privileges, or status.

Disability is also a "necessarily laminated system" (Bhaskar & Daner-mark, 2006, p. 278), by which it is meant that it is a multi-dimensional and multi-modal system which has many integrated influencing compo-nents. The ICF/ICF-CY presents us with one possible way of gaining such a multi-perspective viewpoint. However, to be completely bound by either the ICF/ICF-CY or one of the social models is too restrictive for the all-encompassing nature of disability and will also create divi-sions and dichotomies which tend to do more harm than good to the field. For these reasons the case is presented for Gustavsson's (2004) critical interpretation and, as a further development, Bhaskar and Danermark's critical realism (Bhaskar & Danermark, 2006). Both will offer an interesting relative interactionist perspective without being too restrictive as theories for disability research.

THEORETICAL APPROACHES TO DISABILITY AND PARTICIPATION

By taking the polar standpoint of either a medical/individual approach to disability or to completely reject it in favour of a purely social ap-proach is not necessarily helpful as both approaches neglect the person with a disability's standpoint – specifically their psychological state. It has been suggested that the consequences of disability rather than the medical diagnosis or classification label produce a more accurate de-scription of a person's functioning (Stein, 2006). These consequences are invariably linked to society as it is part of the environment which will promote or impede a person's functioning.

Criticism of the social model for being too reductionist is presented in a post-modernist perspective by Shakespeare and Watson (2001). They call for the model to be rejected and replaced as in its current 'strong' form it has outlived its usefulness. They are particularly critical of the model's separation of the disability and impairment constructs and its

assertion that people with impairments are disabled by society and not their impairment. Shakespeare also critiques the social model in other texts (Shakespeare, 2005, 2006) arguing that by separating impairment this neglects the suffering that a person with an impairment has. Similarly strong criticism for the strong social model has come from medical sociologists, such as Simon Williams (1999) who calls for a critical realist perspective to be taken because he believes that excluding the body leads to a form of essentialism (Williams, 1999, p. 803) similar to that seen in feminism (Spelman, 1988) and in post modernism due to its ethereal belief in the discursive body (Williams, 1999).

Creating a dichotomy naturally gives us two opposing forces. In the case of the social and medical models this has led to divisions with followers mainly seeming to exist on the social side because actual evidence of a strong base of support for a 'medical model' is virtually non-existent. One unfortunate consequence of this division created by some proponents of the social approach is that it created and supported other dichotomies such as a division between the concepts of 'impairment' and 'disability', which neglects the reciprocal relationship between the two concepts and that impairment can sometimes be socially created – e.g. by poverty, malnutrition, war etc. (Shakespeare, 2006). A strong division between impairment and disability could even reinforce thinking on the lines of 'disabled' versus 'non-disabled' people. This last division is a dangerous one as it threatens the stability of our very society if we try to separate groups by creating labels – examples from history relating to race and ethnicity must surely provide strong evidence for not letting this happen with disability.

A strong driving force behind the social model of disability is a belief that one of its purposes is to elevate the awareness of the social oppression suffered by disabled people (Abberley, 1987; Oliver, 1996) with strong proponents (Barnes, 1996) and opponents (Bury, 1996) to this

political agenda. Early work in the field of disability studies drew strong parallels with the fields of racism and sexism (Abberley, 1987) as these are both believed to be socially constructed phenomena. Comparing these fields more recently has established a few discrepancies and there have been calls to review these connections (Shakespeare, 2004).

Historically, the sociological discussions about civil rights movements are related to availability, accessibility and affordability of opportunities and support for persons with disabilities (Bickenbach, Chatterji, Badley, & Üstün, 1999) with regulation of this component of participation being done by laws and regulations. Participation is therefore one interesting way to approach disability and ways of practically doing this are discussed in the following sections.

CHAPTER 5

IMPORTANT ASPECTS OF OPERATIONALIZING PARTICIPATION

THE ICF-CY AS A FRAMEWORK TO OPERATIONALIZE AND MEASURE PARTICIPATION OF CHILDREN WITH DISABILITIES

As a person-based social model, as opposed to a deficit-based medical model, the International Classification of Functioning, Disability and Health (WHO, 2001), referred to as the ICF, and the Children and Youth version (WHO, 2007), referred to as the ICF-CY, can be described as bio-psycho-social in nature. The ICF/ICF-CY was devised by the World Health Organization (WHO) as a universal standardized framework to describe health and health-related states such as disability and is a member of the WHO family of international classifications. The ICF/ICF-CY takes the assumption that disability is a normal occurrence

and experience of living and not necessarily comparable to an illness. This is in contrast with the previous WHO International Classification of Impairment, Disabilities, and Handicap (WHO, 1980, the ICIDH, published in 1980 for trail purposes but not fully adopted), which put an emphasis on disability and deficits. The Child and Youth version, the ICF-CY (WHO, 2007), was further produced to address problems surrounding the considerable changes in development, behaviour and contexts for functioning which take place in children. Conceptually both the ICF and the ICF-CY use the same model to construct their frameworks and so can conceptually be considered the same with differences only existing in the number of codes. The framework uses codes to describe functioning and there are four main areas (called domains) of classification: activities and participation, environmental and contextual factors, body functions, and body structures. Within each of these four areas sub-chapters are hierarchically arranged which logically correspond horizontally across body functions, body structures, and activities and participation. For example, each of the third sub-chapters are labelled b3 Voice and speech functions in body functions, s3 Structures involved in voice and speech in body structures, and d3 Communication in activities and participation.

Within the ICF/ICF-CY model (WHO, 2007, p. 17, fig. 1 and my fig. 3) activity and participation are conceived as two separate entities yet when operationalized within the ICF/ICF-CY coding framework they are combined to form one of the main domains. This current situation produces ambiguity in exactly how participation is defined and operationalized within the ICF-CY (and ICF) classification. The ICF/ICF-CY's bio-psycho-social approach to classify aspects of functioning and disability and is derived from both a traditional "medical model" of human functioning, where bodily impairment is the focus, and a "social model" where society's construction of difficulties create participation re-

strictions. The two constructs are bridged by activity as a unifier. The participation component within the ICF/ICF-CY represents the social model's contribution which emphasizes that participation restrictions are socially constructed phenomena, and focuses on the availability and access to everyday activities with participation being described as equal to frequency of attending the same situations as others or given opportunities to perform the same activities as others. As outlined previously, participating in an activity can be seen from two perspectives: the individual, and the society (this distinction is not made in the ICF/ICF-CY framework where the constructs of 'activity' (individual) and 'participation' (society) are operationalized as one domain). The lack of a bi-dimensional approach in the ICF-CY's representation of participation makes it problematic to use as it currently stands, therefore some changes or modifications are required in order to effectively operationalize participation; this will be discussed further in the discussion section of this thesis.

As outline previously, when measuring participation it is important to look at a person's involvement in their environment by considering if you are interested in frequency of attendance or intensity of engagement in a life situation and also the context this occurs in. The theoretical standpoint of looking at participation from the frequency and intensity dimensions is where this thesis diverges from the ICF/ICF-CY's interpretation of participation. This is how this work intends to advance the participation concept with a view to improving the involvement of children with disabilities in school-based life situations.

SOCIAL CAPITAL

THE ROLE OF SOCIAL CAPITAL FOR THE INCLUSION OF PERSONS WITH DISABILITIES

Social capital – consisting of formal and informal social networks, trust and civic norms (Kaasa & Parts, 2008) – is a notion which enters in the discussion of social determinants of health within the World Health Organization (WHO) proposed comprehensive national health equity surveillance framework (CSDH, 2008). The combination of community participation and the social cohesion it causes has been considered as the definition of social capital (Putnam, 2001), and participation is considered as a component of structural social capital – in terms of social formal and informal networks – while cohesion is considered as a component of cognitive social capital – in terms of psychosocial interactions between persons (Berry, 2008). These two aspects of social capital (structural and cognitive) allow the construct to be represented by social capital indicators as proposed by Kaasa and Parts (2008). Structural social capital consists of both formal (e.g. belonging to a religion) and informal networks (e.g. meeting socially with friends), and cognitive social capital can be represented by general and institutional trust (e.g. trusting people and trusting the police) and norms (e.g. perceptions of benefits entitlement).

Similarly, it is known that inclusion – the integration, valuing, and involvement of all in society – is a social determinant of health (CSDH, 2008). Although ongoing debate on the conceptual context of the terms of social capital and social exclusion exists (Daly & Silver, 2008), it is evident that they are both widely used in human services and social policies for people with disabilities, and is suggested that promoting social capital as an aim of human service can be a long-term solution to the isolation that people with disabilities face (Bates & Davis, 2004). Since

social capital is flourishing in all-inclusive environments, there are a number of implications that persons with disabilities and their families encounter (such as social isolation, rejection, bullying and invisible voluntary contributions to society by persons with disabilities) which have to be considered towards building, bridging and bonding social capital (Chenoweth & Stehlik, 2004). In addition, the approaches of policy reviews/reports to inclusive education demonstrate various differences between countries.

The theorertical structuring of social capital – from the two dimensions of structural and cognitive – is also thought to match current theorising and operationalizing of participation which is represented from two dimensions – the frequency of attending and the intensity of the involvement experience.

CHAPTER 6

THE SETTING

The environment is integral to participating in an activity as it provides resources, in both positive (facilitator) and negative (barrier) form, and can so be described as the 'scene-setter' (Badley, 2008). In this thesis education is used as a context to represent childhood disability. The rationale is that school is a major part of a child's life and so can be used to accurately represent the whole of the lived experience of the child. A central aspect to the school setting and its relation to the environment acting as facilitator/barrier is inclusion.

The influence of the environmental setting can also be described using Bronfenbrenner's Ecological systems theory (Bronfenbrenner, 1979) which describes four nested and inter-connected environmental systems: Mesosystem, Exosystem, Macrosystem, and Chronosystem. The Mesosystem describes microsystems and their inter-connections, examples include a child's relation to school, family, and peers. Exosystems

refer to the connection between a social setting in which the person is not active and the person's immediate environment, an example is how a parent's job influences a child. Macrosystems describe the social and cultural context and can change over time. Chronosystems features the dimension of time and describes how environmental events change, evolve, and develop.

INCLUSION

In the last couple of decades, there have been several influential international steering documents which have shape the direction in which special education, and thus inclusion, has gone. These include the Salamanca statement (UNESCO, 1994), the Dakar framework (UNESCO, 2000), and more recently, the United Nations Convention on the Rights of Persons with Disabilities (UNCRPWD, United Nations, 2006). These documents have greatly influenced national policies and approaches to the integration and inclusion of children with disabilities in regular or 'mainstream' schooling as all of them call for complete integration solutions where all children are educated in the same school under the same education system – the notable exception to this is the UNCRPWD which has some notable exceptions for the deaf and blind communities. Globally, this has given rise to a diverse range of inclusive approaches to delivering education, for example: the social democratic approach of Northern Europe (particularly in the Nordic countries), civil rights in North America (and to some extent the United Kingdom), and communist local government in Italy. Specific examples can been seen with countries now promoting high levels of integration through inclusive education policies – e.g. Sweden (Göransson & Nilholm, 2009) with its 'school for all' ideal, Scotland (Tisdall & Riddell, 2006) with its extensive support for pupils 'additional support needs', and Italy with its 'integrazione' agenda (D'Alessio, 2008) which dates back to 1979.

Thomas and Loxley (2007) suggest that special education is constructed from a mixture of Piagetian, psychoanalytic, psychometric and behavioural theoretical models. Recent thinking from social justice with new ideas like David Marquand's 'moral activism' (Marquand, 1996) and Nancy Fraser's 'recognition' (Fraser, 1999), as has been seen in the disability domain also, provide the background to the case for inclusion. These new ideas have led to inclusion becoming more than just an ideal with good intentions and have been aided by a general move away from the localizing of children's difficulties in the children themselves and taken as more of a collective responsibility. Needs have become rights in the domain of special or specific pedagogy and this led to an initial ideal about inclusion rather than practical solutions, but has more recently gained ground base on social justice and human rights as a society which is striving to be inclusive requires an education system to be active in this manner also.

Three specific perspectives on special education are outlined by Nilholm (2007), these are: the Compensation perspective, the Critical perspective, and the Dilemma perspective. These have been extensively researched and discussed in the academic literature and only a brief overview is given here. The compensation perspective simultaneously compensates the individual and places the problem and its cause in the child with medical and psychological groups and diagnoses are used categorically to provide support. The critical perspective is democracy-focused and moves the problem from within the child to become the responsibility of the school or education system. It came as a direct response to the compensation perspective (Skrtic, 1991) with medical and psychological diagnoses being rejected in favour of more subjective descriptors of problems. The dilemma perspective takes a critique of both of the previous perspectives. Dyson and Millward (Clark, Dyson, & Millward, 1998; Dyson & Millward, 2000) specifically critique the critical perspec-

tive based on the claim that it solves the dilemma that is presented when the modern educational system has to deal with a wide range of student diversity. The critical perspective would potentially remove special education as an entity (as it currently exists), but this would present new and challenging dilemmas relating to delivering specialized support. The dilemma perspective also criticizes the compensatory perspective in particular for the risk that larger groups of children would be defined as deviant and that this could consequently lead to children being unilaterally described as inadequate (Nilholm, 2007). The dilemma perspective has the potential to give research more political scope, and, in terms of school and teaching, a school's particular way of delivering support positively corresponds with the students' experiences.

CHAPTER 7

THE EMPIRICAL STUDIES

RELATIONSHIPS BETWEEN STUDIES

The five papers presented in this thesis form four distinct studies which have an over-arching participation framework which becomes progressively more focused. The first paper provides a foundation in the literature. Paper two is a policy-review exercise which describes how participation or participation-related concepts are expressed in the current inclusive-education legislative situation. The third and fourth papers represent one study with two dependent parts represented by the papers. The third paper theoretically explores and models how societal influences affect participation by shaping policy through social capital values. Paper four then practically implements the proposals from paper three with a cross-national European study. The fifth paper then expands on the conceptualization of the intensity and frequency of participation of persons with disabilities at school by focusing on the individual level

and whether a measure for involvement can be constructed. The different ecological levels and sociological stratification covered by the studies are outlined in table 1 along with the main participation perspective (frequency or intensity) present in the aim and the results. As definitions the international level covers aspects related to global phenomenon, and the national level identifies items which influence countries; both can be connected to the macro-level. The regional level describes how national actions are carried out in a devolved manner, and the local level involves the carrying out of actions which directly affect people; both can be connected with the meso-level. The individual level represents the people themselves and so corresponds with the micro-level.

Table 1. Connecting the different ecological levels and participation in the five studies

Paper	Sociological stratification/Bronfenbrenner's ecological level	Main participation dimension represented (frequency or intensity)	
		Aim/theory	Results
I (A review study)	International/macro National/macro Regional/meso Local/meso Individual/micro	Both	Both
II (A vertical study)	National/macro Regional/meso Local/meso	Both	Frequency
III (Theory)	International/macro	Both	Not applicable
IV (A cross-national study)	International/macro National/macro	Both	Frequency
V (An exploratory study)	Individual/micro	Intensity	Intensity

PAPER I: PARTICIPATION AND ENVIRONMENTAL ASPECTS IN EDUCATION AND THE ICF AND THE ICF-CY - FINDINGS FROM A SYSTEMATIC LITERATURE REVIEW

AIM

This paper presents findings from a systematic review of the literature related to participation and the ICF/ICF-CY in educational research. The objectives were to analyse how and investigate the application of participation in educational research. Specifically, how participation is related to the environmental dimensions availability, accessibility, affordability, accommodability and acceptability.

STUDY TYPE

A systematic literature review using database keyword searches and refinement protocols using inclusion and exclusion criteria at abstract, full-text and extraction.

ANALYTICAL METHOD

Data were collected using database keyword searches, keywords were chosen based on the focus of the study and current debate and were refined to include widely used variations and abbreviations. Different combinations were trialled to establish which returned a viable number of studies. The search results were exported and sorted using inclusion and exclusion criteria on two levels: Abstract and full-text level. The protocols aimed to ensure a standardized qualitative and semi-quantitative content analysis of the documents. In addition to the abstract and full-text level protocols, another protocol was designed and applied to review and extract the content of the selected works; this protocol focused on the research aims of this paper and also recorded

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quality aspects such as relevance, appropriateness and trustworthiness based on critical review methods (Auperin, Pignon, Poynard, 1997; Letts, Wilkins, Law, Stewart, Bosch, & Westmorland, 2007).

Literature reviews are intended to synthesize the understanding of a topic, demonstrate rigorous research dedication, and justify future research (Hart, 2006). The completed doctoral thesis summarizes, analyses, criticizes, and builds on the literature review with a view to facilitating further academic discussion (Okoli & Schabram, 2010); using a systematic approach ensures that a broad selection of the literature is efficiently covered in a concise and consistent manner which provides a strong foundation in the literature for the whole thesis.

The overall rigour of the systematic literature review study itself was ensured by reflecting on works which critically review systematic literature reviews. From a quality perspective, and coming from the health-sciences field where a large number of systematic literature reviews are found, Schlosser, Wendt, and Sigafoos (2007) provide a useful reflection on quality guidelines and a critical appraisal for systematic literature reviews. Their quality-indicators include the use of a protocol, its validity and rigour, the presence and relevance research questions, the sources used, and any biases in the source-selection, geographical and cultural constraints. In terms of data handling, a reliable selection of studies and a log of rejected studies along with clear descriptions of how data was extracted and coded from the original studies in conjunction with a quality assessment of these studies should be present. Other restrictions include the language included, study-design constraints, and the populations being considered. As other studies have also highlighted (Moher, Tetzlaff, Tricco, Sampson, & Altman, 2007) Schlosser et al. (2007) comment that the quality of many reviews varies, and by reviewing the reviews they hope to provide a set of quality-indicators to guide the researcher. The systematic review used protocols to guide the investiga-

tors on the inclusion and exclusion criteria and it was also found that within the results gathered, as a good indication of their appropriateness, there were references to all of the categories which had been previously defined.

An alternative to a systematic literature review would be a more narrative-based literature review. Although these can be structured by using clear aims and research questions, a logical flow of ideas, and presented with current and relevant references to give an unbiased overview of previous research, they require considerable more resources to cover the same scope of literature that can be accomplished using a systematic approach.

Paper I's main aim was to provide an overview of how participation is currently situated in the education field. The study specifically focused on how participation was described theoretically and used practically in educational research. A literature review was chosen as the best suitable means to address this and a systematic approach was used to sort and analyse the data generated by the search.

MAIN RESULTS

Four hundred and twenty-one initial works were found. Twenty-three met the inclusion criteria. Availability and accommodations are the most investigated dimensions. Operationalization of participation is not always consistent with definitions used.

IMPLICATIONS

The main conclusion from this paper is that research is developing a holistic approach to investigating participation as, although all papers reference at least one environmental dimension, only four of the 11 empirical works reviewed present a fully balanced approach when theoriz-

ing and operationalizing participation; hopefully this balanced approach will continue and influence educational policy and school practice.

PAPER II: HOW ARE CONDITIONS FOR PARTICIPATION EXPRESSED IN EDUCATION POLICY DOCUMENTS? A REVIEW OF DOCUMENTS IN SCOTLAND AND SWEDEN

AIM

This study approaches inclusive schools by looking at how conditions for participation are expressed for pupils with additional support needs in education policy documents in Sweden and Scotland. By using five dimensions of the environment – availability, accessibility, affordability, accommodability and acceptability – expressions of conditions for participation are explored in 41 documents. This is done in a vertical manner by analysing national laws, regional policy documents, and local-level documents that directly influence classroom practices.

STUDY TYPE AND DESIGN

A policy review study that investigated policy documents on national, regional, and local levels by comparing two cases in Scotland and Sweden. Two case studies were built in each country to provide a representative overview of policy documents that refer to participation. Scottish documents were all reviewed in English and Swedish documents in Swedish with some national documents reviewed in English. Documents had to be current and in use, describe educational rights, and participation or the child's involvement. Example documents included, national policy/law, local interpretations of national policies, classroom-practice guidelines, etc. Documents were analysed using a deductive content analysis approach using a protocol based on the five environ-

mental dimensions is used to extract information and identify meaning units. In the meaning units, meaningful concepts are identified and linked to International Classification of Functioning, Disability and Health: Child and Youth (ICF-CY) categories; these are used as reference points. A vertical approach with a small number of select cases was chosen for this study to give in-depth information at various levels of policy (e.g. national, regional, and local).

Paper II investigated from a macro to micro level how participation is expressed. In order to achieve this multi-level approach a case-study approach was used to make data handling manageable for the small number of researchers involved in this study. Document analysis of educational policy documents was used as the data collection method; this adequately addressed the multi-level nature of the study and participation based on the frequency of attending and intensity of involvement model was used as the theoretical framework.

ANALYTICAL METHOD

Using a deductive approach, a form of manifest content analysis (Krippendorff, 2004) was used to investigate the correspondence of expressions of participation conditions in education policy documents; this allowed the documents' text to be unitized and reduced in a systematic way using a prescribed protocol to minimize interpretation of the texts being reviewed. Other methods exist to provide an interpretive approach to analyzing texts, such as the philosophical hermeneutics promoted by Martin Heidegger, however these tend to be more concerned with the existential understanding of communication rather than the interpretation aspects of the text and so were not chosen to be used. Manifest content analysis was principally chosen to avoid differing interpretation of the texts by the small number of researchers involved

and to ensure stability, reproducibility, and accuracy of results (Krippendorff, 2004).

MAIN RESULTS

It is suggested, from the documents analysed, that conditions for participation are easy to express as available, accessible opportunities, or affordability issues, but not as involvement experiences linked to accommodations made and acceptability issues within a context. Documents in Scotland and Sweden also have different foci in terms of conditions for participation.

IMPLICATIONS

The ICF-CY has provided a useful linking mechanism to show that conditions for participation can be expressed on a spectrum in terms of availability, accessibility, accommodability and acceptability. These four concepts would appear to fit in a spectrum from frequency of attending to intensity of involvement (see figure 4 in discussion) and merit further investigation of the intensity of participation.

PAPER III: USING SOCIAL CAPITAL TO CONSTRUCT A CONCEPTUAL INTERNATIONAL CLASSIFICATION OF FUNCTIONING, DISABILITY, AND HEALTH CHILDREN AND YOUTH VERSION-BASED FRAMEWORK FOR STRONGER INCLUSIVE EDUCATION POLICIES IN EUROPE

AIM

This theoretical paper outlines a proposal to represent inclusive education with social inclusion; therefore, social capital can be linked to inclusive education policy and practice. This association is explored in this

article, and a practical measure is proposed. Specifically, the World Health Organization's International Classification of Functioning, Disability and Health Children and Youth Version (ICF-CY) is proposed as the link between social capital and inclusive education. By mapping participation and trust indicators of social capital to the ICF-CY and by using the Matrix to Analyse Functioning in Education Systems (MAFES) to analyze the functioning of inclusive education policies and systems, a measure for stronger inclusive education policies is proposed. Such a tool can be used for policy planning and monitoring to ensure better inclusive education environments.

TYPE OF STUDY

The third paper in this thesis is an entirely theoretical work that presents the synthesis of combining the ICF-CY and social capital as a way to represent and measure inclusive education. The paper is the theoretical introduction to paper IV – which also brings in the bi-dimensional approach to participation – which attempts to practically put the ideas into operation. This theoretical paper was necessary as, to date, nobody has attempted to combine the ICF/ICF-CY with the concept of social capital.

ANALYTICAL METHOD

Paper III is a conceptual paper and provides an opportunity to theorize on and propose a new model which connects social capital and inclusive education and so provide a macro-level representation of participation.

IMPLICATIONS

A model to combine social capital and inclusive education by using the ICF-CY as a bridge is proposed. By combining enhanced social capital

linked to stronger inclusive education policies with the ICF-CY, potential outcomes are better health and well-being for all.

PAPER IV: EVALUATING SOCIAL CAPITAL INDICATORS AND NATIONAL INCLUSIVE EDUCATION POLICIES IN SIX EUROPEAN COUNTRIES USING THE ICF-CY

AIM

This paper uses a cross-country comparative analysis for six European countries – Germany, Greece, Romania, Spain, Sweden, and the United Kingdom – based on social capital indicators from the European Social Survey (Round 4 – 2008, ESS), along with comparison on the level of inclusive education policies within these countries in specific. The results provided evidence for the degree of correlation between the level of social capital and the content of inclusive education policies within countries of different European regions for developing more inclusive education policies through social capital building.

TYPE OF STUDY

Paper IV is the practical implementation of the model proposed in paper III and aimed to provide a practical international measure of participation through using social capital within inclusive education environments. To achieve this two main methods to gather data were used: surveying, and policy review. The study took place entirely at the macro level with data coming from a large trans-European survey of social capital values and a review of national inclusive education policy documents in six European countries. By keeping data source at the same ecological levels and ensuring similar data were gather in each country, these data sources ensured that valid international comparisons could be made.

Both the document review and an analysis of the social capital indicators used in the survey used a theoretical interpretation of participation based on the frequency of attending and intensity of involvement model.

ANALYTICAL METHOD

This paper used a form of manifest content analysis (Krippendorff, 2004) to investigate the correspondence of expressions of participation conditions in education policy documents from six countries (Germany, Greece, Romania, Spain, Sweden, and the United Kingdom). This approach reduced documents' text and unitized it in a systematic way using a prescribed protocol to reduce interpretation of the texts being reviewed. Alternatives have already been discussed in the analytical method section of paper II so will not be covered here. The document analysis of inclusive education policies for each country used a protocol based on the five environmental dimensions to extract information and identify meaning units. In the meaning units, meaningful concepts are identified and linked to International Classification of Functioning, Disability and Health: Child and Youth (ICF-CY) categories. These were used as reference points. A horizontal approach was used because of the cross-national comparative nature of the study. In this study six European countries (Germany, Greece, Romania, Spain, Sweden, and the United Kingdom) were compared taking one or two national policy documents which pertained to inclusive education from each country.

The social capital indicators selected from the ESS were also analysed for their content in a similar manner to the document analysis by using a deductive content analysis based on the five environmental dimensions and the ICF-CY to categorize the indicators.

The analysis of social capital data was based on variables selected from the ESS to represent the following social capital indicators: formal networks, informal networks, general trust, institutional trust, and norms. A cross-country comparative analysis of point-by-point was performed. Contingency coefficient was applied on cross-tabulation analyses for all social capital indicators apart from the social capital indicators on general and institutional trust for which ANOVA analysis was performed. Design weight was applied to all types of data analyses according to the ESS user guides for cross-country comparison of the ESS data. The statistical significance of differences (Pearson's Contingency Coefficient) was set at a p-value ≤ .05.

MAIN RESULTS

Regional patterns based on the level of social capital can be discerned with three distinct groups emerging. The first is a Southern-Eastern European regional group represented by Greece and Romania; this group reported high levels of religious membership, low levels of meeting socially, and low levels of trust. The second group is a Southern-Western group which contained Spain, Germany, and the United Kingdom; this group exhibited medium levels of religious practice, medium to high levels of meeting socially, and medium levels of trust. Sweden formed the third group on its own and showed low levels of religious membership, high levels of social meeting, and high levels of trust.

Great cross-country differences were found in the distribution of the five environmental dimensions within inclusive education policies and no distinct pattern emerged among countries. However, the most similar results appear to be the results for Sweden and United Kingdom in particular on availability and accommodability dimensions, but with variations in the other dimensions.

IMPLICATIONS

The results indicate that the ICF-CY is a useful tool for measuring both social capital and inclusive education policies, and although no connections could be drawn between social capital and inclusive education policy, the ICF-CY provided a consistent and common language for describing health and its related topics.

PAPER V: 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

AIM

Participation can be defined as involvement in a life situation and includes two dimensions; doing the activity and the experience of being involved. The World Health Organization's International Classification of Functioning, Disability, and Health (the ICF) only measures doing using the capacity and performance qualifiers, and a dimension measuring the experience is needed; a third qualifier. The present study uses the hypothesis that the experienced involvement of pupils in school activities was higher when thinking and doing coincided to construct and index of the subjective experience of involvement.

TYPE OF STUDY AND DESIGN

Paper V investigated the frequency of attending and intensity of involvement approach to participation on the micro level by gathering data from individual school children. The study investigated its hypothesis by comparing self-reported experience of involvement of both pupils with and without an additional support need (including children with

disabilities). The study specifically investigated the intensity of participation component of the approach and did this by analysing the involvement in school activities of school-aged children with disabilities in an educational setting within the ICF-CY framework. Data about what children were thinking or doing during activities were gathered from self-reporting questionnaires from 22 children with and 22 without additional needs in inclusive classrooms. A specific aim is to construct a measure of the subjective experience of involvement and the study was carried out on the micro-level in order to produce valid evidence for the involvement component of the frequency-intensity participation model.

ANALYTICAL METHOD

Experience sampling method (Csikszentmihalyi & Larson, 1987, ESM) was used in paper V and is based on students' ratings of their subjective experiences of involvement and their activity in school when a pager signals. ESM is one means to understand contextualized behaviour and refers to a method of collecting data in which participants respond to repeated assessment at random moments over a course of time in their natural setting; this gathers data from participants themselves, which increases agency and empowerment, and is a record of the experience in real time. In paper V several measure points per person were gathered to receive a picture of everyday activities, and patterns over a week. ESM gave an insight in to both the internal and the external landscape of the child and importantly reliably brings in the child's own perspective. When using this method the researcher can investigate various dimensions of a psychological phenomenon within the real-life setting, creating a high ecological validity (Napa Scollon, et al., 2003). Care needs to be taken in terms of how the researchers conduct themselves when carrying out the research along with awareness of power shifts during data collection; this will help researchers understand the subtle-

ties that the data presents (Koro-Ljungberg, Bussing, Williamson, & M'Cormack-Hale, 2008).

Very few alternatives exist which gather data in both real time and directly from participants themselves. Interviews or focus groups involve the participants but can not necessarily be held in real-time (unless the interview is part of the phenomenon being studies). Observation study (e.g. researcher observation/recording, ethnographic study) can be held in real-time but lack the direct input from the participants as the data are recorded by the researcher.

MAIN RESULTS

The results reveal that there is a strong relation between an index of the subjective experience of involvement and whether children were thinking and doing the same things.

IMPLICATIONS

The index of the subjective experience of involvement can be accurately constructed by using measures of concentration, control, involvement, and motivation. The subjective experience of involvement relates to feelings of acceptance and that adequate adaptations and accommodations have been made to include the child. Choice is also influential as knowledge about why an activity is undertaken affects involvement. Results show more structured situations lead to less choice and so lower levels of involvement and thus a stronger need to measure involvement to ensure effective engagement or inclusive practices. Evidence for a third qualifier representing the subjective experience of involvement is presented for the activities and participation component of the ICF-CY. Findings indicate that an increase in the subjective experience of involvement leads to improved psychological well-being and so a more fully functioning person; this enhances inclusion.

EPISTEMOLOGICAL FRAMEWORK

The thesis presented here is based on the ICF/ICF-CY framework because it is seeking to provide further validity for it in the education field. This means that it will naturally be influenced by the theoretical background of the ICF/ICF-CY, but not necessarily constrained by it. By virtue of looking at the interactions between the environment and the lived participation experience of children with disabilities in the school setting my work will take on a social dimension. This will necessitate the use of a social approach such as the relative interactionist perspective as proposed by Gustavsson (2004). This social dimension is intransitive, transfactual, and stratified (Williams, 1999) and so a critical realist approach is applicable also.

The presented thesis here has elected to conform to a critical realist perspective because, being part of the disability research field means that, by definition, it is inter-disciplinary (Bhaskar & Danermark, 2006) which suits this philosophical standpoint. The work is also being undertaken as part of two multi-disciplinary research team – one Sweden-based, the other European – which comprise of health professionals, teachers, pedagogical experts, philosophers, psychologists, physio- and occupational-therapists, to name a few, and is a good example of a laminate system similar to that described by Bhaskar and Danermark (2006) in relation to disability research.

When measuring participation it has been argued in this thesis that it is important to look at a person's involvement in their environment by considering both the frequency of attendance and the intensity of engagement in an activity. This can be done using self-reports or rating, observations, interviews, or questionnaires. However, all these methods require care to ensure you gather the data you are looking for. To measure frequency questions like: "Are you there?" (To establish if a person

can actually get there), "How often do you...?", "When and why do you do X?", will yield answers which relate to how often situations occur whereas questions like: "How engaged are you?", "How do you perceive this situation?" will give intensity-related answers. In order to provide effective interventions we need to know whether improving frequency or improving intensity will have the most influential effect on improving the overall participation of the child.

How can a person's subjective experience of involvement be operationalized? The subjective experience of involvement and motivation are probably related, thus for a person to perceive full participation they need to feel motivated. Motivation is felt in the moment and is therefore relevant when subjective experience of involvement is investigated. Flow is a subjective psychological state that occurs when one is totally involved in an activity (Seligman & Csikszentmihalyi, 2000). One aspect of participation will therefore be to have an interesting task. The flow experience is characterized by the ability to concentrate on the activity, a sense of control over one's actions, and a clear sense of purpose or goals (Emerson, 1998). Having flow in school activities is related to being motivated to learn and finding the chores interesting (Hunter & Csikszentmihalyi, 2003). One problem in school is that many students find school boring and uninspiring (Csikszentmihalyi, Rathunde, & Whalen, 1993). This can affect school achievements negatively and make students perceive lower levels of participation. By looking at flow (Hektner & Csikszentmihalyi, 2003), and using the method experience sampling method (ESM) to capture it (Csikszentmihalyi & Larson, 1987), an understanding of contextualized behaviour can be achieved. ESM captures experiential data and refers to a method of collecting data in which participants respond to repeated assessment at random moments over a course of time in their natural setting. When using this method the researcher can investigate various dimensions of a psycho-

logical phenomenon within the real-life setting, creating a high ecological validity (Napa Scollon, Kim-Prieto, & Diener, 2003).

ETHICAL CONSIDERATIONS/CONFLICT OF INTEREST

Paper V uses data that have already been gathered and come from highly credible sources which have previously passed their methods through ethical approval systems; this is a broad and potentially difficult assumption to make. However, given that data will have been de-personalized and will be handled following national Swedish research guidelines to ensure integrity and confidentiality there will not be any problems with using it. Use of the data also falls into the same overarching aims of the original studies which have already gained their ethical approval.

Paper IV uses data from the European Social Survey which subscribes to the Declaration on Ethics of the International Statistical Institute (ISI, http://www.cbs.nl/isi/ethics.htm) and required all contributing to adhere to this standard (in addition to any current code obligations they may have).

CHAPTER 8

DISCUSSION

The first paper indicates that research is developing a holistic approach to investigating participation and that this balanced approach will continue and influence educational policy and school practice. The second paper suggests that conditions for participation are easy to express as available, accessible opportunities, or affordability issues, but not as involvement experiences linked to accommodations made and acceptability issues within a context. Paper III theorizes, synthesizes, and proposes a model to link social capital to inclusive education policy and practice with the ICF-CY and the Martix to Analyse Functioning in Education Systems (MAFES, Hollenweger, 2010) as practical links. As the findings from paper I suggest that a more balanced approach to participation is becoming present in inclusive educational policy, the model proposed in paper III can be used for policy planning and monitoring to ensure stronger inclusive education policies and better health and well-

being for all. Paper IV leads on from paper III as the practical application of the proposed model to link social capital and inclusive education policies and while the results indicate that the ICF-CY is a useful tool for measuring both social capital and inclusive education policies by providing a consistent and common language for describing health and functioning, unfortunately no clear connections could be drawn between social capital and inclusive education policy which perhaps indicates that the balanced approach to participation found in paper I has not yet filtered through to policy. Similarly, when carrying out the investigation for paper IV, the easier operation of the environmental dimension availability, accessibility, and affordability, compared to accommodability and acceptability, correspond with the results from paper II which suggest that these three dimensions are easier to express in policy documents. Paper V presents evidence for a measure of the subjective experience of involvement which can be constructed from measures of involvement, control, motivation, and attention; this in turn gives evidence for a third qualifier representing the subjective experience of involvement is presented for the activities and participation component of the ICF-CY.

PARTICIPATION FROM TWO PERSPECTIVES

The two perspectives of participation outlined in this thesis can be connected to the various perspectives which exist in disability theorizing and research. In essence the sociological approach to participation corresponds with the social approach to disability, and the psychological approach is connected to the medical or individual approach to disability. Participation from two perspective is represented by the five environmental dimensions of availability, accessibility, affordability, accommodability, and acceptability. From the results in papers II and IV four of the concepts would appear to fit in a spectrum from frequency of attending to intensity of involvement (see Figure 4); affordability does

not as it does not appear to be especially aligned to either the social or psychological perspectives.
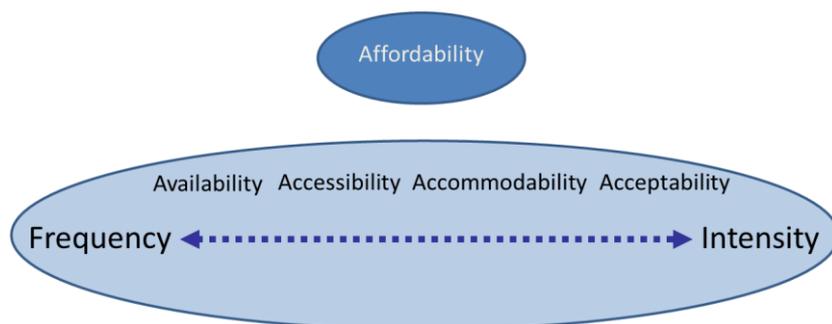
Figure 4. Frequency and intensity spectrum

SOCIOLOGICAL

Paper I shows that Availability and accommodations made are the most investigated dimensions. Operationalization of participation is not always consistent with definitions used, however most empirical studies applying the participation concept in educational research use a balanced approach in which both sociological and psychological aspects of the concept are used when measuring participation. The definitions of the concept seem partly to be independent of the manner in which the concept is operationalized.

Paper II shows that the ICF-CY has provided a useful linking mechanism to show that conditions for participation can be expressed on a spectrum in terms of availability, accessibility, accommodability and acceptability. The results show that the focus is on providing equal opportunities to participation rather than focusing on the subjective experience of participation; there is still a tendency for inclusive education policies to refer to the availability, accessibility, and affordability of opportunities to participate rather than the acceptability of the actual expe-

rience of being involved when representing participation. This is both evidence that these dimensions are easier to conceptualize and operationalize – as seen in papers II and IV – and the influence of a more social approach to disability which has been prevalent during the last three decades – see for example the social theory of disability (Gustavsson, 2004; Gustavsson & Söder, 1990) or the social theory of embodiment (Shakespeare, 2004).

PSYCHOLOGICAL

The findings from paper II suggest further investigation of the intensity component of participation as this was the least well represented and constructed aspect of this study. Similarly, when undertaking the investigative part of paper IV, specific difficulties were encountered during both the theoretical construction and practical operation of the intensity-related environmental dimensions of participation accommodability and acceptability. These two challenges both suggest that these parts of the frequency-intensity spectrum require further synthesis, particularly in relation to using them for textual analyses such as the policy reviews carried out in papers II and IV. The lack of a developed understanding of the psychological components is perhaps linked to the lack or neglect which the medical approach to disability has received in recent years, with calls for the body or biomedical aspects to be re-introduced to provide a more balanced representation of disability (Williams, 1999). This is partly due to the strength and dominance of the social approach which has had a stronger political and social impact, and the difficulties which exist investigating the involvement. Furthermore, the results from papers II and IV which show that acceptability, and to some extend accommodability, are poorly expressed by policy documents could be attributed to human rights as taking this approach to inclusive education could violate these human rights by forcing or defining involvement.

Paper V investigates the subjective experience of involvement and shows that there is a strong relationship between an index of the subjective experience of involvement and whether children were thinking and doing the same things. This index can be accurately constructed by using measures of concentration, control, involvement, and motivation. Strong evidence is thus provided for adding a third activities and participation qualifier to the ICF-CY which represents involvement. Choice is also influential as knowledge about why an activity is undertaken affects involvement. Additionally, increased subjective experience of involvement leads to better psychological health and well-being.

OPERATIONALIZING PARTICIPATION FROM TWO PERSPECTIVES

One assumption is that constructing and using participation from both a frequency of attendance and an intensity of involvement perspective creates a more accurate and balanced representation of the phenomenon. However, the distribution and weighting of either the two perspectives or the environmental dimension sub-components is not currently know and is potentially difficult to justify and qualify.

USING BOTH PERSPECTIVES

From paper I, although all of the study's papers reference at least one environmental dimension, only four of the 11 empirical works reviewed present a fully balanced approach when theorizing and operationalizing participation. Paper I used the five environmental dimensions and integrated them into a document-review protocol to investigate the validity of the frequency-intensity representation of participation. The results suggest that conditions for participation are easy to express as available, accessible opportunities, or affordability issues, but not as involvement

experiences linked to accommodations made and acceptability issues within a context.

Papers III and IV set out theoretically to use all five environmental dimensions and the results from the study show that although there are no discernible cross-country trends, availability and accommodability are the most prevalent dimensions. The same pattern is also seen in study II and both demonstrate that although the influence of the social approach to disability is still strong, there is some countenance from a more individual-approach as is seen in the strong presence of the accommodability dimension. The outcome of the linking process of the social capital indicators to ICF-CY categories indicates that the majority of the structural social capital indicators are located in the ICF-CY component of Activities and Participation, while the cognitive social capital indicators are linked to Body Functions, and Personal Factors (which are recognized theoretically, but are not included in the operation of the ICF/ICF-CY classification). None of the social capital indicators were linked to the Body Structures or the Environmental Factors components of the ICF-CY, and the Norms was the only indicator of social capital that was found not to link to any of the existing ICF/ICF-CY categories. One theoretical proposition of this study was that structural social capital corresponded with sociological participation aspects, and cognitive social capital corresponded with psychological participation aspects. This appears to be partly true but the sociological influence of the contextual factors seems to be missing. The linking of inclusive education policies to ICF-CY categories showed that more than half of the total of the meaningful concepts found were linked to the ICF-CY's Environmental Factors component; a similar trend is also seen in paper II. Additionally, almost one quarter of the meaningful concepts were not covered or definable within the ICF/ICF-CY framework, while Body Structures was the component to be linked the least, since only

two of the six countries were found to have even one meaningful concept regarding this ICF component. Again, as per the environmental dimensions results, no discernible trends or clusters could be asserted from the results of linking the inclusive education policies to ICF-CY categories however the strong presence of the ICF-CY's Environmental Factors and low prevalence of body structures indicates a strong social approach, however the lack of an ability to link a large proportion of the data to any ICF-CY categories indicates that the framework is still lacking in these areas.

THE ENVIRONMENT SETS THE SCENE

Parallels can be drawn with Bronfenbrenner's ecological systems theory (Bronfenbrenner, 1979), Bhaskar and Danermark's modelling of disability as laminated layers (Bhaskar & Danermark, 2006), and the five environment dimensions of participation used and described in this thesis. Availability, accessibility, and affordability are more related to the macrosystem, whereas accomodability and acceptability can be related to the mesosystem and microsystems as they occur on the micro-level (see figure 5).

Frequency of attending

Availability	Macrosystem
Accessibilty	
Affordability	(exosystem)
Accommodability	Mesosystem
Acceptability	Microsystem

Intensity of involvement
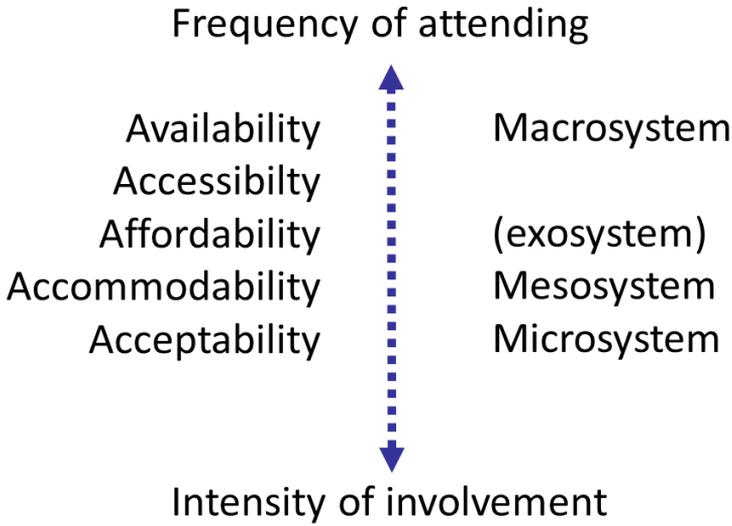
Figure 5. Bronfenbrenner's ecological levels related to the five environmental dimensions of participation

The five environmental dimensions act as descriptors for the participation experience and are intrinsically linked, but not in a way in which they are necessarily directly influential upon each other. In this way they follow the laminated system modelling used by Bhaskar and Danermark (2006) to model and describe disability. It is intended that the environmental dimensions and the bi-dimensional participation model proposed conform to a balanced relational approach to disability, also called relative interactionism, which will produce a more accurate and reliable representation of taking part in activities.

On the macro-level papers III and IV deal with social capital and its influence on inclusive education policies. The results showed that in different ways both the level of social capital and the content of inclusive education policies differed between the European countries selected. Based on the outcomes of the linking of social capital indicators and

inclusive education policies to the ICF-CY, the proposal outlined in paper III – where it is argued that the ICF-CY is a useful tool for measuring both topics in relation to health, functioning and disability – has been confirmed. Although the data collected which represents social capital indicators and inclusive education policies were diverse (and as such, no direct comparisons could be made), linking the data to the ICF-CY showed that the ICF-CY is a consistent and common language for identifying the compatibility of these two topics with health, functioning and disability. As structural social capital was linked only to the ICF-CY domains of Activities and Participation, while cognitive social capital was linked to domains of Body Functions and Personal Factors, it is proposed that structural social capital refers to participation in terms of social network mechanisms, while cognitive social capital refers to cohesion in terms of psychosocial interactions among individuals. These findings would confirm the earlier suggestion that structural social capital relates to the frequency of attending and activity and cognitive social capital refers to the intensity of involvement.

From paper IV all of the analyzed text extracts from the policies were mapped to at least one environmental dimension and the findings showed that the policy documents from all countries contained a high number of codes referring to Availability, with Sweden and United Kingdom presenting almost the 80%. Similar results were found in the study for paper II. These findings were expected since the legislative type of the documents analyzed in both studies mainly outlined the ways and support for one to enter inclusive education. Accommodability was also well represented in all policy documents, and the low incidence of Accessibility and Affordability show that the policy documents provide only a little guideline in these areas, however this apparent absence is off-set with the existence of provisions which facilitate inclusion. It is also evident from the results of papers II and IV that the five environ-

mental dimensions are not equally distributed within policy documents. It could be presumed that the policy documents used in the current analysis were not coherent in terms of fair coverage of the environmental dimensions for supporting inclusive education environments, however the exact weighting of the distribution of the five dimensions has yet to be fully established so no firm conclusion can be drawn from this finding.

FURTHER CLARITY ON DEFINING AND MEASURING PARTICIPATION: A WAY TO MEASURE THE SUBJECTIVE EXPERIENCE OF INVOLVEMENT

The papers combined in this thesis present both the current state of participation in terms of frequency and intensity and also investigate the practical implications of combining the two dimensions.

Paper I shows that research is defining and using participation in a relatively consistent manner in terms of the social and psychological representations of participation. However, evidence from papers II and IV would indicated that this approach has not yet permeated the practical branches of inclusive education as no inclusive education policy documents present the balanced social/psychological approach seen in the research field. Caution should be used when making this comparison as the realms of academia do not always match those of reality and further investigative work is required to establish the relative importance of each environmental dimension when the social/psychological approach is applied in practice.

Paper V sets out to provide empirical evidence for a third involvement qualifier for the ICF-CY's activities and participation component, as originally called for by Granlund et al. (2012). Paper V investigates and

provides evidence on the meso and mirco levels and provides good evidence for how to construct and measure the subjective experience of involvement based on measures of concentration, control, involvement, and motivation (see previously).

Within the ICF-CY (and of course the ICF) the current representation of participation does not take into account the involvement aspects outlined in this thesis. Researchers and practitioners can of course modify the ICF's theoretical underpinnings, but they cannot then use the coding framework and must construct their own measures; this has been recently tried by Coster et al. (2012) with their Participation and Environment Measure for Children and Youth (PEM-CY) which was constructed with a participation model containing three perspectives: frequency, extent of involvement, and desire for change. In order to use the ICF/ICF-CY's coding framework the current coding guidelines within the document itself allow for the use of an additional qualifier which is left undefined in the guidelines outlined in the annex (WHO, 2007, p. 244). Using the ICF/ICF-CY as it is currently written could provide an immediate way to use and represent the subjective experience of involvement, however, awareness that the theoretical representation of participation in the current ICF/ICF-CY model does not make the frequency-intensity distinction would have to be carefully considered and this is unlikely to create a satisfactorily useful tool. A better option would be to use this thesis's findings to contribute to the next revisions of the ICF, which would certainly involve some changes to the theoretical underpinnings, and thus the bi-dimensional representation of participation would be correctly represented and could be accurately used to represent the participation experience.

GENERAL CONSIDERATIONS

One of the main subjects covered here is disability; which is also a "necessarily laminated system" (Bhaskar & Danermark, 2006, p. 278), by which it is meant that it is a multi-dimensional and multi-modal system which has many integrated influencing components. By comparison the construction of participation from two perspectives also creates a multiple-layer system based on the different ecological levels and differing theoretical and practical viewpoints.

The ICF/ICF-CY presents us with one possible way of gaining such a multi-perspective viewpoint. However, to be completely bound by either the ICF/ICF-CY or one of the social models is too restrictive for the all-encompassing nature of disability and will also create divisions and dichotomies which tend to do more harm than good to the field. Another theoretical standpoint is the capability approach (Sen, 1993) which could provide an interesting alternative, particularly for the construction of the involvement component of participation when capabilities can be considered the choice or opportunity to achieve functioning; this corresponds with the acceptability environmental dimension. Perhaps the capability approach could be combined with ICF/ICF-CY. It should be noted that Reindal (2009) previously proposed combining the capability approach with the ICF-CY to provide a theoretical basis for special education. However, Reindal erroneously dismissed the ICF for having too restrictive a definition of disability; this Reindal cited based on a poor representation of the theoretical underpinnings of the framework where she used the overview table (WHO, 2007, p11), which misleadingly contains 'disability', rather than the more usual figure (WHO, 2007, p18, my figure 3), which shows the interactive nature of the main theoretical components of the ICF. It is certainly worth returning to the case for combining the ICF/ICF-CY and the capability approach.

For and overall theoretical frame for this thesis I present the case for Gustavsson's (2004) critical interpretation and, as a further development, Bhaskar and Danermark's critical realism (Bhaskar & Danermark, 2006) as theoretical standpoints to attach this thesis to. Both offer an interesting relative interactionist perspective without being too restrictive as theories for disability research.

METHODOLOGICAL LIMITATIONS

A broad range of methods and approaches are used in this thesis; these were specifically chosen to reflect the inter-disciplinary nature of the work and to complement the aims and research questions of both the individual studies and of the thesis. The methodological choices have been previously introduced and discussed; these will naturally have their limitations which alternatives may not. These points are discussed here.

SYSTEMATIC LITERATURE REVIEW (PAPER I)

The overall rigour and quality of systematic literature reviews has been previously presented and discussed and an alternative would be a more narrative-based reviews. While systematic reviews are commended for their rigour, they can be criticized for being too concise and so lacking in-depth reflection. Had a narrative-based review been used for paper I then perhaps more reflective, if less consistent, results with more scope for detailed discussion could have been obtained.

DOCUMENT ANALYSIS (PAPERS II & IV)

A document analysis was used in paper II to get a consistent over-view at a variety of ecological levels, and in paper IV to give consistent cross-national data on the one ecological level (macro). Alternatives would be some kind of expert consultation, for example interviews or by using a Delphi process; this would give media-based data for analysis which

would require careful consideration when comparing the data to ensure consistency. By using interviews there would be more scope for in-depth discussion to be carried out which would create a richer source of data for analysis. A Delphi method would also potentially give more detail since experts in the field are being consulted. The richer data sourced from these alternative approaches would have also given more scope for interpretation which, in terms of reliability when comparing within or across ecological levels, would have been more challenging to carry out consistently and reliably.

THEORETICAL POSITION PAPER (PAPER III)

An alternative to a theoretical position paper is a review paper, although this was not chosen for this paper as a review paper had already been produced for the thesis. Reviews give an overview of the current state of knowledge and offer some scope for theorising of ideas. Had a review been chosen then this paper would have given more evidence for the lack of research with both social capital, the ICF-CY, and inclusive education policy, but there would have potentially been less scope for theoretical discussion and argument. Careful structuring of the review (such as using a systematic approach as seen in paper I) can give good discursive results and is another way of presenting and synthesising a new concept.

EXPERIENCE SAMPLING METHOD (ESM, PAPER V)

As presented earlier, ESM is one of very few methods which simultaneously gives results directly from participants and in real-time. An alternative, which would give similar results, would be to combine two methods; one to give direct participant input and another to give real-time data recording. For example, real-time recording could be achieved by using observations or an ethnographic approach, and participant input

could be gleamed by using interviews or focus-groups (either before or after the event being studied). Had this combined-method approach been used for this paper then more diverse data would have been gathered and combining these multiple data-sets would be difficult to ensure accuracy and reliability. There is, however, the possibility to gather more in-depth data which would give more potential for a more detailed discussion.

CONCLUSION

This thesis outlines a new way to represent participation from both a sociological (frequency) and psychological (individual) perspective. This new and arguably more balanced approach to participation is operationalized by using the five environmental dimensions of availability, accessibility, adorability, accommodability, and acceptability. In combination this contributes to a new theory on the subjective experience of involvement which can be measured using concentration, involvement, motivation, and control. The findings presented in this thesis along with the new theory on the subjective experience of involvement will add further to the discussion about the distinction between activities and participation in the ICF/ICF-CY (see Whiteneck, 2005, for a review) and specifically add validity to the participation construct by bringing in the child's own personal subjective experience.

RECOMMENDATIONS

This thesis presents a broad selection of evidence from a selection of different ecological levels for the construction and operation of participation from two perspectives: the frequency of attendance, and the intensity of involvement. It is the author's belief that this provides a more accurate representation of the participation construct as most previous constructions neglected the involvement component. The author thus

recommends that when theoretically constructing and practically using participation it should be done by using both of these two perspectives.

In terms of practical influences on the field, the ICF-CY – as it currently stands – is to be considered lacking both theoretically and practically if it were to be used to operationalize the new frequency-intensity approach to participation proposed in this thesis. The ICF-CY in its current form could be practically used in a limited way with the addition of a third qualifier to the activities and participation component to represent the subjective experience of involvement. The ICF/ICF-CY would permit this under the guidelines outlined in the annex (WHO, 2007, p. 244); however, this solution is a compromise as the theoretical underpinning does not match the practical operation. It is the author's intention and hope that this newer modelling of participation will be brought in to any future revisions of the ICF/ICF-CY – a so-called 'ICF-2', which would likely also include the existing ICF-CY revisions – which would thus create an accountable classification of the involvement experience.

REFERENCES

Abberley, P. (1987). The Concept of Oppression and the Development of a Social Theory of Disability. *Disability & Society, 2*(1), 5 - 19.

Almqvist, L., & Granlund, M. (2005). Participation in school environment of children and youth with disabilities: A person-oriented approach. *Scandinavian Journal of Psychology, 46*, 305-314.

Auperin A., Pignon J. P., & Poynard T. (1997). Review article: Critical review of meta-analyses of randomized clinical trials in hepatogastroenterology. *Alimentary Pharmacology & Therapeutics, 11*, 215–225.

Badley, E. M. (2008). Enhancing the conceptual clarity of the activity and participation components of the International Classification of Functioning, Disability, and Health. *Social Science & Medicine, 66*(11), 2335-2345.

Bandura A. (1998). *Self-efficacy: the exercise of control*: W.H. Freeman.

Barnes, C. (1996). Disability and the Myth of the Independent Researcher. *Disability & Society, 11*(1), 107 - 112.

Barnes, C., & Mercer, G. (1996). *Exploring the divide: illness and disability*: Disability Press.

Bates, P., & Davis, F. A. (2004). Social capital, social inclusion and services for people with learning disabilities. *Disability & Society, 19*(3), 195 - 207.

Bear, G. G., Minke, K. M., Griffin, S. M., & Deemer, S. A. (1998). Achievement-related perceptions of children with learning disabilities and normal achievement:... *Journal of Learning Disabilities, 31*(1), 91-105.

Berry, H. (2008). Social capital elite, excluded participators, busy working parents and aging, participating less: types of community participators and their mental health. *Social Psychiatry and Psychiatric Epidemiology, 43*(7), 527-537. doi: 10.1007/s00127-008-0331-3

Bhaskar, R., & Danermark, B. (2006). Metatheory, Interdisciplinarity and Disability Research: A Critical Realist Perspective. *Scandinavian Journal of Disability Research, 8*(4), 278-297.

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. *Social Science & Medicine, 48*(9), 1173-1187.

Björck-Åkesson, E., Granlund, M., & Simeonsson, R. J. (2005). A systems theory perspective. In E. Heimdahl Mattson, A.-L. Lange, L. Roll-Pettersson & M. Westling Allodi (Eds.), *Mångsidigt samspel: en vänbok till siv fischbein*. Stockholm: HLS Fötlag.

Björnsdóttir, K. (2010). Resisting the Reflection: Identity in Inclusive Life History Research. *Disability Studies Quarterly, 30*(3/4).

Bronfenbrenner, U. (1979). *The ecology of human development: experiments by nature and design*: Harvard University Press.

Brown, M., & Gordon, W. A. (1987). Impact of impairment on activity patterns of children. *Archives of physical medicine and Rehabilitation, 68*, 828-832.

Bury, M. (1996). Disability and the Myth and the Independant Researcher: a reply. *Disability & Society, 11*(1), 112 - 115.

Buttimer, J., & Tierney, E. (2005). Patterns of leisure participation among adolescents with a mild intellectual disability. *Journal of intellectual disabilities, 9*(1), 25-42.

Chenoweth, L., & Stehlik, D. (2004). Implications of social capital for the inclusion of people with disabilities and families in community life. *International Journal of Inclusive Education, 8*(1), 59-72.

Clark, C., Dyson, A., & Millward, A. (1998). Theorising special education: time to move on? In C. Clark, A. Dyson & A. Millward (Eds.), *Theorising special education*. London: Routledge.

Clarke, M. T., Newton, C., Griffiths, T., Price, K., Lysley, A. and Petrides, K. V. (2011). Factors associated with the participation of children with complex communication needs. *Research in Developmental Disabilities, 32*, 774-780.

Coster, W., & Khetani, M. A. (2008). Measuring participation of children with disabilities: Issues and challenges. *Disability & Rehabilitation, 30*(8), 639 - 648.

Coster, W., Law, M., Bedell, G., Khetani, M., Cousins, M., & Teplicky, R. (2012). Development of the participation and environment measure for children and youth: conceptual basis. *Disability and*

Rehabilitation, 34(3), 238-246. doi: doi:10.3109/09638288.2011.603017

CSDH. (2008). Closing the gap in a generation : health equity through action on the social determinants of health : final report of the commission on social determinants of health. Geneva: World Health Organization.

Csikszentmihalyi, M., & Larson, R. (1987). Validity and reliability of the experience-sampling method. *The journal of nervous and mental disease, 175*(9), 526-536.

Csikszentmihalyi, M., Rathunde, K., & Whalen, S. (1993). *Talented teenagers; the roots of success and failure.* Cambridge, USA: Press syndicate of the university of Cambridge.

D'Alessio, S. (2008). 'Made in Italy': Integrazione Scolastica and the New Vision of Inclusive Education In L. Barton & F. Armstrrong (Eds.), *Policy, Experience and Change: Cross-Cultural Reflections on Inclusive Education*: Springer Netherlands.

Daly, M., & Silver, H. (2008). Social exclusion and social capital: A comparison and critique. *Theory and Society, 37*(6), 537-566. doi: 10.1007/s11186-008-9062-4

Danermark, B., & Gellerstedt, L. C. (2004). Social justice: redistribution and recognition--a non-reductionist perspective on disability. *Disability & Society, 19*(4), 339-353. doi: 10.1080/09687590410001689458

Davis, P., & Florian, L. (2004). Teaching Strategies and Approaches for Pupils with Special Educational Needs: A Scoping Study. *Research report no. 516*: Department for Education and Skills.

Dyson, A., & Millward, A. (2000). *Schools and special needs: issues of innovation and inclusion*: P. Chapman.

Egilson, S., & Hemmingsson, H. (2009). School participation of pupils with physical and psychosocial limitations: a comparison. *The British Journal of Occupational Therapy, 72*(4), 144-152.

Egilson, S., & Traustadóttir, R. (2009). Theoretical perspectives and childhood participation. *Scandinavian Journal of Disability Research, 11*(1), 51-63. doi: 10.1080/15017410802461970

Eriksson, L. (2005). The relationship between school environment and participation in students with disabilities". *Pediatric Rehabilitation, 8*(2), 130-139.

Eriksson, L., & Granlund, M. (2004a). Conceptions of participation in students with disabilities and persons in their close environment. *J dev phys disabil, 16*(3), 229-245.

Eriksson, L., & Granlund, M. (2004b). Perceived participation: A comparison between students with disabilities and students

without disabilities. *Scandinavian Journal of Disability Research, 6*(3), 206-225.

Eriksson, L., Welander, J., & Granlund, M. (2007). Participation in Everyday School Activities For Children With and Without Disabilities. *Journal of Developmental Physical Disability, 19*, 485-502.

Finn, J. D., & Cox, D. (1992). Participation and withdrawal among fourth-grade pupils. *American Educational research Journal, 29*(1), 141-162.

Fraser, N. (1999). Social justice in the age of identity politics: redistribution, recognition, and participation. In L. J. Ray & R. A. Sayer (Eds.), *Culture and economy after the cultural turn* (pp. 25). London: Sage.

Fraser, N., & Honneth, A. (2003). *Redistribution or recognition?: a political-philosophical exchange*: Verso.

Goodley, D. (2010). *Disability Studies: An Interdisciplinary Introduction*: SAGE Publications.

Goodwin, D. L., & Watkinson, E. J. (2000). Inclusive physical education from the perspective of students with physical disabilities. *Adapted Physical Activity Quarterly., 17*(2).

Granlund, M. (2006). *Studies of participation related to ICF-CY*. Paper presented at the Invited presentation MHADIE meeting, Prague, Czech Republic. http://urn.kb.se/resolve?urn=urn:nbn:se:hj:diva-5082

Granlund, M. (2009). *Environmental dimension of participation related to ICF-CY*. Paper presented at the Invited presentation MURINET meeting, Zürich, Switzerland. http://www.hhj.hj.se/doc/8320&personid=33

Granlund, M., Arvidsson, P., Niia, A., Bjorck-Akesson, E., Simeonsson, R. J., 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(13) Supplement*(1), S84-S96.

Granlund, M., Eriksson, L., & Ylvén, R. (2004). Utility of international classification of functioning, disability and health's participation dimension in assigning ICF codes to items from extant rating instruments. *Journal of Rehabilitation Medicine, 36*, 130-137.

Gustavsson, A. (2004). The role of theory in disability research - springboard or strait-jacket? *Scandinavian Journal of Disability Research, 6*(1), 55 - 70.

Gustavsson, A., & Söder, M. (1990). Social forskning om människor med psykisk utvecklingsstörning. En bibliograferad kommentar (Social research on people with intellectual disabilities) (Vol. 1). Stockholm: FoU-rapport.

Gustavsson, A., Tøssebro, J., & Traustadóttir, R. (2005). Introduction: approaches and perspective in Nordic disability research. In A. Gustavsson, J. Sandvin, R. Traustadóttir & J. Tøssebro (Eds.), *Resistance, Reflection and Change* (pp. 23-44). Lund: Studentlitteratur.

Göransson, K., & Nilholm, C. (2009). Inclusive education in Sweden?: Ideas, policies and pracitices. *La nouvelle revue de l'adaptation et de la scolarisation, 5*, 83-98.

Hallberg, U., Klingberg, G., Setsaa, W., & Möller, A. (2010). Hiding parts of one's self from others – a grounded theory study on teenagers diagnosed with ADHD. *Scandinavian Journal of Disability Research, 12*(3), 211-220. doi: 10.1080/15017410903478964

Hart, C. (2006). *Doing a literature review: releasing the social science research imagination*. London: Sage.

Hektner, J. M., & Csikszentmihalyi, M. (2003). The experience sampling method: measuring the context and content of lives *handbook of environmental psychology*.

Hestenes, L. L., & Carroll, D. E. (2000). The play interactions of young children with and without disabilities: Individual and environmental influences. *Early Childhood Research Quarterly, 15*(2), 229-246.

Hollenweger, J. (2010). MHADIE's matrix to analyse the functioning of education systems. [Article]. *Disability & Rehabilitation, 32*, S116-S124. doi: 10.3109/09638288.2010.520809

Horenczyk, G. (1996). Migrant identities in conflict: acculturation attitudes and perceived acculturation ideologies. In E. Lyons & G. M. Breakwell (eds.), *Changing European identities: social psychological analyses of social change* (pp. 241– 250). Oxford, UK: Butterworth Heinemann.

Howard, L. (1996). A comparison of leisure-time activities between able-bodied children and children with physical disabilities. *British journal of Occupational therapy, 59*(12), 570-574.

Hunter, J. P., & Csikszentmihalyi, M. (2003). The positive psychology of interested adolescents. *Journal of Youth and Adolescence, 32*(1), 27-35.

Hurst, R. (2003). The International Disability Rights Movement and the ICF. *Disability and Rehabilitation, 25*(11-12), 572-576. doi: doi:10.1080/0963828031000137072

James, A., Jenks, C., & Prout, A. (1998). *Theorizing Childhood*: Teachers College Press, P.O. Box 20, Williston, VT 05495-0020; phone: 800-575-6566; fax: 802-864-7626; e-mail: tcp.orders@aidcvt.com; Web site: http://tc-press.tc.columbia.edu/ ($20.95).

Kaasa, A., & Parts, E. (2008). Individual-level Determinants of Social Capital in Europe: Differences between Country Croups. *Acta Sociologica, 51*(2), 145-168.

Kelly, M. P., & Field, D. (1994). Reflections on the rejection of the bio-medical model in sociological discourse. *Medical Sociology News, 19*, 34-37.

Koro-Ljungberg, M., Bussing, R., Williamson, P., & M'Cormack-Hale, F. (2008). Reflecting on the Experience Sampling Method in the Qualitative Research Context: Focus on Knowledge Production and Power during the Data-Collection Process. *Field Methods, 20*(4), 338-355. doi: 10.1177/1525822x08320201

Krippendorff, K. (2004). *Content analysis: an introduction to its methodology*. London: Sage.

Law, M., King, G., King, S., Kertoy, M., Hurley, P., Rosenbaum, P., . . . Hanna, S. (2006). Patterns of participation in recreational and leisure activities among children with complex physical disabilities. *Developmental Medicine & Child Neurology, 48*, 337-342.

Leonardi, M., Bickenbach, J., Üstün, T. B., Kostanjsek, N., & Chatterji, S. (2006). The definition of disability: what is in a name? *Lancet, 368*(9543), 1219-1221.

Letts L., Wilkins S., Law M., Stewart D., Bosch J., & Westmorland M.. (2007). *Critical review form – Qualitative studies (Version 2.0)*. Ontario: McMaster University.

Marquand, D. (1996). Moralists and hedonists. In D. Marquand & A. Seldon (Eds.), *The ideas that shaped post-war Britain*. London: Fontana Press.

McConachie, H., Colver, A. F., Forsyth, R. J., Jarvis, S. N., & Parkinson, K. N. (2006). Participation of disabled children: how should it be characterised and measured? *Disability and Rehabilitation, 28*(18), 1157-1164.

Moher, D., Tetzlaff, J., Tricco, A. C., Sampson, M., & Altman, D. G. (2007). Epidemiology and Reporting Characteristics of Systematic Reviews. *PLoS Med, 4*(3), e78. doi: 10.1371/journal.pmed.0040078

Napa Scollon, C., Kim-Prieto, C., & Diener, E. (2003). Experience sampling: promises and pitfalls, strengths and weaknesses. *Journal of Happiness studies, 4*, 5-34.

Nilholm, C. (2007). *Perspektiv på specialpedagogik*. Lund: Studentlitteratur.

Okoli, C., & Schabram, K. (2010). A Guide to Conducting a Systematic Literature Review of Information Systems Research. *Sprouts: Working Papers on Information Systems, 10*(26). Retrieved from http://sprouts.aisnet.org/10-26

Oliver, M. (1996). *Understanding disability: from theory to practice*. Basingstoke: Palgrave Macmillan.

Penchansky, R., & Thomas, J. W. (1981). The Concept of Access: Definition and Relationship to Consumer Satisfaction. *Medical Care, 19*(2), 127-140.

Priestley, M. (2003). *Disability: a life course approach*: Polity.

Putnam, R. D. (2001). *Bowling Alone*: Simon & Schuster.

Reindal, S. M. (2009). Disability, capability, and special education: towards a capability-based theory. *European Journal of Special Needs Education, 24*(2) ,155-168.

Schenker, R., Coster, W., & Parush, S. (2005). Participation and activity performance of students with cerebral palsy within the school environment. *Disability and Rehabilitation, 27*(10), 539-552.

Schlosser, R. W., Wendt, O., & Sigafoos, J. (2007). Not all systematic reviews are created equal: Considerations for appraisal. [Article]. *Evidence-Based Communication Assessment & Intervention, 1*(3), 138-150. doi: 10.1080/17489530701560831

Seligman, M. E., & Csikszentmihalyi, M. (2000). Positive psychology an introduction. *American Psychologist, 55*(1), 5-14.

Sen, A. (1993). Capabilities and well-being In M.C. Nussbaum, A. Sen and World Institute for Development Economics Research (Eds.), *The quality of life*. Oxford, UK: Clarendon Press.

Shakespeare, T. (2004). Social models of disability and other life strategies. *Scandinavian Journal of Disability Research, 6*(1), 8 - 21.

Shakespeare, T. (2005). Disability studies today and tomorrow. *Sociology of Health & Illness, 27*(1), 138-148.

Shakespeare, T. (2006). *Disability rights and wrongs*. London: Routledge.

Shakespeare, T., & Watson, N. (2001). The social model of disability: An outdated ideology? *Research in Social Science and Disability* (Vol. 2, pp. 9-28): Emerald Group Publishing Limited.

Simeonsson, R. J., Bailey, D. D., Scandlin, D., Huntington, G. S., & Roth, M. (1999). Disability, Health, Secondary Conditions and Quality of Life: Emerging Issues in Public Health. In R. J. Simeonsson & L. N. McDevitt (Eds.), *Issues in Disabiltiy &*

Health: The Role of Secondary Conditions in Quality of Life. Chapel Hill, NC: University of North Carolina.

Simeonsson, R. J., Carlson, D., Huntington, G. S., McMillen, J. S., & Brent, J. L. (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.

Skinner, E. A. & Zimmer-Gembeck, M. J. (1998). Individual differences and the development of perceived control. *Monographs of the Society for Research in Child Development, 63*, 1-220.

Skrtic, T. M. (1991). *Behind special education: a critical analysis of professional culture and school organization*: Love Pub. Co.

Skär, L. (2003). Peer and adult relationships of adolescents with disabilities. *Journal of Adolescence, 26*(6), 635-650.

Spelman, E. V. (1988). *Inessential woman: problems of exclusion in feminist thought*. Boston: Beacon Press.

Szönyi, K. (2005). *Särskolan som möjlighet och begränsningar-elevperspektiv på delaktighet och utan förskap.* doctrorial dissertation, stockholms universitet, Stockholm.

Söder, M. (2005). *Forskning om funktionshinder : problem - utmaningar - möjligheter*: Studentlitteratur.

Tamm, M., & Skär, L. (2000). How I play: roles and relations in the play situations of children with restricted mobility. *Scandinavian Journal of Occupational Therapy, 7*, 174-182.

Thomas, C. (2004). How is disability understood? An examination of sociological approaches. *Disability & Society, 19*(6), 569-583.

Thomas, C. (2007). *Sociologies of disability and illness: contested ideas in disability studies and medical sociology*: Palgrave Macmillan.

Thomas, G., & Loxley, A. (2007). *Deconstructing Special Education and Constructing Inclusion (Inclusive Education)*: {Open University Press}.

Tisdall, E. K. M., & Riddell, S. (2006). Policies on special needs education: competing strategies and discourses. *European Journal of Special Needs Education, 21*(4), 363-379.

Tøssebro, J. (2004). Introduction to the special issue: Understanding disability. *Scandinavian Journal of Disability Research, 6*(1), 3-7. doi: 10.1080/15017410409512635

UNESCO. (1994). The Slamanca Statement and Framework for Action on Special Needs Education. Paris, France: United Nations Educational, Scientific and Cultural Organization.

UNESCO. (2000). The Dakar Framework for Action. Education for All: Meeting our Collective Commitments. Dakar, Senegal: United Nations Educational, Scientific and Cultural Organization.

Convention on the Rights of the Child, 44/25 C.F.R. (1989).

Convention on the Rights of Persons with Disabilities, 44/25 C.F.R. (2006).

Wehmeyer, M. & Schwartz, M. (1997). Self-determination and positive adult outcomes: A follow-up study of youth with mental retardation. *Exceptional Children, 63*, (winter), 245-255.

Whiteneck, G. (2005). Conceptual Models of Disability: Past, Present, and Future. In M. J. Fields, A. M. Jette & L. Martin (Eds.), *Workshop on Disability in America: A New Look*. Washington DC: National Academies Press.

WHO. (1980). International Classification of Impairment, Disabilities, and Handicap. Geneva: World Health Organization.

WHO. (2001). International Classification of Functioning, Disability and Health (ICF). Geneva: World Health Organization.

WHO. (2007). International Classification of Functioning, Disability and Health – Version for Children & Youth (ICF-CY). Geneva: World Health Organization.

Williams, S. J. (1999). Is anybody there? Critical realism, chronic illness and the disability debate. *Sociology of Health & Illness, 21*(6), 797-819.