From the Department of Woman and Child Health
Child and Adolescent Psychiatric Unit
Karolinska Institutet, Stockholm, Sweden

PARTICIPATION AND DISABILITY- A STUDY OF PARTICIPATION IN SCHOOL FOR CHILDREN AND YOUTH WITH DISABILITIES

Lilly Eriksson

Karolinska Institutet

Stockholm 2006

All previously published papers were reproduced with permission from the publisher.

ABSTRACT

Participation in everyday life is vital to a child's development and well-being and is a basic human right. One definition of participation is engagement in life areas. The objective of this study is to investigate participation in school activities of children and adolescents with disabilities; the study focus on personal factors and factors in the environment, which are closely related to participation. Data were collected in a large survey and a smaller observational study.

In the survey, students, parents, teachers, and special education consultants responded to statements about participation and factors related to participation such as autonomy, interaction, availability, support, and environment.

In the observational study, participation was observed during various school activities during an entire school day and after school. Children were interviewed about their school day, friendships, and autonomy.

The results revealed that participation is multidimensional, with an emphasis on personal experiences, interactions, and context. The theoretical assumption of the International Classification of Functioning, Disability, and Health (ICF) states that the body, participation, and the environment are related. The research results proved this assumption and support the multidimensionality of the participation construct. As indicated in previous research, children and adolescents with disabilities show a lower degree of participation in school than their peers. Participation seems to be more related to autonomy and interactions with significant others than to disability type and general environment. A closer look at various school activities reveals that children with disabilities primarily have a lower degree of participation in math, practical subjects, and science. Being included and having many friends, who provide emotional support, facilitate participation. While, frequently receiving support from teachers and assistants lowered participation. This indicates that there is a relation between support and participation: providing too much support during class can be detrimental to class participation, whereas a good social support network of other children is vital.

In this thesis, participation is measured in two ways: by participation *frequency* and by participation *intensity*. By counting the number of activities that children participate in, and how often they participate in these activities, a measure of an individual's average participation is obtained, that is, participation frequency. This measure depends more on internal rather than contextual factors, and it changes more often because of internal rather than contextual changes. Intensity measures of participation refer to the amount of involvement within a specific situation, and are contextually dependent. Involvement change based on the situation and the individual's present state. Participation is personal—it is about feeling good about what you are doing and feeling competent in using available opportunities. Participation is dependent on interaction with significant others. Participation for children with disabilities also depends on being provided with necessary support. Participation frequency seems to be less dependent on support than participation intensity. The fact that intensity seem to be more dependent on support and context, short-term interventions facilitating participation within situations are probably the most fruitful way to enhance participation.

KEYWORDS: participation, disability, inclusion, school, autonomy, interaction, school environment, engagement

LIST OF PUBLICATIONS

I. Eriksson, L., & Granlund, M. (2004). Conceptions of participation in students with disabilities and persons in their close environment. *Journal of Developmental and Physical Disabilities, 16*(3), 229-245.

II. 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.

III. Eriksson, L., & Granlund, M. (2004). Perceived participation. A comparison of students with disabilities and without disabilities. *Scandinavian Journal of Disability Research, 6*(3), 206-224.

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

V. Eriksson, L., Welander, J., & Granlund, M. (accepted). Participation in everyday school activities—for children with and without disabilities. *Journal of Developmental and Physical Disabilities.*

CONTENTS

1 INTRODUCTION

Children's participation in everyday life activities is a central theme of this thesis, with a specific focus on children and youth with disabilities in the micro context of school. Participation is a positive term, emphasized as something good that is often cited as a key outcome in school, especially for children and youth with disabilities. Swedish educational policies and curricula is in line with five international agreements: the United Nations Universal Declaration of Human Rights, the UN Convention on the Rights of the Child, the Salamanca Statement, the UNESCO Recommendation concerning Education for International Understanding, and the UNEP Declaration and Recommendations of the Conference on Environmental Education (Skolverket, 1999). Ensuring involvement and participation of children in age-relevant activities creates optimal opportunities for learning and development. Focus is often on the fact that children and adolescents with disabilities do not have optimal opportunities and that society must work more toward making them equal participants with other children in society and school. To reach the goal of equality, it is necessary to study participation in school and school activities of children with and without disabilities to discover whether there are differences. If differences are found, another aim is to study factors on the micro system level that seem to influence these differences for individual children.

In Sweden, research on children with disabilities in school often has a societal or organizational focus, with relatively little focus on individuals in the classroom (Björck-Åkesson, Granlund, & Simeonsson, 2005). Research studies, which focus on participation of individual children with disabilities in school activities, are needed. This thesis focuses on participation in school activities of children with disabilities; it is based on material from two data collections, which are presented in five sections: four sections for the first data collection (Study I to IV) and one for the second (Study V).

This introduction presents societal and political ideas that led society to the focus on children's participation in school. It describes theories that form the conceptual framework for studying school participation of children with disabilities and presents the participation construct and factors related to it. Then it presents the objectives of the five sections that form this thesis, along with methods used and research results. After that, it discusses the conceptual and empirical difficulties of studying participation as a multidimensional construct. It ends with a discussion on applied results and how knowledge from the empirical studies can be used to support participation of students with disabilities in school.

1.1 PARTICIPATION: A HUMAN RIGHT

Participation is something that is positive, an asset. In order to participate a person needs to be an active part of their own life, being able to decide how and what type of activity they wish to participate in and to be given the opportunity to take part in desired activities. Participation can be considered part of a healthy life and thus as a human right. Participation is important for optimal development and learning. Even though this thesis focuses on children and their micro settings, the discussion on participation emanates from a macro-setting discourse, which views participation as a national and international political objective, based on the premise of equal rights for all humans. Participation is stressed in various international agreements. The UN

Standard Rules on the Equalization of Opportunities for Persons with Disabilities (1993) state that there is a need for increased awareness about people with disabilities and their rights. This includes ensuring that public education programs reflect the principle of full participation and equity in all their aspects (Rule 1). Another international convention (Convention on the Rights of the Child, 1989) states that no child should suffer from discrimination (Article 2), and that mentally or physically disabled children should enjoy a full, comfortable life in conditions that ensure dignity, promote self-reliance, and facilitate the child's active participation in the community (Article 23). All children have the right to engage in play and recreational activities (Article 31). The political goal of supporting participation of all citizens has a solid foundation within these international agreements; it is a *need* of the individual and a *right* protected by law.

Another reason for focusing on participation is the health and well-being of a country's citizens. Health is more than being in a good physical and mental state; it is being able to execute tasks and to be involved in life in a physical, social, and attitudinal environment. For children and adolescents with physical and mental impairments, it is crucial to focus on their activities and participation within specific contexts, to promote optimal development and learning. Focusing on how they function in their close environment will provide more information about their health and well-being than focusing on the diagnosis, degree and type of disability as characteristics for participation and health. Defining health on a macro level, it can be said that all people have the right to participate in their own life. It is necessary for positive function and well-being. According to the World Health Organization, participation is a health-related concept and is one of the International Classification of Functioning, Disability and Health (ICF) components (WHO, 2001).

Inclusion and participation are according to the Salamanca Statements (1994) essential democratic rights, and people with disabilities require support to frequently experience full participation and few instances of participation restrictions. During the past two decades, the trend in social policies has been to promote integration and participation and to combat exclusion. Inclusion and participation are essential to human dignity and to the enjoyment and exercise of human rights. The Salamanca Statement provides a framework for action in special needs education; it focuses on promoting inclusive education, enabling schools to serve all children, building an inclusive society, and achieving equal education for all children. Inclusion is required if schools are to support all children's participation. The Swedish National Agency for Education (2005) states that inclusion is not negotiable if we wish the Salamanca Statement to mean that all students may participate in education, and that inclusion is a democratic and human right.

Persons with disabilities often experience participation restrictions and require support to experience full participation, which is something on which the disability advocacy movement focuses. In Sweden, the law for providing support and services for specific disabilities (LSS 1993:387) states "… the activities regulated by this law must strive for equality in living conditions and full participation in community life. The goal shall be to create opportunities for the individual to live as others" (section 5). This goal of service and support does not merely discuss participation; it connects participation to the right to live a normal life. For children, who require support, encouraging inclusion in academic and social activities is a way to support their later participation in society.

Participation as a political goal is closely connected to the idea of normalization as stipulated by Bengt Nirje in the late 1960s (Nirje, 2005). His principle intent was not to make mentally retarded people normal but to make their everyday routine normal, based on cultural norms. Nirje emphasized having a normal rhythm of day, week, and

year, having normal developmental phases, growing up with caretakers in a warm atmosphere, going to school, having experiences outside of school, and becoming adults with marked changes in context and living conditions. Other aspects of a normal life are having needs met and living in a dual-sex world with a normal economic standard (Nirje, 2005). Normalization and integration to achieve participation in society and equality in living conditions became the new goal for the national handicap movement in Sweden (Skolverket, 2005). In Sweden today, some of the requirements stated by Nirje, such as living in society and not in institutions, have been fulfilled, while other areas still require more work. This includes helping people with disabilities to be self-determined and to participate fully in all major life areas, especially ensuring work and a social life with leisure activities and friends. Inclusion, equal goals, and educational requirements can also be seen as a continuation of the normalization process, and education should be implemented with flexibility, based on the prerequisites, needs, and interests of individual students (SOU, 1998:66). Relevant education and optimal development will occur in a school environment in which self-esteem and self-concept are strong, with an emphasis on participation and solidarity (SOU, 1998:66). Although society is working for inclusion and against discrimination, it was not until recently that a new law (2006:67) against discrimination of students in school came into force as a way of supporting equal rights of students and of working against school discrimination regarding issues such as sex, ethnicity, religion, sexual disposition, or disability. This shows that on a macro level, there is political and social emphasis on enhancing participation. For the individual, participation is experienced within a close setting, i.e. on a micro-level. How do children and youth with disabilities, in Sweden, participate in school settings? Are children and youth with disabilities participating in school to the same extent as their peers? What individual differences within the group are there?

1.2   A SCHOOL FOR ALL

In Sweden, modern schools were not founded until 1842, when children from poor backgrounds were given access to schooling. Education has been reformed many times since then but the basic principles remain: schools in specific buildings with teachers, classrooms, and blackboards. Classes with a division of students into different groups began with the normal plan for education in 1878 (Swedish National Agency for Education, 2005). In 1882, general compulsory school attendance, from ages 7-14, was implemented. In certain aspects since the nineteenth century, schools have remained the same: schooling starts at a specific age and ends after a fixed number of years, and the children's achievements in school are evaluated in the form of grades based on what is considered normal achievement. At first, school did not include children with disabilities. Children with hearing impairments were not educated until 1889, and children with visual impairments were included in compulsive education starting in 1896. Demand for special education in Swedish schools did not arise before the 1920s-1930s (Persson, 2003). The concept of social justice forms the historical foundation of special education (Haug, 1998). As the welfare state redistributed resources to support the weakest, opportunities for disabled persons increased. During the twentieth century, people with disabilities strengthened their position in society through integration and access to education, but for some children with intellectual disabilities, compulsory education was not enforced until 1968. This indicates that the notion of compulsory education is relatively new and a school for all is even newer, being founded in the 1980 school curricula. The political

goal was to create opportunities for all children to have a meaningful education within the mainstream school as a part of the new welfare state.

There is a close conceptual link between participation and inclusion. Inclusion rose from a democratic perspective with participation and solidarity as central values (Haug, 1998). The right of all children to be included equally in activities is the foundation of integration policy. All children have the right to be present in the classroom without exception (Haug, 1998). Integration, inclusion, and participation can be seen as an offshoot from normalization values (Nirje, 2005; SOU, 1982). Integration can be seen as the precursor of inclusion and was introduced in Sweden in the 1960s. Integration was criticized for failing to provide full inclusion and for the fact that students with special needs were supported separately from their peers (SOU, 1982), resulting in exclusion rather than integration. While integration demands to have the involvement of all differences in a system, inclusion wants a system that can handle the heterogenic group (Emanuelsson, 2004). The shift from integration to inclusion came with the Salamanca Statement (1994), which generated a discussion about support, inclusion in a global perspective, and how to support all children's needs for development and participation in school. Inclusion, as stated in the Salamanca Statement, would ensure that schools attempt to adjust for the diversity of their students, allowing them equal education and full participation in school (The Salamanca Statement, 1994). Emphasizing the link between inclusion and participation. In the US, inclusion emerged as a concept to mark a new view of children requiring special support, and was introduced as a critique against *mainstreaming*, arguing that mainstreaming had become equivalent to adjusting students to the school situation instead of adjusting the school situation to the students.

Education in Sweden has been based on a normative view of what normal achievement is. Support provided in school has a tradition of being based on relations to the normal achievement goal (Skolverket, 2005). Children who cannot reach the goals in normal ways receive special support to do so (Göransson, 2006). Including students who require special support in the regular elementary school created challenges for teachers, who found it difficult to manage heterogeneity within the group of students. Haug (1998) argues that special education arose from a segregating integration in which students, who require special support, were put into different excluding solutions—perhaps more often based on teachers' requirements rather than students' requirements. One reason for this could be the difficulties teachers experienced, which may have led to more students being labeled as requiring special support (Persson, 2003). This phenomenon resulted in the segregation and stigmatization of these students in a system of special remedial and observational classes.

In Sweden, there is a system of special schools focusing on specific disabilities, often segregated from mainstream education. Children with more severe learning disabilities and children with mental retardation are placed in special schools. Sweden also has special schools for children with severe hearing impairments. The discussion about normal achievements, special support in school, and teachers' need to manage the class, usually concern grey zone children attending regular school, not students attending special schools, these students have already been taken out of the regular classroom.

Today, schools want to have a more inclusive perspective, focusing on the social and democratic aspects of education and special education. Democracy forms the basis of the national school system (Lpo94, 1998). The curriculum for compulsory school states: "The school's task is to encourage all pupils to discover their own uniqueness as individuals, thereby actively participating in social life by giving their

best in responsible freedom." (Lpo94, 1998, p 3). The aim is not to compensate the child's weaknesses but to formulate the institution's rules, based on variations within the system, that is, to make the school fit the students (Haug, 1998). This is referred to as equivalent education in the national curriculum: "Furthermore schools have a special responsibility for those pupils who for various reasons experience difficulties in attaining the goals that were set for their education. For this reason, education can never be the same for all." (Lpo94, 1998, p. 4). Social training and development of friendships and solidarity are emphasized within an inclusive perspective (Haug, 1998). Being a part of society is important for the individual's well-being—to remain motivated and to have friends. It includes being part of the school community and being given opportunities to experience a sense of belonging (Haug, 2003). The inclusion of students, who require special support, has a history that is affected by society's political values—a society that is becoming increasingly inclusive and focusing on individuals' rights to learn, based on their own prerequisites.

In Sweden, discussions on inclusion often take a societal or organizational perspective, based on needs perspectives and the obligation of schools to fulfill these needs. Exclusion from school leads to exclusion from several social and societal arenas (Persson, 2001). Discussions on inclusion become discussions on democracy, with spokespersons for segregated schools, i.e. special schools, advocating that mainstream schools drain resources from children who require support to participate in school. Persson (2001) argues that with diminishing financial resources, special resources are limited as well, something that increases the demand for support to be proven effective. The arguments against special schools often mention exclusion, with their creation of subcultures that risk social and financial exclusion from mainstream society.

Göransson (2006) argues that even though the idea of a school for all has been on the agenda for a long time, it is a long way from concept to realization, and that the purpose of education and curricular goals are normative, based on what all children should learn even if they are learning in different ways. In theory, education supports humanitarian values, of which participation is one, but this is not always the case in practice (Göransson, 2006). Participation, for example, is a political goal not equally emphasized as something that should be achieved in schools. Students and teachers must also reach learning and education goals and failure to reach these goals could lead to resignation and distress (Persson, 2003). Perhaps resistance to inclusion in education comes from the difficulty of handling diversity in relation to traditional ideas about conformity in goals, knowledge, and teaching. This resistance might be based on the distance between idea and practice.

In conclusion, on an organizational level, discussions on inclusion and participation often focus on the school rather than on classroom environments or individual children. Integration is described in terms of distance from the other students—from being physically located in the same school to being socially integrated in the classroom. Discussing integration as distance, or as school strategies for support, constitutes an organizational perspective. For the children, the differentiation will only be a matter of being or not being a part of the context. They will not recognize whether the distance is long or short. For children, being a part of the classroom (and classroom activities) means that they are included and they are given possibilities to participate fully in school activities. Research that studies differences in participation in relation to classroom factors, such as peers, support, and availability and individual differences between children is needed.

2 THEORETICAL BACKGROUND

The theoretical framework used in this thesis is system theory, focusing on Bronfenbrenners bio-ecological model as a model for child development. Health and disability are related both to development and participation and the ICF is used as a model for explaining health and disability in this thesis.

2.1 SYSTEM THEORY

Children's optimal development, well-being, and health are justifications for facilitating and focusing on participation. To participate fully, children must develop multiple roles within their micro environments, interacting with other people and with objects and characteristics in the context. Interactions between an individual's genetic and biological prerequisites and the environment shape development. Children are not passive receptors influenced by environments—they are active participants who affect their surroundings, while being influenced by elements in the context (Council, 2000; Sameroff & Fiese, 2000). Children interact dynamically within their micro settings, such as home, school, and playground; these settings provide various experiences, which affect the child. Children's personalities and other biological and physical prerequisites also affect interactions, including how they react to stimulus and how the surroundings react to them. A child's active involvement in this process is necessary for achieving full participation.

System theory views people as systems interdependent on the context. This interaction is multidimensional, and many factors (not just one) are necessary for a specific outcome. For example, no genetic disease is determined by one gene. And having a genetic disposition for a disease does not indicate that the person will become sick. Usually, more factors than simply genetic disposition have an impact on outbreak and prognosis. According to von Bertalanaffy (1969), living organisms are open systems; they exchange energy and information with their environment as biological units—not physical units. Open systems function by principles of equifinality and feedback. Equifinality indicates that the final state can be reached from various initial conditions. For example, children will learn to walk at varying ages and will focus varying amounts of energy on it. But they all reach the same goal. Another example might be that although children grow up in various life situations with varying prerequisites, most become healthy, well-adjusted adults. Feedback, communication, and control help the system to self-regulate, stabilize, and direct the system toward a goal (von Bertalanaffy, 1969). General system theory describes systems as hierarchically built, often with a stable structure (Bronfenbrenner, 1979). Elements on one level can change without affecting the other levels, so the system is stable but still flexible. But changes on single or multiple levels in the system can affect other levels. For example, children who do not sleep at night will have tired parents who perhaps will not function equally well at work. A school's reorganization may not always affect children in the classroom even if such effects were intended.

Bronfenbrenner (1979) defines the ecology of human development as "the scientific study of progressive, mutual accommodation between an active, growing human being and the changing properties of the immediate settings in which the developing person lives, as this process is affected by relations between these settings, and by the larger contexts in which the settings are embedded" (p. 21). Bronfenbrenner describes the effects of environment as something broader than the direct environment, which creates a system of levels—from *micro* to *macro*—which

can affect interactions in the immediate setting between a child and his/her environment. An environment can be seen as any event or content outside the person that either influences or is influenced by the developing person (Sontag, 1996). The micro level is the direct level of interaction in which the person exists and is defined as patterns of activities and roles and interpersonal relations experienced directly by the person. Settings are places in which people interact face-to-face using activities, roles, and interpersonal relationships as the micro system's building blocks. Interaction refers to the exchange between an active human organism and the people, objects, and symbols in its immediate environment (Sontag, 1996). Children will develop skills by playing with other children and with toys. The next level, the *meso* level, is a system of micro environments and refers to the interrelations between two or more settings in which a person actively participates, such as parents talking to the teacher when picking their children up at preschool or reading notes left in their child's school bag. The remaining two levels do not directly involve the person in focus. In the *exo* system, events occur that either affect or are affected by what happens in the micro system, such as the school's organization and what happens in the teacher's lounge or in parents' workplaces. The macro system is the framework of the lower levels, which include beliefs, culture, and ideology (Bronfenbrenner, 1979).

There is a distinction between context and process, with process being central and defined in terms of its functional relationship to the context and person (Bronfenbrenner, 1999). Bronfenbrenner (1979) hypothesizes that learning and development are enabled by the child's participation in gradually more complex patterns of joint activity with someone to whom the person has developed a strong, stable, emotional attachment. Two decades later, he defines these proximal processes as either with persons or with the environment—claiming that human development occurs through a reciprocal interaction between the individual and the micro setting, which over time becomes more complex in proximal processes. Proximal processes are "processes of progressively more complex reciprocal interaction between an active, evolving, biopsychological human organism and the persons, objects, and symbols in the immediate external environment. To be effective, the interaction must occur regularly over extended time periods." (Bronfenbrenner, 1999, p. 5). The form, strength, content, and directions of the process are a joint function of the person's characteristics and the close and distal environment. The process has a general effect of reducing, or buffering against, environmental differences in developmental outcomes (Bronfenbrenner, 1999). Children require more that just interaction with the environment to develop. This interaction must be of a quality that occurs regularly over time and becomes increasingly complex as the child develops. It must also be reciprocal, that is, the child cannot be passive and the person or object must respond. Attitudes and availability for activities can affect the number of processes, thus affecting a child's experiences. For example, people may have an opinion about children in wheelchairs and based on that, they may interact in a certain way with these children.

Bronfenbrenner and Ceci (1994) argues that proximal processes are presumed to lead to particular kinds of developmental outcomes, such as differentiated perceptions and responses, directing and controlling behavior, coping under stress, acquiring knowledge and skills, and modifying and constructing one's environment. The proximal processes are necessary elements of development. In disadvantageous settings, positive processes will reduce the maladjustments, while within supportive settings, the same proximal process will lead to increased skills for children (Wachs, 2000). Sontag (1996) argues that one reason why it is of interest to focus on this process is that some traits of a child with a disability may put the child at risk for disruptive, non-normative interactions that result in adverse context-based and

context-differentiated relationships. But the child's personal attributes can provide protections against such relationships. The concept proximal processes are closely related to the concept participation. Full participation requires participation in proximal processes in environmental niches.

2.1.1 Niches

The *niche* is the unique part of the person-environment interaction in which proximal processes occur. The nodal point between the person and the environment is described as a niche, which is "the part of the environment in which the person in a specific activity interacts relatively continuously with physical and social aspects of the immediate setting" (Wachs, 2000). Another way to describe the ecological niche is as a particular region in the environment that is especially favorable or unfavorable to development of persons with specific traits (Sontag, 1996). Niches can, depending on their organizational structure, either stimulate or inhibit development of participation in life situations. The niches available for a specific individual, that is, the niche potential, will be affected by the person's biological prerequisites in interaction with the close environment. So based on the context, various parts of the person will be stimulated. Having a specific feature or temperament might affect a child's interaction patterns and that will affect the child's experiences. One activity might suit a child better than another based on the availability of niches fitting that specific child. So certain school activities will suit certain children better than others. A disability can affect the child's experiences. Over time, a disability can lead to a child having various kinds of experiences that children without disabilities do not have, such as interacting with the environment with the support of an assistant. By having a reduced number of experiences or various kinds of experiences, children with disabilities might experience participation restrictions and a limitation of available niches (Wachs, 2001).

The niche is a stable pattern of roles, functions, and relations to a specific context or activity with specific physical and social characteristics. This might indicate that a person can choose one type of niche in many varying situations but might have other niches available if the preferred niche does not fit. Niches are not equally available for various individuals, and the level of specialization of person-environment interaction decides how many niches are available for a specific individual. The level of centralization around one or several factors in the child's life affects the number of available niches and the child's niche potential. The more centralized the person is, the less the chance of getting in contact with new types of niches. Various niches are important in various stages of a person's life (Wachs, 2000). For example, when a child is young, the family is very important. While growing up, friends, and leisure time spent with them, become increasingly important. When getting married and starting a new family, the family becomes central. A person does not interact with all aspects of an immediate setting (Wachs, 2000). Actual availability of the environment, and the degree to which children perceive possible entry into an available situation, will affect the degree of participation they experience in a specific life situation. Earlier experiences will affect a person's interpretation of the current situation. A recurring theme in a study of play experiences (recalled by adults with disabilities) was that they actively searched for access to niches that had a good fit with their skills and interests and avoided niches with a bad fit (Sandberg, Björck-Åkesson, & Granlund, 2004). So *subject characteristics*, such as locus of control, and *physical and social properties of the environment*, will affect a person's niche potential.

This indicates that children in the same context can have varying outcomes. This phenomenon is called *multifinality*. By the same token, different starting points or contexts for children can lead them to the same goal, that is, *equifinality*. Through interactions with the environment, a person's niche potential will become realized and more specialized. The relationship between the child and his/her caretaker will have a strong impact, as will other factors such as temperament, social class, culture, social support networks, caretaker's health, and so on. While a visible disability might narrow the niche potential, being cute might increase the number of niches. Having a broad niche potential is something that will increase the child's opportunities for many learning situations, while being overspecialized might close opportunities for other niches. A restricted niche potential may affect a child's well-being.

2.2 HEALTH AND DISABILITY

Health and disability are not opposites on the same scale; people with disabilities can be just as healthy and perceive well-being as much as others. Participation is mentioned as a health-related concept and can be seen as a positive way of describing health, that is, to measure health as something different than absence of disease. Positive psychology, focusing on salutogenic factors rather than pathological, focuses on strengths rather than weaknesses and rests on three pillars—positive subjective experience, positive individual traits, and positive institutions—moving away from focusing on diseases and toward focusing on positive functioning and qualities (Seligman & Csikszentmihalyi, 2000). This focus fits well with participation as a measure for positive functioning. Children who are engaged and participate in activities are most likely happier and healthier.

Other human phenomena promoted through environment, which are described as examples of positive functioning, are resilience, competence, and optimism (Clonan, Chafouleas, McDougal, & Riley-Tillman, 2004). To focus on positive development and functioning is to aim at what makes children and adolescents healthy. Functioning well in life situations will probably have a larger impact on a person's health than the existence of a disability will have. Positive development is an interplay between multiple, interdependent processes that involve the entire organism over time (Mahoney & Bergman, 2002). Positive functioning is making use of psychological and contextual resources to achieve a good developmental outcome (Mahoney & Bergman, 2002), and the outcome of good development is a healthy, well-adjusted adult. The interplay between the psychological processes that motivate the individual and the contextual conditions that influence such processes are necessary Prerequisites of positive functioning.

If participation is viewed as health-related and as an indicator for positive functioning, it is vital to define disability and its relation to health. Traditionally, disability was defined based on a biomedical perspective (Bickenbach et al., 1999; Simeonsson, 2005; Skolverket, 2005; Üstün, Chatterji, Bickenbach, Kostanjsek, & Schneider, 2003). The biomedical perspective regards disability as an attribute of the person, and defines disability as an observable deviation from normal structure or function (Bickenbach et al., 1999). According to the more contemporary definitions, disabilities can be viewed as human conditions characterized by limitations in function, performance, and adaptation when meeting environmental requirements (Lollar, Simeonsson, & Nanda, 2000). However, there are no unified ways of defining disability, especially for children and adolescents. Most definitions of disability consist of either having a medical, social, or more functional construct (Simeonsson, 2005). There are problems with only having a medical perspective on disability, especially for children. The younger the child, the greater the challenge in

defining disability, and it is often connected to atypical development (Simeonsson, 2005). Using a social model for disability does not sufficiently account for biological variance. A functional model has not been used with the same consensus as the medical and social model, but the basis for a functional model defines disability based on functional limitations rather than diagnosis or social failings. Defining disability in relation to positive functioning, participation becomes an indicator for degree of disability.

Simeonsson (2005) connects the reasoning on how to define childhood disability back to the transactional model (see, for example, Sameroff & Fiese, 2000), reinforcing the relevance of interactions between child and environments for defining developmental outcomes. Focusing on functional models that emphasize functional activity limitations is very compatible with a transactional perspective and the ICF bio-psychosocial model. The ICF combines the medical and social models of explanations. It defines disability as "an umbrella term for impairments, activity limitations or participation restrictions" (WHO, 2001). The introduction of barriers and facilitators in environment in the model makes it well suited for a functional perspective.

2.2.1 THE INTERNATIONAL CLASSIFICATION OF FUNCTIONING, DISABILITY, AND HEALTH

ICF is an interactional model, combining using a biopsychosocial perspective. One reason for using the ICF as a model for disability and health is that it provides us with a unified, standard language for describing health and health-related states, avoiding a cause-effect relationship between health and handicap. Another reason is that participation is a part of the model described as a relevant health component in describing health and disability, which makes personal experience and personal engagement a part of defining health (WHO, 2001). In the ICF, *handicapped* and other negative terms were eliminated; instead, it focuses on positive terms such as functioning, structure, activity, and participation. So the ICF is aligned with a functional disability model, with a systemic theoretical framework, and a focus on individuals and the environment.

Lollar et al. (2000) argue that the ICF is useful in documenting and describing children and adolescents with special needs and disabilities and in measuring outcomes of development or intervention, complementing to ICD-10. A broader perspective than simply a biological one is needed, and the ICF allows for measuring disability on all levels, not just the body level. The ICF provides better information about difficulties for individual children than information generated by diagnosis. Educators and service providers in the social sector have more use of information about areas in which the child has activity and participation limitations than information about the diagnosis (Florian et al. 2006). The ICF also focuses on environment as consisting of barriers and facilitators that affect child functioning (Florian et al., 2006).

The ICF structure consists of body *functions* and *structures* and of *activity* and *participation*. These components must be seen in relation to the environment, that is, they do not merely focus on the individual; they also acknowledge that there is a contextual factor to disability. Body functions are the body system's physiological functions, and body structures are the body's anatomical parts, such as organs, limbs, and their components. Impairment consists of functional and structural problems. Activity is an individual's execution of a task or act, and activity limitations are an individual's execution difficulties. Participation is involvement in life situations, and participation restrictions are problems an individual may experience in involvement

in life situations. Environmental factors make up the physical, social, and attitudinal environment in which people live and conduct their lives (WHO, 2001; p. 10). According to the ICF model, a person should be able to have participation restrictions without activity limitations. Ueda and Okawa (2003) give an example of a person with a visible birthmark, which could create participation limitations because of environmental attitudes. Perenbloom and Chorus (2003) identify difficulties in distinguishing between the activity and participation domains. Activity is an individual's execution of a task, while participation is an individual's involvement in life situations (WHO, 2001). These are measured by capacity and performance (Perenbloom & Chorus, 2003). One problem with capacity and performance is that both can be seen as dimensions of activity, which makes it difficult to pinpoint a person's participation, with a focus on his/her engagement in life situations. Persons, who are not capable of performing the activity (activity restrictions), can still participate. Participation as performance is not the same as being engaged in a situation, and this difference might create difficulties in separating activity from participation. In this thesis, the perception of participation is also included in the construct. To conclude there is a close link between development, health, and disability. Participation is a key component in this relation.

3 PARTICIPATION

In order to participate a person need to be an active part of their own life, being able to decide how and what activity they wish to participate in, and to be given the opportunity to take part in desired activities. Thus, participation is a multidimensional concept with an internal personal dimension, an activity dimension, and a contextual dimension. Participation in life situations is part of a child's development, learning process, and life. Participation enables children to explore their potential, and it affects future life satisfaction (Law et al., 2004). Full participation in school supports academic achievements (Finn & Cox, 1992). Opportunities to participate in desired activities and to make decisions about everyday life are necessary for the individual's experiences of participation and well-being. To be engaged in an activity, an individual must be aware that the activity exists, have access to the activity, and be interested in participating in the activity (Molin, 2004). An individual's personal involvement and participation in activities can be observed and experienced at the nodal point between the person and the immediate setting, that is, the person-environment niche (Wachs, 2000).

Participation can be observed on all levels of the environment not just on a person's proximal setting. Participation is mentioned in societal documents for governing preschool, school, and support systems. Participation is defined as something important to facilitate on the personal level, but it is not always clearly defined. The national curriculum for preschools (Lpfö98, 1998) states that "Each child is to be given opportunities to establish his/her opinions based on his/her prerequisites and based on his/her ability to make choices. This will lay the foundation for the significance of participation and confidence in his/her abilities." (p. 2) Participation can also have a civil rights perspective and be a part of the advocacy movement in which participation is used together with concepts such as normalization, integration, good living conditions, and being an equal member of society with the same rights as others (Gustavsson, 2004).

The concept participation consists of more than just performing an activity. Research that focuses solely on one dimension of participation, such as activity, loses vital parts of the participation concept (Dudgeon, Massagli, & Ross, 1996). Gustavsson (2004) states that participation can have various meanings—depending on where and when it is used. Participation can be seen in several ways, such as being part of something and having a feeling of kinship. On a higher level, the feeling of participation is one of the prerequisites for a society in order to create solidarity in various societal settings (Gustavsson, 2004). Participation is commonly measured as activity. While the ICF definition of participation is to be engaged in life situations (WHO, 2001), participation is measured as performance, and activity is measured as capacity. Capacity and performance are various aspects of activity. To focus on activity, rather than participation, facilitates dividing people into groups based on disability type. Participation is something other than being able to perform activities. People can participate even if someone else, such as an assistant, performs the activity for them. The individual alone can determine his/her own level of participation (Perenbloom & Chorus, 2003).

To summarize, participation can have multiple locations, such as internal, interaction between person and environment, and contextual, and can be placed in various settings, from micro to macro. Participation is a part of the individual, such as a feeling of involvement. It is also doing something, participating in activities, and it is dependent on context prerequisites, facilitators, or barriers in the environment. The

degree to which persons are actively engaged in life situations is related to how they perceive themselves and their context. On an individual level, there is a close link between engagement and participation—engagement is a part of the participation definition.

Table 1

The participation concept in various environmental settings

Dimensions of participation			
Setting	**Location**		
	Experiences	**Activity**	**Prerequisites**
Person and close environment	Belonging Competence Reciprocity Understanding Motivation	Engaged Active Focused Interacting	Autonomy Locus of control Social skills	Interaction Means of assistance School form Instruction groups, teachers
Relations between environments	Having control Controlling	Planning, Deciding Expressing opinions	Education Competence	Action plans Teacher parent discussions
Society	Identification with the group	Politically active Getting information Participating in extra curricula activity and other interest groups	Well-informed Basic needs satisfied	The structure of school organization

Table 1 (taken from Granlund et al, 2004) illustrates the multidimensionality of participation—over the levels of settings that range from a close, micro setting to a broader societal macro setting. Factors can be located within the person as experiences, shown as interaction or activity, and depend on personal and environmental prerequisites. In relation to different environments, participation is part of the relation and interaction between settings. The level of participation in various settings and the similarity between them is relevant (Granlund et al., 2004). In relation to society and work, equality, influence, and democracy are often concepts related to participation (Granlund et al., 2004). This thesis mainly focuses on the individual level, that is, the person and his/her close environment. One way to visualize the multidimensionality of participation for individuals is to put various concepts within participation into a time relationship, talking about the personal experience, the activity, environmental prerequisites, and the relationship to niches (Figure 1) in relation to the arrow of time.
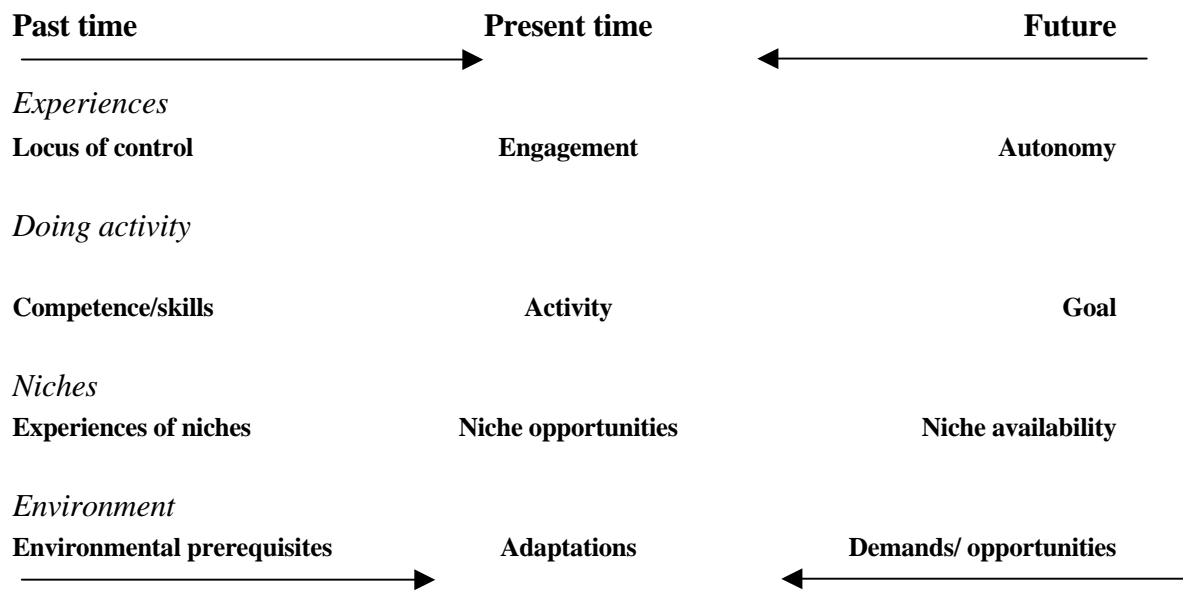
Past time →	**Present time**	← **Future**

Experiences

Locus of control	**Engagement**	**Autonomy**

Doing activity

Competence/skills	**Activity**	**Goal**

Niches

Experiences of niches	**Niche opportunities**	**Niche availability**

Environment

Environmental prerequisites →	**Adaptations**	← **Demands/ opportunities**

Figure 1. Factors within the person, niche, and environment related to participation. Taken from Almqvist et al. (2004).

This model (Figure 1, Almqvist, Eriksson, & Granlund, 2004) focuses on the fact that participation in the present situation depends on what has already happened, how the future will be interpreted, and what is expected. A person's participation is developed over time, and earlier experiences affect a person's locus of control. The skills a person has and the kind of environment that the person knows about will have an impact on participation. Opportunities taken within a situation, together with goals set up by the person (often short-term), will also affect present participation in conjunction with expected environmental opportunities. The number of available niches for a student in school is related to the way in which the student scans the surroundings for opportunities and the degree to which the opportunities are aligned with the student's previous experiences.

For young children, engagement and participation are manifested through play (see Johnson, Christie, & Yawkey, 1999; Pramling, Samuelsson, & Sheridan, 1999; Sandberg, 2002). In play, imagination, feeling, communication, symbolic thinking, the ability to cooperate, and solving problems evolve (Vygotsky, 1980; 1995). In a study that asked children, ages 4-5, about health, the results indicated that play was important for feeling good. Healthy children were happy and had many friends (Almqvist, Hällnäs, Stefansson, & Granlund, accepted). Play and other leisure activities are an important part of a child's life and can be used as quality-of-life indicators. Other children are an important part of play and play experiences. Loneliness is often a problem for children with disabilities; it is one factor that children, who left regular school for special school, mentioned as something negative in regular school (Szönyi, 2005). Lonlieness is related to negative self-worth and negative attitudes about school (Grue & Heiberg, 2000), indicating that social participation and academic achievements are related to inclusion. Children with disabilities often play alone or with adults who seem to replace friends that children and youth with disabilities lack (Tamm and Skär, 2000). Further, children with disabilities are not just more frequently solitary; they are engaged in on-looking activities more frequently than children without disabilities (Hestenes and Carroll, 2000). Having a less rich play experience than their peers

14

(Howard, 1996), children with physical disabilities spend more time in self-care and passive activities in their homes (compared to non-disabled peers), and their activities often require assistance (Brown & Gordon, 1987; Buttimer and Tierney, 2005). Children with disabilities are restricted in their participation in play experiences.

Past and present experiences shape participation and so do future expectations. Over time, niche potential and the fit between the person and situation will take a certain direction based on previously available niches. If children with disabilities are unable to participate in the same activities as other children because, for example, they're involved in solitary activities or activities with adults rather than other children, then differences in participation between children and youth with disabilities and their peers will increase with age. They will participate in various activities in varying ways and expect different outcomes from it. Brown and Gordon (1987) showed that differences in how children with and without disabilities spend their time increased as they became older. The differences in experiences between children with and without disabilities are visible early in life. The results of a small, unpublished observational study of children around age 2 (with and without physical disabilities), revealed that young children without disabilities were frequently actively occupied in solitary play that involved manipulating objects, while children with disabilities were passive with adults, often in care situations (Eriksson, Öhlen, & Granlund, in prep). If children with disabilities experience differences in participation from early in life, then they will develop different skills and different interaction patterns, which might not be optimal for them in adult life. If the child also has behavioral problems, something that can be common in children with developmental delays, teachers' responses will further undermine their experiences of positive proximal processes (Almqvist & Granlund, submitted).

Being self-determined and making decisions is one aspect of participation. Kjellberg (2002) interviewed adults with intellectual disabilities about participation in everyday life and society, defining participation as the level of independence in decision-making in micro settings. Adults with intellectual disabilities made most decisions together with personnel or not at all. The personnel made the decisions, especially regarding work, and the persons with intellectual disabilities were more independent in leisure activities (Kjellberg, 2002). Kjellberg found that persons with intellectual disabilities had a gap in societal participation in relation to everyday life. Just as for adults with intellectual disabilities (Kjellberg, 2006), participation of children in decision-making often depends on adult attitudes (BarnOmbudsmannen, 2006). Students with disabilities often feel that adults in school respect their wishes but that peers do not, and that peers do not ask about their opinions (BarnOmbudsmannen, 2006).

Another research perspective focuses on special schools and participation. Szönyi (2005), for example, focused on the perspective children with mental retardation in special elementary schools and found various perspectives on school participation. Some students had an unproblematic view of participation in school, a view that exclusion was fairly ordinary, or that exclusion was common for children who were different. This indicates that children with intellectual disabilities recognize participation problems and that being a part of a group (even this group that is not the *mainstream* group) is really important for enjoying school. Students identified social aspects of participation more often than academic aspects and problems. Special schools were seen as something positive for their participation even though they usually felt that they wanted to be a part of the regular school (Szönyi, 2005). Molin (2004) defines participation with a focus on students with mental retardation in special high schools by placing activity and participating in activities as central

concepts. Being involved and being able to make decisions were important. Molin argues that maximal participation happens in interaction with context. It is marked by acceptance and reciprocity, together with a sense of belonging; hence it also focuses on personal, interactional, and contextual factors. Molin (2004) claims that you cannot talk about participation without mentioning belonging. But belonging by itself is not the same as participation. Molin divides belonging into formal, vertical, and specific in time, and informal, horizontal, and more daily over time. Participation, inclusion, and belonging are important factors for children with disabilities. Being able to make decisions, to be involved in everyday activities, to belong to groups, and to have friends are vital aspects of life—regardless of setting.

3.1 FACTORS RELATED TO PARTICIPATION

It is difficult to distinguish between what is participation and what are factors related to participation. The reason for this difficulty is that participation is a multidimensional concept, consisting of personal traits, interactions, and contextual prerequisites. According to modern theories of development, most outcomes related to developmental processes such as participation are consequences of multiple functional and structurally interrelated factors of influence (Bronfenbrenner, 1999; Shonkoff & Phillips, 2002; Super & Harkness, 1999; Wachs, 2001). Depending on type of outcome, these factors might vary, so in studying participation in school activities, it is important to define participation and to delimit factors that are directly and indirectly related to participation.

The degree of participation depends on patterns of factors related to participation. For example, Almqvist and Granlund (2005) found that having an overall positive rating of several personal and contextual factors was the strongest predictor of frequent participation in school. A literature review of factors related to participation in young adults with intellectual disabilities found that factors related to participation were personal factors such as involvement, self-efficacy, self-determination, and well-being, and environmental factors such as social support, having choices, opportunities, availability of activities, and people's attitudes (Arvidsson, Thyberg, & Granlund, submitted). Factors related to participation seem to vary based on context and on the person's current life situation, that is, factors related to participation in school might vary from factors important in adult life.

Disability research has a tradition of focusing on groups of subjects categorized according to disability type and of using just one group of disabilities in doing the research (Dudgeon, et al., 1996; Schenker, et al., 2005; Skär, 2002; Hemmingsson, 2002). Research is perhaps focused on diagnostic groups because interventions and services are traditionally planned based on diagnosis, even though there is little evidence concerning the validity of using diagnosis as basis for service (Law et al., 2004). Having a disability is related to participation, but the diagnostic category does not seem to affect participation intensity and diversity (Almqvist & Granlund 2005; Brown & Gordon, 1987; Law et al., 2004). One explanation for this lack of relationship is that participation is multidimensional and that disability is only one of several factors that affect participation and that the effects of other factors are stronger.

Using disability type as a criterion for choosing respondents is perhaps not relevant when conducting research about participation, but some studies have found differences. Simeonsson et al. (2001) found that teachers rated students with more severe disabilities as participating less in school than children with mild to moderate disabilities. Schenker et al. (2005) found that activity performance limitations had an impact on participation for children with cerebral palsy. The largest participation

variation between groups was during play at recess, and the smallest variation was at mealtime. The degree of participation, as perceived by students with disabilities, is probably more strongly related to personal characteristics other than the person's type and degree of disability (Almqvist and Granlund, 2005; Grue and Heiberg, 2000). But for adults, there could be environmental differences that affect participation, which depend on disability severity. Tideman (2004) argues that severity of disability has an impact, because persons with milder disabilities have better living conditions than persons with more severe disabilities. In a literature review focusing on adults with mild intellectual disabilities, Arvidsson et al. (submitted) found that environmental factors, such as housing and finances, were directly related to participation factors, while personal factors, such as IQ, had no strong relationship to participation. But IQ was related to the type of living a person experienced, thus indirectly affecting participation.

3.1.1 Personal factors

Self-determination is emphasized as vital for persons with disabilities—factors such as having choices, making decisions, solving problems, and setting goals. Self-determination is related to quality of life (Lachapelle et al., 2005; Wehmeyer & Schwartz, 1998). It is defined as "acting as the primary causal agent in one's life and making choices and decisions regarding one's quality of life free from undue external influences or interference" (Sand & Wehmeyer, 1996, p. 24). The essential characteristics of self-determined behavior were a) the individual actes autonomously, b) the behaviors are self-regulated, c) the person initiates and responds to events in a psychologically empowered manner, and d) the person acts in a self-realizing manner (Sand & Wehmeyer, 1996; Wehmeyer, Kelchner, & Richards, 1996). Being a causal agent is necessary for being self-determined (Wehmeyer, 2004). A causal agent is someone who makes or causes things to happen in his/her life (Wehmeyer et al., 1996). They take participation opportunities that *they want* to take, when they find them motivating, and will therefore participate more frequently and more intensively in different situations.

Autonomy appears to be essential for facilitating optimal functioning, social development, and personal well-being. Clark, et al. (2004) states that facilitating autonomy enhances psychological health. Autonomy can be seen as a personal factor or as taking available opportunities. In this thesis, autonomy is the part of self-determination that is measured. To execute an autonomous behavior, environmental opportunities must be provided, so even though self-determination can be seen as a personal factor, environmental factors can support or undermine it (Ryan & Deci, 2000). Persons with disabilities often experience low self-determination and autonomy (Clark et al., 2004; Wehmeyer, 1998; Wehmeyer & Schwartz, 1998), therefore teaching self-determination skills to students with disabilities is important. Teachers often find instructing and teaching self-determined behavior to be more relevant for students with minor disabilities and not as relevant for students with severe disabilities (Wehmeyer, Agran, & Hughes, 2000). But autonomy and having the opportunity to make choices and decisions in ones life is important for well-being (Lachapelle et al., 2005) and participation (Almqvist & Granlund, 2005) for all persons. Self-determination in school supports societal participation, finding employment, independent living, access to health services, and financial independence (Wehmeyer & Palmer, 2003). Being an adolescent, who requires support from adults, could hinder self-determination. In a study by Skär (2003), students with motor disabilities reported that their disability was the reason for their lack of self-determination and social relationships with peers.

Having self-regulation skills, being psychologically empowered, and feeling good about one's abilities can support motivation and participation in school activities. The image people have of themselves affects their participation. Bandura (1997) claims that self-efficacy is related to development and growth. Perceived control and academic achievement have a reciprocal relationship. Feeling in control over outcomes builds self-efficacy; succeeding in tasks builds a robust belief in personal efficacy and failure undermines it (Bandura, 1997). This is especially the case for children before a sense of efficacy is firmly established. Teachers can support students' self-efficacy by supporting their sense of control over their academic achievements (Skinner, Zimmer-Gembeck, & Conell, 1998). Explaining success and failure as something controllable by the child will support a sense of control. Bandura (1997) argues that support, through explaining cognitive strategies, does not increase the sense of self-efficacy. But reminding students that they exercise better control over academic tasks by using the strategies does increase self-efficacy. Failing in school and requiring more help from teachers, together with a feeling of not being able to control schoolwork, will affect the academic self-concept negatively. With age, students will increasingly associate achievement with capacity. Students having an external locus of control will doubt their own capacity, while students having an internal locus of control will believe in themselves (Skinner et al, 1998). Believing that the outcome is based on effort and hard work will increase students' academic performance and their motivation and participation in school activities. It can be argued that children who require special support are at risk for experiencing more failure in school than other children. Special support can undermine their self-efficacy, and they may lose their motivation for academics (Westling Allodi, 2000). Children with disabilities are more likely to have lower self-concept and feel that their academic outcomes are out of their control, but there are large individual differences within the group of children with disabilities regarding self-concept (Durrant, Cunningham, & Voelker, 1990). But Finn and Cox (1992) did not find a relation between self-concept and school participation, which indicates that self-concept, at least in early grades, is not a prominent mediator of school performance. Grue and Heiberg (2000) also support this notion. They found that children and adolescents with disabilities did not vary from peers without disabilities in their overall self-perception. However they found that students with disabilities had lower self-esteem in athletic abilities, practical skills, and romantic appeal.

3.1.2 Social relationships

There is a growing consensus that children with disabilities should be educated within mainstream school settings and not segregated in special schools (Holt, 2003). Children with disabilities are included in regular school classes to increase their opportunities of gaining theoretical and social knowledge (Bronson, Hauser-Cram, & Warfield, 1995; Gustavsson, 2004) and to promote their independence and social participation (Hartup, 1996; Kennedy et al., 1997; Simeonsson, et al., 2001). Children with disabilities, especially those with mild disabilities, have long been integrated into regular schools, but they often have problems with social integration, such as peer acceptance, friendship, and participation in group-activities (Cullinan, Sabornie, & Crossland, 1992). Cullinan et al., (1992) defines being socially integrated as being socially accepted, having at least one reciprocal friendship, and being an active, equal participant in activities performed by the peer group. According to Cullinan et al. (1992) teachers can facilitate the integration of students by creating rules in the classroom and explaining and modeling the activities for the students. Adjusting the environment can support social relations and friendships for severely disabled

students as well as educating teachers and peers in giving social support, placing the peers close by, and providing support within the school setting (Kennedy, Cushing, & Itkonen, 1997).

Children who have friends probably have more frequent opportunities to participate in various desired activities. Their niche potential is greater in school and in leisure activities. Problems with friendships and loneliness can lead to less participation in school and leisure activities and to less motivation and lower levels of academic achievement (Buttimer & Tierney 2005; Guralnick & Groom 1987; Guralnick & Groom, 1988; Skär, 2003; Szyöni, 2005). Children with disabilities often have fewer friends than their peers in school (Buysse, Davis Goldman, & Skinner, 2002; Pavri & Monda-Amaya, 2001; Skär, 2003), and they are less preferred as playmates (Guralnick & Groom, 1988; Hestenes & Carroll, 2000; Nowicki & Sandieson, 2002). In school, children with disabilities often play alone or observe (Nordström, 2002), and they are often rejected as playmates (Jacobs, Sandstrom & Coie, 1999). There are many indicators that children with disabilities are at risk for social exclusion. This is not just a problem in regular schools; children in special schools also benefit from support in peer relationships (Hall & Strickett, 2002). Students enrolled in special schools often recognized social exclusion as a problem in their former school and often felt that they had more friends in the special school and felt more welcome in the special school (Szönyi, 2005).

Participation in leisure and extracurricular activities is related to having and creating friendships. Children with disabilities seem to be less liked as playmates. Participating in extracurricular activities, together with an internal locus of control and social status, seems to improve the status of rejected children and adolescents as playmates (Jacobs et al., 1999). Participating in extracurricular high school activities contributes to educational success and supports good relation with peers (Mahoney et al., 2003). Participation in extra curricular activities seemed to be of extra importance to students with below average interpersonal skills. Participation in recreational activities, together with positive behavioral functioning, predicted the prosocial behavior of children and adolescents (King et al., 2005). Children with disabilities often participate in solitary leisure activities and usually only interact with peers by telephone (Buttimer & Tierney, 2005). Lane et al., (2004) state that without vital social skills, students risk academic underachievement, peer rejection, and strained relationships with teachers. One reason for the problem in interacting with other children might be that even though children have a positive view of including children with disabilities, when asked, they are less positive when it concerns activities that they are involved in (Magiati, Dockrell, & Logotheti, 2002).

Social support from adults and peers is related to well-being and achievements in school. Social support networks are claimed to be resources for the individual (Dunst, Trivett, & Jodry, 1997). This is especially true for the informal social network. The informal social network consists of family, friends, and other important persons who are not paid to interact with the person. Formal support is from professionals paid to care for the individuals. Having a large social network increases the person's niche potential. Social support is often divided into three subtypes: emotional, instrumental, and informational. A child's emotional support is related to the amount of value, love, and caring available from other people such as teachers or peers. Instrumental support refers to practical help, such as aid or assistance, and informational support relates to decision-making and receiving appropriate feedback (Jones & Bright, 2001). The peer support that children and adolescents experience is related to scholastic motivation and problem-solving abilities (Guthrie & Davis, 2003; Wentzel & Watkins, 2002). Children with disabilities can often name people in their social network, but often feel lonely, having less social support, especially emotional support (Pavri & Monda-

Amaya, 2001). One reason might be that children with disabilities have fewer social skills than their peers, and they experience more problems in creating and maintaining social relationships (Carlson, 1987). Adults with spinal cord injuries, who perceive their social support as insufficient, have problems making decisions and realizing their desires in a way that could negatively affect their self-determination and participation in everyday life (Larsson Lund, Nordlund, Nygård, Lexell, & Bernspång, 2005).

Teachers' attitudes and behavior affect children's motivation and participation. Teachers are often positive to the inclusion of students with disabilities but prefer that they receive support outside their own classroom (Heiman, 2004; Holt, 2003). Teachers often feel that removing the child from the class is a good solution that helps them manage the class. Being removed from the class reduces opportunities for inclusion, and participation in activities with friends and peers might be hindered. One reason for excluding students who require special classroom support is pressure to maintain standards regarding inclusion as a social intervention and not an academic intervention (Holt, 2003). Excluding children from class does not increase their academic performance. Cole, Waldron, and Majd (2004) found no difference in performance and learning between children with disabilities in inclusive and special classes. But the diversity benefited the learning of students without disabilities. In athletics, Ninot, Bilard, and Delignieres, (2005) found that segregated sports supported the perceived abilities of students with disabilities and that integrated sports increased their performance. Girls, who were included, compared themselves with the other girls and valued their performance as worse even though the competition increased their performance.

Students with disabilities included in regular classes risk experiencing inappropriate educational interactions. Students who require special support were found to be over-represented in teachers' indifference and rejection categories. One reason for this is that teachers feel they do not have the knowledge and training to support these students (Cook, 2001). This risk of receiving inappropriate teacher responses starts early in life for students with behavioral difficulties. Almqvist and Granlund (submitted) found that over time, teachers withdraw their interaction with young children with behavioral problems, perhaps because they find it difficult to know how to handle them. A teacher's behavior affects children's behavioral and emotional involvement, and teachers spend more time and give more support to involved students and neglect passive students more (Skinner & Belmont, 1993). Involved students receive more emotional support and uninvolved students receive responses that further undermine their motivation. When students receive less support and experience the teacher as inconsistent, they may develop an external locus of control (Skinner & Belmont, 1993), so teachers and their attitudes and behavior are a vital part of the proximal environment.

3.1.3 Environmental factors

Contextual factors are important for children's experiences and outcomes in school. The environment consists of physical and social elements that can create *and* limit participation opportunities. While the actual environment is relevant, the perceived context is perhaps even more relevant. The way in which children perceive the environment will probably affect participation opportunities that they feel they have, which in turn affects situations they participate in, based on interest. An environment that is suitable for the child has a good personal fit in which the child can find opportunities that facilitate participation. Facilitators and barriers in the environment can be social and physical—factors that the ICF accounts for. King et al. (2005) state

that there are five main barriers to participation in leisure and recreational activities: interests or preferences, time, money, facilities, and skills. Facilities can be barriers because they are often constructed for average persons, and children with physical disabilities will encounter restrictions (Law et al., 1999). Buttimer and Tierney (2005) and King et al. (2005) found similar barriers to participation in leisure activities. Students with disabilities identified barriers such as having enough time, ways to get there, places to do it, and feeling allowed to do it. Parents reported factors such as having a friend to do it with, knowing how to do it, and feeling welcome (Buttimer & Tierney, 2005).

The way in which children perceive a context plays an important role in their level of participation within that specific context. For example, if they cannot recognize available opportunities, then they will not participate; if the situation is not identified they do not know the situation exists. One means of measuring children's perceptions of their context is to measure perceived availability. Almqvist and Granlund (2005) found availability necessary for a student's perceived participation, that is, to participate in a situation, the situation must be identified as available. Planning and preparing for play and interactions will support and enhance children's play, development, and social relationships (Doctoroff, 2001). Preparing environments can support children with disabilities by providing opportunities to play together with peers. Because of contextual barriers, children with physical disabilities often play in other locations compared to their peers (Howard, 1996).

Support and aids constitute another environmental element relevant for participation. Without good support and aids, participation could be restricted. Adjustments to the environment might increase the personal-environmental fit, facilitating participation within that setting. As an example, children with physical disabilities perceive indoor environments as harmonic without barriers, and they can participate in peaceful activities such as listening to music, watching TV, or playing with puzzles. Being outdoors is full of enjoyment and barriers, with difficulties getting to playgrounds, limited accessibility during the winter, and facing difficulties getting to desired places (Skär, 2002b). Buttimer and Tierney (2005) and King et al. (2005) claim that having problems getting to and from desired activities constitutes a barrier. Regarding technical aids, children feel that they are a natural part of them but that the aids sometimes create problems in their relations with peers. If the aids support students' ability to keep up with peer activities and to be autonomous from adults, then the aids were perceived as having a higher social value (Skär & Tamm, 2000).

There are difficulties in identifying research that focuses on the relation between students' environments and their participation within the environments. Hemmingsson (2002) argues that there is little research focused on environmental factors that affect participation in school. Hemmingsson and Borell (2002) found that most students with physical disabilities experience participation restrictions in their physical and social contexts. Even though older students perceived more barriers, many of the contextual barriers were generated from the organization and execution of teaching and not from type and degree of disability (Hemmingsson and Borell, 2002). Children experience school as a social arena, with a focus on the children's actions and activities (Westling Allodi, 2002). Westing Allodi (2002) found that problems in school were lack of stimulation and control, something that Specht et al. (2000) also found, which indicates that students with disabilities risk being under-stimulated.

Support is a necessary tool for removing barriers and facilitating participation. A common support mechanism is a personal or classroom assistant. Having an assistant can facilitate development, but sometimes having an assistant can create obstacles for

participation in school. Assistance is important for children's inclusion and participation (Howes, Farell, Kaplan, & Moss, 2003). The way that assistants work can either facilitate or inhibit participation and social relationships. Just having an assistant was not sufficient for facilitating participation. For assistants to be supportive, they needed to be valued members of the educational team, working as mediators between various groups in school and being good at tapping into the students' socio-cultural aspects of life. Assistants who stay in close proximity to the students could prevent interactions with peers and teachers and become barriers to inclusion, participation, and social relationships (Hemmingsson et al., 2003). Assistants, who invite other students into games and other activities, support participation in social interaction of students who require special support, while support for learning during class time may need to be provided differently. The relative role of assistants, based on how they choose to work, can make students who require support ambivalent to this type of support (Skär & Tamm, 2001). For children with physical disabilities, assistance is important to play, but older children often questioned their need for assistance (Hemmingsson et al., 2003; Skär, 2002a). If assistants become barriers to interacting with peers (by being close by), then students, especially older students, will see assistants as barriers to independence and participation (Hemmingsson et al., 2003). Adolescents often want to develop independence and manage without adults, and by having assistants, the students risk losing opportunities for taking initiatives and being self-determined (Hemmingsson et al., 2003; Skär & Tamm, 2001). Not having control over their own assistance might create a barrier to their participation.

To conclude, participation is today brought up in international agreements, political documents, and research as necessary for children's health, well-being, and development. There seems to be consensus that persons with disabilities participate less. There has been focus on the societal level of participation, such as human rights, normalization, and self-determination, but more focus on the child in his/her everyday setting is needed. It is also necessary to focus on participation as a multidimensional concept related to many factors. Participation can be defined in various ways, and it is necessary to know how children and adolescents with disabilities define participation. It is also necessary to recognize what factors are relevant in relation to participation, and students' perceptions of their participation. Previous research indicates that social factors, such as social skills and friendship, play a more prominent role in level of participation than disability type. Environments seem to consist of facilitators and barriers. So finding out what role environments have on participation is necessary, especially in relation to how participation for children and adolescents with disabilities is measured. There are two primary ways of measuring participation, as frequency of being active in an activity and as intensity in the engagement in the activity

4 RESEARCH OBJECTIVE

The objective of this thesis is to investigate participation in school activities for children and adolescents with disabilities and to particularly focus on personal factors and factors in the close environment that are related to participation. To fulfill this comprehensive objective, five studies with different goals were implemented.

4.1.1 Study I

In this study, the conceptions of participation of students, parents, teachers, and special education consultants are compared and related to the students' chronological age and disability type. The study had three purposes:

1. Investigate whether conceptions of participation in children and students with disabilities are related to chronological age.
2. Investigate whether conceptions of participation are related to the students' type of disability.
3. Study how important persons in the students' close environment perceived participation, and investigate whether the conceptions varied—depending on the respondent's role, the student's age, or disability type.

4.1.2 Study II

1. The first aim of this study was to investigate whether assigning ICF codes to items from extant questionnaires (aimed at reliably and validly measuring participation-related phenomena) was possible—as suggested by Peerenboom and Choros (2003) and Cieza et al. (2002).
2. The second aim was to investigate the ICF theoretical assumption that the environmental component interacts with the body function and participation components.
3. The third aim was to investigate whether groups of individuals with similar participation profiles could be identified.

4.1.3 Study III

A hypothesis based on previous research is that factors, such as perceived availability of activities, interaction, autonomy, and the attitudes and values of others over time, are orchestrated into patterns of factors that affect the degree of participation in school activities, as perceived by children and adolescents with disabilities. The research questions raised in this study were:

1. Do students with disabilities vary from students without disability in how they perceive their participation in school activities?
2. Do students with disabilities vary from students without disabilities in how they perceive availability of activities?
3. Do students vary in perceived autonomy and locus of control dependent on whether or not they have a disability?
4. Do students rate their interaction with teachers and peers differently—depending on whether or not they have a disability?
5. Do differences between the groups in perceptions about participation, availability, autonomy, locus of control, and interaction increase with age?

4.1.4 Study IV

The aim of this study was to investigate how environmental factors, such as support given by the community, general support in the school, and specific support to individuals, are related to participation in school activities for students with disabilities. The research questions were:

1. Are environmental factors related to participation of children and adolescents with disabilities in school activities?
2. Is the degree of the school's general and specific environmental adaptations related to students' participation in school activities?
3. What are the statistical relationships between having a personal assistant and participation in various types of school activities for students with disabilities?

4.1.5 Study V

Based on observations of students with and without disabilities, the aim of this study was to study the degree of participation of children with and without disabilities in school activities. The research questions were:

1. Is there an overall difference in participation between the groups, and does this difference vary, depending on type of activity?
2. Is there a relationship between inclusion and participation?
3. Is there a relationship between received support and participation in activities?

5 METHOD

Two data collections were conducted. Studies I-IV are based on one data collection, and study V is based on another data collection. In study III, data are supplemented by material from children without disabilities, who answered the same questionnaires in other data collections. The four studies, based on data collection I, focused on various parts of the material. Data collection I will be explained first, then the methodological considerations for studies I to IV, followed by explanations of data collection II and study V. Data collection I was a large survey that measured how often students perceived themselves as participating in school activities. It also investigated factors relevant to participation according to earlier studies. Data collection II was a small-scale observational study of participation of children with and without disabilities in school activities. Data collection II focused on participation intensity rather than participation frequency, thereby supplementing results of data collection I.

5.1 DATA COLLECTION I

5.1.1 Participants

Material was gathered from children and adolescents with disabilities, their parents, teachers, and special education consultants. The data were collected in collaboration with the Swedish Institute for Special Needs Education (SIT). Counselors working at the SIT were asked to collect material from 10 students, their parents, and teacher. Of the 140 counselors who were asked to provide information about students, 110 agreed to participate in the study. On average, they gathered information from six children each. A total of 2411 questionnaires were gathered (students = 513, parents = 612, teachers = 619, special education consultants = 670). For some students, information from teachers and/or parents was gathered, but the counselor's rating was missing. The questionnaires for these students were removed, which resulted in a total of 2397 questionnaires. The material was divided into four age groups (ages 1-6, 7-12, 13-17, adults). Replies from students were gathered for three of the four age groups, because children in the youngest group (ages 1-6) were considered too young to respond to the questions.

Based on the support children received from the SIT, they were divided into groups of children with visual impairments, physical impairments, and multiple impairments, and in the adult age group, into deafness and blindness. Children's impairments were rated using the ABILITIES questionnaire (Simeonsson & Bailey, 1984). As shown in Table 2, many children also have body limitations in areas other than the area of impairment for which they receive support from SIT.

Table 2

Impairment rated by counselors using ABILITIES

Frequency of students with specific impairments				
Body function	Ages 1-6	Ages 7-12	Ages 13-17	Adults
Hearing	5	13	13	12
Motor function	46	102	85	13
General health	25	37	17	5
Social skills	81	95	67	22
Behavior	78	88	53	21
Communication	69	106	59	23
Visual	149	128	92	40
Cognitive	55	65	60	26
Muscle tone	20	87	61	6

Fotnote: In this table, impairment is rated as a limitation if higher than 2.0 on a scale of 1-6, where 1 is typical function.)

Not all gathered material was used in the thesis, and different studies used somewhat different parts of the material. For example, study I is the only one in which all respondents are represented. Because of this, the number of questionnaires used in the studies varies, based on inclusion criteria for the studies. For example, in studies II, III, and IV the 1-6 age group is excluded and in studies II and III adults are excluded. The reason for excluding the 1-6 age group is that there are no student self-ratings. In study III, only student responses are relevant and all other respondent groups are excluded.

There was a fairly equal number of boys (47.3%) and girls (52.6%) in the data collection I from all over Sweden (percentage of boys ages 1-6 = 48.4%; ages 7-12 = 50%; ages 13-17 = 47.8%; adults = 42.9%). The geographical distribution was fairly representative when accounting for populations in various regions in Sweden, that is, the north of Sweden is less densely populated than the east, west, and south.

The mean age in the age groups was: 1-6 = 3.8; 7-12 = 10.0; 13-17 = 15.0; adults = 22.5. In the 7-12 age group, 17 children are missing an age value, in the13-17 age group, 18 children are missing the value, and in the adult group, 12 people are missing the value, which indicates that quite a few respondents did not report their age. Some children were older in the 1-6 age group, which consists of children enrolled in preschool; some (17 children) had turned 7 but were still in preschool and belong to the 1-6 age group. A more ideal name for this group would have been *preschool* children. In the same manner, the 7-12 group could have been called *elementary school* students, the 13-17 group, *high school* students, and the adult group *adults who receive support from the SIT*. The reason for not defining them according to school is for the sake of consistency with the rest of this thesis.

5.1.2 Material

Participation and availability. This scale was an adapted version of an instrument used by Simeonsson et al. (2001). Participation and availability were measured on the same scale. Because the focus was on participation, this scale was used in studies II, III, and IV. The questionnaire contained a list of 25 common school activities. The students were asked to rate how available the activities were on a scale of 0-3 and how much they participated in the various activities on a scale of 0-3. This can be seen as a participation-frequency measure. In Simeonsson et al. (2001), teachers rated

students' participation and availability. One adaptation was to let students rate their participation. Examples of school activities are recess and lunch breaks, gym, student council, library, school dance, or group activities. The listed activities varied somewhat depending on age, because some are more typical in one age group than another. One activity mentioned in the 13-17 group, which was not mentioned in the others was *planned trip*, while for the 7-12 group *playing outdoors* was mentioned. This rating of participation and availability was central to data collection I. The consistency of this scale was quite stable throughout the various groups and when children without disabilities were included (Table 3).

Autonomy and locus of control. Questions about autonomy and locus of control were a translated, and a short version of the Association for the Rights of Citizens (ARC) self-determination scale was adapted (Wehmeyer & Kelchner, 1995). Wehmeyer and Kelchner (1995) based their autonomy scale on Sigafoos, Feinstein, Damond, and Reiss (1988). The ARC self-determination scale consisted of four parts. Section one was on autonomy. Section two, on self-regulation, was not used in our study because it is not a scale; it's more of a test that is based on giving open-ended responses that refer to problem-solving. Part three was on psychological empowerment and part four was on self-realization. We found the autonomy part most useful; it was used in all studies except study I. The autonomy part was further divided into these sections: a) Routine personal care and family oriented functions, b) Interaction with the environment, c) Recreational and leisure time, d) Community involvement and interaction, e) Post-school directions (answered only by students older than 13), and f). Personal expression. The autonomy scale consisted of 23 items on a 4-point scale, from 1 = "I do not even if I have the chance" to 4 = "I do every time I have the chance"; this scale measured if the student would get involved in various activities if given the opportunity. Examples are: prepare snacks, talk to personnel in stores, and buy presents for friends. This scale had good internal consistency (Table 3).

The psychological empowerment section from the ARC self-determination scale (Wehmeyer & Kelchner, 1995) was also used. Psychological empowerment referred to multiple dimensions of perceived control, such as locus of control, and the scale was based on a locus of control scale (Wehmeyer, 1995). The scale consisted of 12 questions with each question consisting of two statements for the respondent to choose from, such as "I usually do what my friends want", "I tell my friends if they are doing something I don't want to do", "I will have a hard time making new friends", or "I will be able to make new friends in new situations". This scale had low internal consistency (especially for younger students) and was excluded or combined with section four in the ARC (self-realization).

Self-realization refers to self-knowledge and self-understanding, and this scale also consisted of 12 statements for which respondents either agree or disagree. Examples of such statements were "I am loved because I give love", "Other people like me", and "I like myself". Study II focused on attempting to recode the items and reported that the internal consistency of psychological empowerment was low (Table 3). The self-realization scale had better internal consistency than the psychological empowerment scale. The problem with consistency was related to the fact that the scale is dichotomous. Merging these two scales into a regular Likert scale and validating it in a pilot study (Kindwall-Fredblad, 2004) resulted in higher internal consistency (Table 3).

Interaction with peers and teachers. Granlund and Olsson (1998) developed this scale, which Granlund and Björck-Åkesson (1999) adapted for use with students and teachers. The scale consisted of eight questions regarding students' interactions with their peers and eight questions regarding their interactions with their teachers. The

questions regarding interactions with their peers were about how the peers responded (e.g., "my peers talk to me" and "my peers understand what I say to them") and how the student acted (e.g., "I talk to my peers" and "I understand what my peers say to me"). This was measured on a 5-point scale from 1 = seldom to 5 = usually. The internal consistency was good for both parts of the interaction scale but somewhat better for teacher-student interaction (Table 3).

ABILITY index. Types of impairment were measured with the ABILITY index (Simeonsson & Bailey, 1984), which was translated into Swedish by Simeonsson and revised by Granlund and Roll-Pettersson (Granlund et al., 1999). This scale, rated by special education counselors, was used to measure a student's abilities in nine areas, including hearing, vision, cognitive functioning, communication skills, and general health. The scale ranged from 1-6, where 1 is normal and 6 is not usable. The validity and reliability of the ABILITIES index was investigated. Bailey, Simeonsson, Buysse, and Smith (1993) found it to be satisfactory. Their inter-rater agreement, which allows one, scale-step difference, was 85% between parents and teachers and between parents and specialists (Bailey et al., 1993). The Swedish translation of the ABILITIES inter-rater agreement was 72% between parents and special educators (Granlund & Roll-Pettersson, 2001) and the stability of test-retest for special educator ratings was 90% (Granlund et al., 1999).

Environmental questionnaires. In these questionnaires (Granlund, Björck-Åkesson, Åsbrink, & Karlsson, 2000), which were partly based on Simeonsson et al. (2001), teachers and special education consultants assess the environment. The environmental survey was divided into these sections: a) General school environment, b) Students' school environment, c) Specific students' school environment, and d) School demographic ratings. This material was only used in studies II and IV and not in the other studies.

The general school environment was rated by teachers using 28 questions that focused on the physical and social environment. Examples were: "there is plenty of educational material" and "the principal knows the students". Special education counselors rated two scales. The first scale focused on specific student school environments and consisted of 14 questions on support and aids. Examples were: "teacher has sufficient education about student's disability" and "student has the technical aids necessary". These were rated on a scale of 1 = "do not agree" to 4 = "agree completely". The second scale focused on the general environment and consisted of questions such as the size of town, how many students attend school, and the range of classes served. Another question was "Which of the following support forms are available for students with disabilities in your school?" with a list of common means of support such as occupational therapy, speech therapy, and a welfare officer. In table 3 internal consistency for various scales in data-collection I is displayed

Table 3
Internal consistency for various scales in data collection I

| | Reliability | | | | | |
| | Studies II & IV | | Study III | | Other relevant ratings | |
Questionnaire	7-12	13-17	7-12	13-17	7-12	13-17
Participation	.73	.84			Parents .86[*] Teachers .73[*]	Parents .78[*] Teachers .83[*]
Participation in free activities			.58	.74		
Participation in structured activities			.69	.68		
Availability	.71	.74	.74	.78	Parents .75[*] Teachers .71[*]	Parents .79[*] Teachers .74[*]
Autonomy	.83	.93	.84	.93		
Psychological empowerment	.25	.57			.78[#]	
Self-realization	.57	.69			.69[#]	
Locus of control			.62	.78		
Interaction with peers	.69	.76	.80	.85		
Interaction with teachers	.77	.84	.81	.89		
General school environment	.86	.88				
Student's school environment	.83	.84				
Specific student's school environment	.82	.83				
School demographic ratings	.80	.67				
ABILITIES	.77	.80	.77	.80		

5.2 STUDY I

This first study examined definitions of participation in the group relevant to this thesis, that is, how students, parents, teachers, and special education consultants define participation and how these definitions compare to and are related to students' chronological age and disability type. Respondents were asked to provide a written response to the question: "How do you define participation?" From a total of 2397 questionnaires, 1727 written definitions were gathered (287 students, 419 parents, 421 teachers, and 600 consultants). The written definitions of participation were analyzed using content analysis, which inductively creates definitions.

The material was divided into respondent groups before being analyzed, first by respondent (student, parent, teacher, or counselor) and then by age group (1-6, 7-12, 13-17, or 18 and older). This generated 15 groups, because no answers were collected from children ages 1-6. When all material in all groups was accounted for, the analysis was considered complete. A second independent judge analyzed the definitions and examples of definitions and determined if they were reasonable or if

---

[*] Taken from Almqvist & Granlund, (2005)

[#] Taken from Kindwall-Fredblad (2004)

something was missing. In the second step of the analysis, the categorized material was coded back into a statistical program as dichotomous variables. Either the respondent's definition contained one of the nine dimensions or it did not. The coded material was then used as the basis for a nonparametric test using log-linear analysis.

5.2.1 Methodological considerations

One relevant question is what identifies respondents who did not define participation. This is especially relevant when referring to students. One group in which many students did not provide definitions was in the younger of the 7-12s, so an attrition analysis was performed for this age group. In the 7-12 age group, about half of the respondents provided definitions. Younger children were more prone to not reply, but this difference was not significant and neither were gender or region. Disability had an effect on the 13-17 age group (chi square = $11.53_{1.4}$; p = .021) in which a large portion of the persons not answering had a motor disability (34 of 78). The conclusion is that age and gender do not matter. But in younger ages, there is an overrepresentation of non-replies. Self-rated autonomy (t = $-2.105_{1.215}$; p = 0.036) is also important for younger children who answer this type of question. Adult students who rated their interactions with peers (t = $-2.674_{1.60}$; p = .01) and teachers (t = $-2.283_{1.56}$; p = .026) as good, provided definitions more frequently.

Another question not addressed was gender differences. In the student responses, there are no big differences in the numbers of boys and girls in the categories of definitions. There is only one significant difference in the category prerequisites for participation in the 7-12 age group (chi square = 5.206; p = .023). Only one boy mentioned this category. In the self-esteem category for adult students, no man mentioned this category, but because the adult group was relatively small, gender differences were not detected.

Participants in data collection I were persons, who at the time of the data collection, received support from the SIT. These groups were primarily children with visual disabilities in preschool and children and adolescents with visual disabilities, motor disabilities, and multiple disabilities in school, together with adults who were deaf and blind. While this group was heterogeneous, the sample was not representative of persons with disabilities in the school population. To obtain a representative sample, other groups (with mild impairments) should have been represented. But because the results indicated that disability type was not related to the type of provided definitions, this under-representation of several types of disabilities was not important for the results.

5.3 STUDY II

The aims of this study were to a) reliably and validly assign items from an extant questionnaire to the ICF, b) test the theoretical assumption that the ICF's environmental component interacts with body function and participation, and c) find out if there are profiles of participation for groups of individuals. The used material was replies from 448 students ages 7-17, their parents (*n* 414), teachers (*n* 418), and special education consultants (*n* 448) for a total of 1728 questionnaires. Student-rated questionnaires measured availability of and frequency of participation in activities, autonomy, psychological empowerment, self-realization, and interaction with peers and teachers. Other questionnaires were environmental surveys that measured general school environment, and students' school environments, as rated by teachers. The specific student's school environment, school demographics, and ability index, as rated by counselors, were also coded into the ICF.

Two independent raters assigned ICF codes to the scale items on a two-digit level. We decided to exclude the activity domain, using the remaining body function, participation, and contextual factors. This decision was made because the scales measured involvement in life situations and self-determination rather than performance of activity. We compared the ratings and calculated the degree of inter-rater agreement by dividing the number of agreements between the two raters with the total number of items rated. To increase the number of items that were assigned codes in the ICF environmental chapter, responses from various respondents (students, teachers and counselors) were put together. Internal attrition became a problem, and persons with more than 25% attrition in a specific ICF chapter were removed from that chapter.

The ICF's participation component consists of nine chapters. The first six chapters relate to proximal environments, such as learning, general tasks, and communication, while the three remaining chapters focus more on societal participation, such as interpersonal relationships, major life areas, and community life. Chapter four (mobility) was not represented in this analysis due to lack of items. In order to find different participation profiles, cluster analysis was done based on the different chapters in ICF. Cluster analysis identified patterns of participation.

5.3.1 Methodological considerations

The methodological problems in study II were that the questionnaires did not cover all nine chapters of participation; mobility was especially under-represented. To be able to move from one location to another and to participate in one's mobility is significant to participation. So lack of items that were assigned ICF codes from this chapter was a weakness. Another problem with assigning codes was that some items could be coded as several different ICF codes, depending on the level of coding and based on the fact that the items had a formulation that contained more than one dimension. The level problem was easily solved by deciding to use the highest level possible. Items with dual meanings continued to be a problem.

Reliability was somewhat low, especially for the younger 7-12 age group. Another problem was chapter seven in the ICF, which dealt with interpersonal relations. This chapter had good item coverage, that is, the items measured nearly all parts of the chapter. So the discussion about few codes and low coverage of chapter content, as mentioned in the study II article, does not seem relevant in this case. The ICF chapters with high internal consistency either consisted of a few items or the items only covered parts of the chapter's content.

5.4 STUDY III

The aim of this study is to compare groups of students with and without disabilities regarding participation and factors related to participation, which are autonomy, locus of control, availability to activities, and interactions with teachers and peers. Materials used were the self-ratings from students in the 7-12 and 13-17 age groups. Data from four studies were used. The total number of students participating was 959, of which 448 had a disability (*n* 251 in 7-12; *n* 197 in 13-17). These students were gathered from the first data collection and 511 students in the comparison group (*n* 211 in 7-12; *n* 300 in 13-17). Data from three different undergraduate studies were used. The undergraduates gathered self-ratings from children and adolescents without disabilities, using the same questionnaires as used in data collection I. There were three studies. One was on rejected children (Eriksson & Mellin, 2002) in which information about 221 children in the fifth grade was gathered and used as the comparison group in the 7-12 age group. The next study was on the school situation

of high school students. In this study, information about 165 senior high students was gathered (Eriksson, 2001). In the third study, responses from 104 students from the seventh grade to the second year in high school were gathered. The datasets were combined after removing all dissimilar items.

5.4.1 Methodological considerations

The internal consistency of the index participation in free activities was low, but the index was kept because there are indications in the literature and previous research that there is a difference in participation between structured activities and free unstructured activities. The fact that the internal consistency of participation in free activities for the 7-12 age group is merely .58 is a weakness of this study. This is probably because the number of activities rated in this cluster is small, and there might be big differences between types of activities, such as playing during recess and going to a school disco. It is not possible to analyze missing values for the comparison group because no information about the students choosing not to participate is available.

Another problem concerning using different data collection is that the children did not attend the same schools as the children with disabilities; they were also not identical in age. Age differences are a special problem in the 7-12 group in which everyone in the comparison group was from the fifth grade, and those in the disability group were ages 7 and older. A control for age showed that only one significant result in the comparison disappeared, having to do with availability. When controlling for age, there were no significant differences between the groups. No other index comparison between groups became statistically significant or lost its statistical significance dependent on age.

Another issue with this analysis was that no control for gender differences was made. Looking at the data, gender information was not gathered in all of the studies in the comparison group, which made that analysis impossible to control in this material. An analysis of the group of children with disabilities revealed no differences due to gender, and the same result was valid for the comparison study the provided information about gender.

Because of the large sample, some of the differences between the groups might have been incidental, such as locus of control, which is a scale that was reported to be less reliable. For that scale, a difference of .04 became significant for the 7-12 group—a difference that might have been coincidental.

5.5 STUDY IV

This study aimed at investigating how environmental factors are related to participation in school activities. To study this, self-ratings from students in school settings were used with the ratings from their teachers and counselors concerning their school environments. Data from a total of 509 students were used, which also provided teacher and counselor ratings. Eight adults were removed because they were working and not students. Regular methods, such as correlations and ANOVA, were used for the analyses. Within the environmental scales, questions on personal assistant and classroom assistant were interesting because one focus for research concerning assistance is on its relation to self-determination. So students' self-ratings of autonomy were also included in the material.

There were several ratings concerning school environments (general environment, specific environment, support given and adjustments made, and self-rated availability). The section on support and adjustments covered support in a community and school setting, and a scale based on the amount of provided support was set. This

scale was then compared to the students' participation ratings. To look more closely at the relations between general and specific environment and participation, groups based on environmental ratings were made. The groups were high-high, low-high, high-low and low-low. Because various types of scales were used in different questionnaires all values were standardized using z-values before group comparisons were implemented.

5.5.1 Methodological considerations

A problem with this material was that there are few adult respondents and a high frequency of internal attrition in this group, so the adult group sometimes had to be excluded from analyses, based on sample size and attrition. Attrition was a general problem because several teachers did not respond to the environmental questions. Perhaps motivation on the part of teachers and counselors for answering questions on environment and support was lower.

5.6 DATA COLLECTION II

In this data collection, the aims were to a) study the degree of participation of children with and without disabilities in school activities, b) analyze whether children with disabilities were included and participated in the same activities as their peers and c) analyze whether there was a relationship between support and participation.

5.6.1 Participants

In this study, 66 children (33 pairs) were observed. In each pair, one child with and one child without disabilities was observed during one school day. The children were in grades 1-6 (ages 7-12). Based on information about school years, the mean age was 9.9 and SD = 1.87 (third grade). The gender distribution was 16 pairs of boys, 16 pairs of girls, and one pair consisted of a girl with disabilities and a boy without disabilities.

Table 4
Frequencies of how teachers rated a child's functioning in nine areas

Body function	Normal	Suspected limitation	Mild limitation	Moderate limitation	Severe limitation
Hearing	28	2	0	0	1
Vision	19	3	7	0	2
Motor function	15	4	5	1	6
Muscle tone	17	5	3	4	2
General health	16	4	5	4	2
Cognitive functioning	13	4	3	6	5
Communication skills	12	4	11	3	0
Social skills	9	0	10	10	2
Behavioral problems	10	3	5	11	2

To estimate the children's type and degree of disability, a simplified ABILITY index was used, based on teachers' perception of the children's functioning. Out of the 33 children with disabilities, we obtained 31 ratings. The most common impairments were social skills, communication limitations, behavioral problems, and low general health (Table 4).

5.6.2 Material

A structured observational sheet was used, including information about activity type, information about inclusion, and whether or not the student was included. Information about support that included type of provided support (such as help starting activity, help continuing activity, and help simplifying activity) was also collected. The observer rated the level of visible engagement within the situation on a scale from fully participating to never participating. For each activity, an observation sheet was filled out. So for each child, several observational ratings were available, with a mean of six ratings per child. The implication is that for some analyses of the material, there are more observations than persons, while other analyses are based on the mean for the individual, that is, only one value per person is used in the analysis. After the school day, the children were interviewed about their school day, and about friends and social support networks—using nine types of questions, such as "You had math today. Can you tell me about it?" Each child was asked these questions twice, once concerning classroom activities and once concerning break activities. These questions about support were divided into instrumental, informational, and emotional social support networks. Examples of questions are: "Who do you prefer to be with?", "Which one(s) can cheer you up or make you happy?" and "Who is the one that you find easiest to understand?".At the end of the interview, the students, together with the interviewer, replied to an autonomy questionnaire (Wehmeyer & Kelchner, 1995) that was also simplified by only having three response options on the scale instead of the four options in the original scale. Otherwise the same questions about autonomy, as described for data collection I, were used.

5.6.3 Methodological considerations

Co-coordinators at special school units and principals helped to identify children with disabilities. This method led to the exclusion of many children with disabilities. When contacts with principals were made, they often identified one or two children in their entire school who had a disability and gave only one name to continue with. Children, who principals found suitable, were children with whom the school had good parental contact—and they were children who they felt functioned well in school, so the sample probably has a positive bias in terms of functioning.

The structure of activities might be important to measure. We did not rate degree of structure. But in the observations, it was evident that children in highly structured activities tended to be not fully participating but not unengaged either. That is, there were less individual differences in involvement when compared with unstructured activities.

6 ETHICAL CONSIDERATIONS

This type of research does not require ethical authorization as per legislation for research conducted on people (2003:460). The studies do not contain intentional intervention on research participants in a manner mentioned in section four of the Swedish ethical approval legislation (2003:460). All information about persons was gathered with informed consent from research participants as per section three.

In data collection I, in which material from studies I-IV were gathered, all participants were anonymous—it is not possible for us to trace individuals. The counselors gathered the material for us from their own student databases. Data collection started in 2001, and the project received support and approval from the Swedish Institute for Special Needs Education and the Swedish National Agency for Education. The ethical considerations and questions raised followed guidelines for humanistic and social research (Vetenskapsrådet, 1990). Material gathered from students without disabilities also followed these guidelines (Vetenskapsrådet, 1990). All material was gathered with informed consent. Parents and students were informed in writing and gave their consent, and all teachers were informed orally by the counselor. All respondents were guaranteed confidentiality. They were informed that it was optional to participate and that no reason for not participating or not completing the questionnaires was necessary. While we cannot track the participants, they can contact us if they wish, provide their questionnaire code, and have the information removed. But we had no list of participants.

In data collection II, the ethical research committee at Mälardalen University examined all material, informational letters, and procedures. Children have less of an ability to understand the study's implications, so the ethical committee was consulted. The committee's evaluation was that the procedures, questionnaires, and observations used did not require medical ethical approval from the regional ethics committee and that they followed guidelines for humanistic and social research (Vetenskapsrådet, 1990). In this study, the researchers met the participants during the observation, but all participants were offered complete confidentiality. No names of children were gathered, and the names of schools were not kept in electronic documents. Informed consent was gathered from parents, teachers, children, and principals. They were all given written information about informed consent, about participation being optional, and about confidentiality. For data collections I and II, feedback was provided to the respondents. For data collection I, a written report (Granlund et al., 2004) was provided to the Swedish Institute for Special Needs Education. For data collection II, a lecture was given to interested participants.

7   SUMMARY OF RESULTS

A summary of the results from the five studies is presented in chronological order.

7.1   STUDY I

The results of study I show that participation, according to the respondents' definitions, consisted of three components: a) experiences of involvement, having positive experiences through active interactions with others, b) being actively involved in activities, being a part of activities, and being involved physically and psychologically, and c) environmental factors, such as availability of activities, information, and physical prerequisites. Activity was the component that students with disabilities emphasized. Participation cannot be seen as just one of these three components—they are interrelated.

According to study I, nine themes of participation were found. These themes were partly independent of the three components of participation. They were: characteristics/self-esteem, fellowship, communication, being a part of activities, self-determination, prerequisites for taking part, conditions in the living environment, adults' roles, and physical environment. These themes indicated not only that participation is located within the person, in the interaction and with contextual factors, they also indicated that participation is multidimensional. It was important to be self-determined and to have the prerequisites in the environment to participate. Children's participation also depended on interaction between various settings on a *meso* level.

An analysis of relations between the provided definitions and respondent groups, categorized according to age, role and disability indicated that disability type did not have an impact on how students with disabilities defined participation, except for one group. Adult students with deafness and blindness mentioned self-determination more often than other groups. counselor definitions of participation focused more on fellowship than the other respondent groups did. Students did not mention communication, something that one-third of the other groups mentioned. Communication between parents and teachers about the students was emphasized in this category rather than communication between students and others. Environmental factors, as a part of the definition of participation, also seemed to be more relevant for other respondent groups than for the students. Even if students gave environmental replies, teachers and counselors were more focused on it.

Age also seemed to have an impact on the provided definitions. Prerequisites for taking part were more important for adult students than for teenagers. A more qualitative analysis indicated a difference within the self-determination category with definitions going more toward democracy with age. In general, it seemed that respondent groups other than the students were more concerned with disability and age when defining participation for children with disabilities.

7.2   STUDY II

This study tested the utility of the ICF coding system by assigning ICF codes to items from extant questionnaires on participation and participation-related concepts. The inter-rater agreement in assigning ICF codes to items from different questionnaires between two raters ranged from 54% in the self-realization questionnaire to 100% in the interaction with peers questionnaire; total agreement was 84%. One explanation for the reliability difficulties in assigning codes to items from the self-realization

questionnaire was the questions' formulations in the original scale. Scales with good reliability, that is, well-formulated items, had better inter-rater agreement. It is possible to code items from extant questionnaires, but then some chapters in the ICF might be over- or under-represented, and complementary items might be needed. Chronbach's alpha was calculated for the items ordered in the ICF chapters, and there were problems with the reliability, especially for the 7-12 age group and for certain chapters such as chapter seven on interpersonal relations.

It was interesting to see how the participation chapters were statistically related to each other. The chapters in the ICF were often interrelated, some chapters more than others. Chapter one about learning had only one interrelation, that being with chapter eight on major life areas. The four remaining chapters that measure person-proximal participation, general tasks and demands, communication, mobility, self-care, and domestic life were interrelated. The societal participation chapters on interpersonal interactions and relationships, major life areas and community, and social and civic life were almost always related to the person-proximal chapters but were not interrelated in the same way as the person-proximal participation chapters. Body function, measured as global psychosocial functions, mental functions of languages, and intellectual functions, had relationships to most participation chapters.

Another question asked in this study was whether the environmental components in the ICF interact with the other domains. The relation between participation and environment was not strong. Most relations were found in chapter one, concerning products and technology and chapter five services, systems and policies on the two-digit level. The relation between environment and body function was based on the division in the ability index and showed that communication function followed by motor ability, global psychosocial functions, and intellectual functions were related to various parts of the environmental domain. To conclude, various ICF domains are related to each other, and chapters within the participation dimension seemed to have an interrelation, especially concerning person-proximal participation chapters.

The third question concerned whether it was possible to identify groups of individuals with similar participation profiles, based on participation chapters in the ICF. A cluster analysis was applied. With a five-cluster solution, the cluster with most members was characterized by overall high ratings and contained students with various disabilities. There was an even distribution of students with various impairments in all clusters, except for one of the more negative clusters that consisted of four students, all with multiple disabilities. Cluster analysis results showed that students with positive or neutral societal participation were also characterized by high ratings in proximal participation. Analysis of the relationship between cluster group membership and environmental factors indicated that the positive cluster group had more positive ratings of products and technology for culture, recreation, and sports. This cluster group also had a somewhat higher rating in language, social skills and behavior, and intellectual functions than the clusters with a more negative profile. The cluster analysis showed that students, independent of degree and disability type, could have high ratings in participation and in environment. The result indicated that the ICF model works well for determining positive health and participation and that participation depends more on functional profile than on diagnosis or disability type.

7.3   STUDY III

The aim of study III was to compare participation and factors recognized as important for participation, such as availability of activities and interaction with peers and teachers, between children and adolescents with and without disabilities. The results revealed that students with disabilities have lower perceived participation than

students without disabilities but that no relation to disability type was found. So factors other than the disability probably explain the level of perceived participation of students with disabilities.

Participation is multidimensional, so the influences of several factors were needed to explain the level of participation perceived by a student. One of these factors was autonomy; children without disabilities had much higher ratings in autonomy than children with disabilities. Autonomy measured whether the students use existing opportunities to do something when given the chance. Children without disabilities used opportunities more frequently than children with disabilities; they had a more autonomous perception of themselves, which was important for participation. It is necessary to be able to recognize opportunities and to use opportunities in unstructured activities. An example of such an activity was recess with peers. Perceived availability to activities also differed between groups; children with disabilities did not perceive that activities were available to the same extent as children without disabilities. Children and adolescents without disabilities also rated their interaction with peers as more frequent and of higher quality than children and adolescents with disabilities. Taken together, these factors might explain some differences in participation, and the fact that the differences seemed to increase with age.

Children and adolescents with disabilities rated their interactions with teachers as more frequent and better than students without disabilities. Teenagers with disabilities also rated their participation in structured activities as high in comparison with students without disabilities. Perhaps the students with disabilities were more dependent on structure and of interaction with adults for participating in school. The difference between the groups were larger for older students, but not because adolescents with disabilities were less involved. On the contrary, teenagers with disabilities rated their participation in structured activities higher than younger students, while students without disabilities of different ages rated the same level of engagement in structured activities. Teenagers without disabilities rated their interaction with peers as more frequent with age, while students with disabilities rated peer interaction on about the sample level—independent of age. So while adolescents without disabilities focus more on peer group interaction and participation than children without disabilities, the students with disabilities remained dependent on teacher interaction.

7.4   STUDY IV

This study focused on school environment factors and participation. The relation between distal factors was investigated, such as size of community, school size, and more specific environments such as type of support provided and participation. This was to determine if a relationship between school environment and a student's perceived participation existed. Results showed no big difference in participation for students related to general school environment. Factors in the specific environment, when rated by the students as perceived availability, had an impact on participation. Students' perceptions of the school environment were related to the niche or the proximal part of the context and not so much on the organization and the school's disposition.

Another issue raised was whether general and specific environmental adaptations made in school were related to participation, and the results showed that support given to students does not have an impact on their participation. Again, specific environments seem to have a stronger impact on participation than general environments. When dividing the respondents into groups of students with high or

low general and specific ratings of the environment, it seemed that students with high ratings of the specific environment had somewhat higher participation independent of ratings of general environment, again indicating the relevance of the close specific environment (the niche).

A third issue concerned the impact of assistants. Assistants are a debated support method in school and are one of the most frequent school-based supports provided. Other commonly provided support methods were secluded workspaces and individual tutoring. These types of support indicate that students could be excluded from their peers, at least in some part of school. Focusing on assistance, either personal or classroom assistant, only between 10-14% of our sample did not have an assistant available, that is, 86-90% had assistants available. Students with assistants seemed to rate availability of activities as higher, while they rated their autonomy as lower, indicating that having proximity to adult support might lower use of provided opportunities.

7.5 **STUDY V**

The aim of this study was to observe students' participation in various activities in relation to inclusion and support. It was also relevant to investigate if it was possible to observe participation, or if participation had to be rated by the persons or persons familiar with them. The results reveal that there was good compatibility between observed engagement and the children's replies about various activities, showing that it is possible to observe involvement within a specific context on a specific day. However, this fact do not indicate anything about what participation usually is like in that activity. It only gives a snapshot independent of past experiences.

The first question this study asks is about activity-dependent differences in participation between the groups. Children without disabilities had generally higher participation in structured activities in class and unstructured activities during breaks. Dividing the structured activities into various classes, such as reading, writing, math, and physical activities, revealed that the differences were primarily in three subjects: math, practical subjects, and science. In these classes, children with disabilities had significantly lower participation. Children with disabilities were observed as uninvolved much more often than children without disabilities, and they were also observed as uninvolved during breaks. They did not participate to the same extent as their peers. But in many activities, there were no significant differences between the groups, such as circle time where they were included and participating.

Another question asked was whether being included was related to participation. The observations of children in classrooms showed that it was necessary for children to be included in activities if they were to be fully involved. To truly be a part of activities meant being with peers, participating in equal activities, receiving necessary support in a manner that facilitates participation, and interaction with peers and teachers. Children with disabilities in the sample were included in most activities. Math was the activity in which they were most often excluded, receiving support outside of class. It was one of the activities with the lowest level of participation. Breaks constituted an activity with low-level participation and quite high exclusion. This exclusion was not due to extra support but to rejection by their peers and active selection by the student to not to play with their peers. Thus, being included facilitates participation.

The last question asked whether there is a relation between support received in the classroom the social support network and participation. Children with disabilities frequently received support in activities except during breaks. Younger children received more support during breaks than older children. Children receiving a lot of

support were less involved. Another type of support relevant for participation is the persons (and the number of persons) in the social support network. Children with disabilities name fewer persons than children without disabilities. Children with disabilities also mention adults, such as teachers and assistants, as being supportive—more often than their peers do. Children who reported that many of their peers provided them with emotional support were more involved. Children who reported that they had many friends, who provided emotional support during class and breaks, were more involved. Good emotional support during class creates opportunities to participate during breaks. Children with a large social support network were also more autonomous, which indicates that there is a relationship between support and participation. So too much support provided during class can be detrimental, but having a good social support network consisting of other children is vital for participation in school.

8 DISCUSSION

The aim of this thesis is to investigate participation of children and adolescents with disabilities in school activities. With a special focus on personal factors and factors in the close environment that are related to participation. Participation was defined and researched in several ways. While there are similarities between various perspectives taken in research concerning participation, few studies have focused on participation for individuals and factors related to individual differences in perceived participation between individuals. Persons vary in how they perceive participation and in factors that contribute to their participation in life situations. The need to find out how individuals with disabilities perceive participation drove study I. If interventions aimed at increasing participation are to succeed, the focus must be on aspects of participation relevant to the individuals or groups that are subject to intervention. Study II investigated the utility of the ICF as a framework for participation and illustrated the proposed multidimensionality of the participation concept. This was done by creating profiles using various domains within the ICF participation dimension and by relating participation to body function and contextual factors. Studies III and IV focused on identifying various factors related to participation. More specifically, study III compared children with and without disabilities regarding factors that previously had been found relevant for participation. Study IV focused on general environment qualities, with a proposed relationship to participation. One reason for this focus was that Simeonsson et al. (2001) found that general environmental qualities had an impact on how teachers rated participation of students with disabilities in school activities. Another reason was to discover on what environmental levels factors related to perceived participation in school activities (as rated by children with disabilities) that could be identified. Study V was motivated by differences in perceived participation between children with and without disabilities found in Study III and the finding that general environmental qualities do not contribute to explaining the perceived degree of participation of students with disabilities in study IV. Study V investigated variations in participation within a situation and between situations. These situations were compared in children with and without disabilities in relation to inclusion.

8.1 THE PARTICIPATION CONCEPT

One of the main aims of this thesis is to describe and analyze various meanings assigned to the participation concept by students with disabilities and other important actors in their proximal environment. The study was motivated by a sense that participation was perceived as something more comprehensive than just taking part or being active. Study I found that participation is multidimensional and that students with disabilities assigned several meanings to participation; *being active* was only one. Participation as perceived by the respondents consists of *personal factors*, such as self-concept, *activity factors*, such as being part of something, performing a task, or playing, and *contextual prerequisites*, such as support, aids, and significant others (study I). The ICF was used as a framework of reference in study II. In the ICF, participation is a component in determining a person's health. The ICF defines participation as engagement in life areas, and a person's life space is divided into nine areas: learning and applying knowledge, general tasks and demands, communication, mobility, self-care, domestic life, interpersonal relations, major life areas, and community, social and civic life. In this way, participation is operationalized in different ways in different settings. Within one setting, such as school or a math lesson, a person can be engaged in several of the important life areas, such as learning

and applying knowledge, while talking with peers and teachers, that is, interpersonal relations and education constitute a major life area. While participation in the ICF is not equal to body functions or contextual factors, the components are related to each other. Participation depends on several factors and participation in one area does not automatically generate participation in another area.

In this thesis, participation was investigated as a multidimensional concept that consist of *personal factors*, such as autonomy and locus of control, of *body function,* such as disability type, and of *contextual factors*, such as school characteristics, support, and availability of activities. These factors are identified as components of participation and as factors contributing to participation. Study III found that participation depends more on personal factors, such as autonomy and on interaction with significant others (with interaction defined as an activity dependent on individual factors and environmental factors), than on body function such as disability type. Study IV focused on environmental factors and their relation to participation and found that perceived participation for individual students has a stronger relationship to specific environmental factors than to general environmental factors. One conclusion is that several factors are relevant for participation, and when an individual's perceptions of participation are in focus, the proximity of the factors measured to the individual is relevant for understanding the influence on participation for a certain factor. Because of this finding, data collection in study V was implemented through observations of participation within activities in the immediate setting. The focus on the specificity of participation within a situation increased the strength of explanations for participation related to contextual factors. Observed participation for students varied between situations. The degree of participation was related to the support provided and to inclusion, that is, the student's physical placement. A conclusion is that participation depends on *personal* and *environmental* factors. Another conclusion is that relationships between participation and factors influencing participation will vary depending on the degree of specificity of the operationalization of the concept participation. Contextual factors will have a stronger relation to participation for more specified operationalizations of the concept.

Participation was measured in two ways: participation frequency and participation intensity. In data collection I, participation was operationalized as participation frequency, that is, the students were asked to rate various activities in terms of how available they were and how often they participated in them (participation rate). It is important that a student takes part in a variety of activities, because participation generates opportunities for more experiences and larger niche potential. But participating in a variety of activities tells us nothing about participation quality within an activity. One way of measuring participation quality within a situation is as participation intensity. In study V, independent observers rated participation intensity within situations. In addition, these ratings were validated against the students' statements about the rated situations.

These two collection processes generated two relevant measures of participation: frequency and intensity. The number of activities the child participates in gives a general measure of participation that presumably is relatively stable over time. Participation intensity gives a more context-specific measure of participation. Participation intensity will vary depending on the situation and over time, thus intensity is more easily affected by contextual factors than frequency. The two measures probably represent various dimensions of participation: a persona-related participation dimension and a context-related participation dimension. Theoretically, there should be a close connection between participation frequency and intensity. Having autonomy and having friends are related to high participation when measured as frequency and when measured as intensity (Study III & V). Persons with stable

personal prerequisites, such as high autonomy and good social skills, will participate in many situations and will probably have a high level of intensity, that is, they will be stable as highly participating. Persons with somewhat lower autonomy and social skills will probably have a somewhat lower frequency of situations in which they participate. They may also define situations as less available. Their participation in situations probably varies depending on contextual prerequisites. Some activities will suit them well, and they will have a high participation frequency. Some situations are less adapted, and they will participate less in these situations. This reasoning also indicates that there should be a third group that is stable in low participation, with a low number of situations in which they participate, that is, they are highly specialized in few niches or situations and probably have low autonomy and problems with social relations (Figure 2).

Person- and context-dependent participation can both be related to system theory. Participation as a relatively stable personal factor can be explained with reference to general system theories such as Bronfenbrenner's bio-ecological model (Bronfenbrenner 1979, 1999), while participation as a context-specific factor can be explained with reference to dynamic system theory, and more specifically, to niches (Wachs, 2001). Regarding participation as a personal factor, frequencies of activities can be seen as the number of micro settings available. The numbers of activities a child participates in will probably have an affect on the experiences of availability. The frequency of activities the child has available and participates in is probably also relatively stable over time. It indicates that individual differences in this type of participation measure are better explained by personal factors than by contextual factors. It might explain the lack of relation between environmental factors and participation reported in study IV. But participation intensity is rated in niches within the micro settings or proximal environments. The participation level will depend on what the student does within a specific context, the student's present state, and the qualities of the context, so the relations between environmental factors and participation are stronger (study V). Dynamic system theory (Wachs, 2001) can be used as a framework to explain changes in participation between and within different settings that are not always predictable.

In conclusion, by counting the number of activities that children participate in and how often they participate in these activities, we obtain a measure of an individual's average participation. This measure depends more on internal factors than contextual factors, and it changes more due to internal changes than contextual changes. But participation intensity measures will be more contextually dependent and will change based on the situation and the individual's present state. This is compatible with the fact that persons with internally supported participation (children with high autonomy and good interaction skills) will be reasonably stable in participation intensity and frequency of participation within various contexts. It is also compatible with the fact that children, who are more dependent on prerequisites in the context for their participation, will exhibit fluctuating intensity in their participation—depending on the contextual fit. As illustrated in Figure 2, participation is internally and externally supported. It is internally supported by a strong sense of self-efficacy and autonomy, and externally supported by a responsive environment. Finally, the reasoning stated previously indicates that high levels of participation triggered by personal traits are more stable over time and situations, while contextually dependent participation will be more located in the present time and context and will fluctuate—depending on the quality of the context (Figure 2). So the short-term aim of intervention is to intervene with contextual factors that support development of a responsive environment. To make the progress stable over situations and time for individuals, the success in

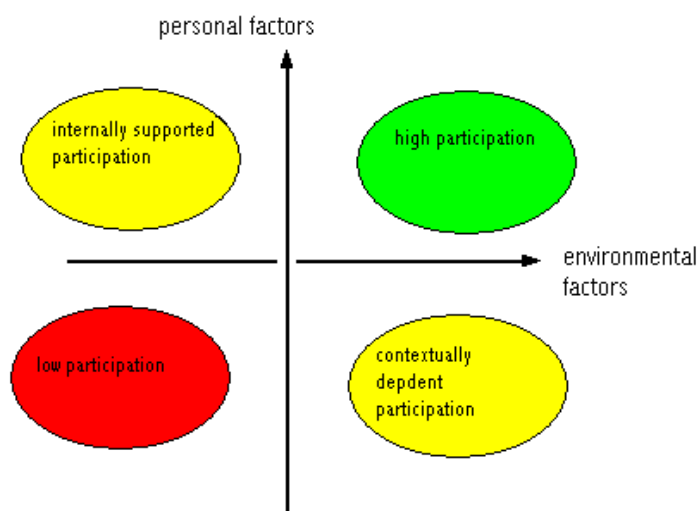participation for the student must be internalized as self-efficacy, locus of control, and autonomy.

Figure 2. Participation as a function of personal and environmental factors.

Continuing the discussion on participation as a multidimensional concept (Table 1, Figure 1), participation consists of three dimensions: focus, setting, and time (Figure 3). Not all dimensions and aspects of participation are measured in this thesis even though it has a multidimensional focus. This thesis focuses on proximal participation within school situations, that is, students' participation within contexts that they experience in school. Time refers to past, present, and future. Participation-frequency measures depend on what has already happened or situations in which the person has been participating. Observing participation intensity gives a *right now* measure, the observer will probably not know what the child's participation was previously. Autonomy is a factor related to expectations (Figure 1). High autonomy indicates that you will take chances when there is an opportunity. The results indicate that time is relevant to how participation is operationalized and measured.
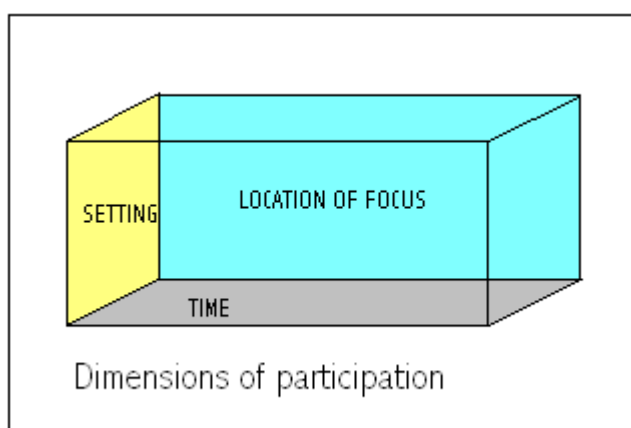
Figure 3. Three dimensions of participation: time, setting, and focus.

Participation is contextually dependent, so settings will be of relevance both within the micro environment as various situations and activities and as different ecological levels, such as relations between school environment and society (Table 1). The third dimension in Figure 3 is location of focus; participation depends on experiences,

activity, and prerequisites within the setting. Individual factors are, for example, feeling part of the activity, reciprocity, motivation, and having control. Focuses on activity are, for example, engaging, interacting, planning, getting information, and being politically active. Prerequisites are situated in the individual as autonomy and social skills and in the environment as teachers, means of assistance, and structure of school and organization. Depending on the location of focus on studied factors, the influence of various factors on participation will vary.
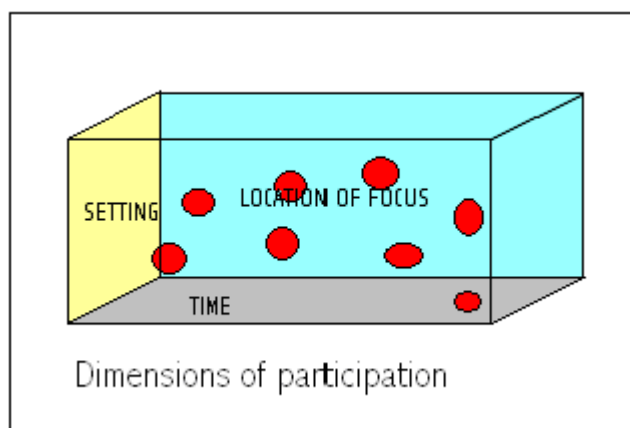
Figure 4. Three dimensions of participation—time, setting, and focus—with various activities within the participation space.

The dimensions of participation have different relations to frequency and intensity. Participation frequency is defined as the number of settings or activities in which the child participates. These activities depend on expectations on the environment and opportunities in the future, and experiences and situations previously available. The frequency of activities also depends on how the individual interprets contexts, how he/she acts, and what prerequisites within the person and the environment actually exist (Figure 4). Participation intensity focuses on one situation at the time and the level of participation right now. In an attempt to visualize the dimensions and activities, within this cube the niches that the child participates in exist within the three dimensions (Figure 4). A frequency measure is an account of the numbers and types of situations in which participation occurs, but the measure does not provide information on how the child perceive participation in various activities. Children can have different niches within a specific situation, that is, within a different circle (Figure 4).

Intensity will focus on just one area (represented by one red circle in Figure 4) and how the child participates in that specific situation. Measures of participation within the situation enable identification of the characteristics of the niches in which the child exhibits high-intensity participation. This will generate information that can relate frequency measures to intensity measures, that is, personal and contextual aspects of participation. Contextually linked measures of participation can, for example, be recorded with field notes, with a specific focus on the relationships between support, inclusion, and participation.

8.2   METHODOLOGICAL CONSIDERATIONS

In the first data collection, it was important to get more general information on participation. The collaboration with the Swedish Institute for Special Needs Education gave us the opportunity to collect data from all over Sweden—from

teachers and counselors, parents and especially from the students. The questionnaires were comprehensive, and we were able to extract a lot of information from them. When analyzing the material, it was felt that some information concerning participation was missing. The information about activities and how often the subjects were participating in these activities did not tell us anything about participation quality or what they were doing in the activities. We did not learn enough about the proximal processes or about the niches—two factors that are theoretically important.

In data collection II, we wanted to have more information that focuses on what is going on right now within an activity. One concern from data collection I was that measuring how often and in what kind of activities made replies dependent on interpretations of previous experiences. The students had to reflect, interpret previous experiences, and consider how they would do it in the future; it did not give us a current picture of participation. In data collection II, it was relevant to get into the activity but at the same time not drown in information, so the focus was placed on participation, support, and inclusion. One concern was that we previously stated that participation is something individual and must be rated by the individual, but is it possible to observe this? To answer that question, all children were asked after the school day about various activities. Their descriptions and our observations were aligned, so it was possible to observe participation intensity. Simply gathering the information needed created another problem. Because we did not ask the students to rate their participation using the frequency measure, it was not possible to study the relationship between participation frequency and intensity. Another concern was that we were just able to study participation for one day and not over time. An analysis of how participation fluctuates over time, together with how students rate participation frequency, can generate good information about how these two measures relate to each other.

8.3   IMPLICATIONS

Participation is personal. It is about feeling good about what you are doing and feeling competent in using available opportunities. It is also vital for participation to involve interactions with significant others. These interactions must have varying qualities depending on context, for example, with adults and peers. Participation for children with disabilities also depends on being provided with necessary support. Participation frequency seems to be less dependent on support than participation intensity. For professionals aiming to facilitate participation of children and adolescents, having a clear intervention goal is vital. Short-term interventions that facilitate participation must be done within a specific situation. Such interventions must focus on an area in which the child has participation restrictions and on factors necessary for participation within that area, that is, focus on the specificity of participation instead of general participation. One reason for the emphasis on context is that high participation in one area will not necessarily lead to high participation in another area. Is it possible to increase participation generally? Over time, children must experience situations that facilitate their autonomy, social relations, and control. Their participation will then become more stable, and they will probably seek activities that suit them. They will support their participation by identifying fitting niches and will be less contextually dependent. The long-term goal with interventions is to enhance personal factors important for participation that are more stable than contextual factors and not as easy to alter.

A significant dilemma that must be dealt with is how to develop a school environment that facilitates participation in inclusive settings, while providing individualized support to students with participation restrictions. For children, friends

often have a higher priority than learning. Children and youth must be close to their peers to feel part of the group. Being included during class also supports participation during breaks. Being seated elsewhere with an assistant or special educator will lead to decreased opportunities to participate in break activities even before the breaks starts (study V). If teachers and assistance succeed in supporting children without excluding or stigmatizing them in relation to their peers, the children will get more involved in school tasks. Another factor related to participation is initiatives, or autonomous self-determined behavior. If support is provided when the adult identifies a need and not the child, it could reduce the child's initiatives. One hypothesis is that if students feel accepted and in control, then they will ask for support more often and learn more. The physical environment is another important factor. It should not segregate the child more than necessary, for example, having the same size benches, even if the bench is adapted, so that the child can be seated with everyone else, having outdoor clothes in the same place as the other students, and being able to use the same exits as everyone else. A future issue might be how to provide support without reducing the child's initiatives and without removing the child from the peer group.

Participation is not as strongly affected by type and degree of disability as by the fact that a person has a disability (study III). A reason for this paradox is the multidimensionality of the concept. Many personal factors contribute to the degree of participation experienced by a student, for example, autonomy and locus of control. Another explanation is contextual factors, where the provided support reduces the specific effects of a disability. One implication is that using diagnosis and disability type as a basis for providing services and interventions is not optimal if full participation for an individual is the goal of intervention.

9 ACKNOWLEDGEMENTS

10 REFERENCES

Almqvist, L. (2006). Participation in school environment of children and adolescents with disabilities: A person-oriented approach. *Journal of policy and practice in intellectual disabilities, 3*, 65-75.

Almqvist, L., Eriksson, L., & Granlund, M. (2004). Delaktighet i skolaktiviteter- ett systemteoretiskt perspektiv [participation in school activities- a system theoretical perspective]. In A. Gustavsson (Ed.), *Delaktighetens språk*. Lund: Studentlitteratur.

Almqvist, L., & Granlund, M. (2005). Participation In School Environment of Children and Adolescentss with disabilities. *Scandinavian Journal of Psychology, 46*, 305-314.

Almqvist, L., & Granlund, M. (submitted). Stability and change in positive functioning for young children with and without developmental delay.

Almqvist, L., Hällnäs, P., Stefansson, M., & Granlund, M. (accepted). I can play! young children's perception of health. *Pediatric Rehabilitation.*

Arvidsson, P., Thyberg, M., & Granlund, M. (submitted). Factors with a positive relation to self rated participation in adolescents and adults with mild intellectual disability- a systematic literature review.

Bailey, D. B., Simeonsson, R. J., Buysse, V., & Smith, T. (1993). Reliability of an index of child characteristics. *Developmental Medicine & Child Neurology, 35*(9), 806-815.

Bandura, A. (1997). Sources of self-efficacy. In A. Bandura (Ed.), *Self-efficacy: the exercise of control* (pp. 79-114). Basingstoke: W. H. Freeman.

BarnOmbudsmannen. (2006). *Röster som räknas, barn och ungas rätt till delaktighet och inflytande*. Stockholm: BarnOmbudsmannen.

Bickenbach, J. E., Chatterji, S., Bradley, E. M., & Üstün, T. B. (1999). Models of disablement, universalism, and the international classification of impairments, disabilities, and handicaps. *Social Science & Medicine, 48*, 1173-1187.

Björck-Åkesson, E., Granlund, M., & Simeonsson, R. J. (2005). Special education: A systems theory perspective. In. E. Hemindahl Mattson, A-L. Lange, L Roll-Pettersson & M. Westling Allodi (eds). *Mångsidigt Samspel*. Stockholm, LHS Förlag, pp41-55.

Bronfenbrenner, U. (1979). *The ecology of human development*. Cambridge: Harvard University Press.

Bronfenbrenner, U. (1999). Environments in developmental perspective: Theoretical and operational models. In S. Friedman & T. Wachs (Eds.), *Measuring environments across the life span: Emerging methods and concepts*. Washington, DC: American Psychological Association.

Bronfenbrenner, U., & Ceci, S., J. (1994). Nature-nurture reconceptualized developmental perspective: a bioecological model. *Psychological review, 101*(4), 568-586.

Bronson, M. B., Hauser-Cram, P., & Warfield, M. E. (1995). Classroom behaviors of preschool children with and without developmental disabilities. *Journal of Applied Developmental Psychology, 16*, 371-390.

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

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

Buysse, V., Davis Goldman, B., & Skinner, M. L. (2002). Setting effect on friendship formation among young children with and without disabilities. *Council for Exceptional Children, 68*(4), 503-517.

Carlson, C. I. (1987). Social Interaction, Goals, and Strategies of Children with Learning Disabilities. *Journal of Learning Disabilities, 20*, 306-311.

Cieza, A., Brockow, T., Ewert, T., Amman, E., Kollerits, B., Chatterji, S., et al. (2002). Linking health-status measures to the international classification of funtioning, disability and health. *Journal of Rehabilitation Medicine, 34*, 205-210.

Clark, E., Olympia, d., E, Jensen, J., Heathfield, L., Tuesday, & Jenson, W., R. (2004). Striving for autonomy in a contingency-governed world: another challenge for individuals with developmental disabilities. *Psychology in school, 41*(1), 143-153.

Clonan, S., M, Chafouleas, S. M., McDougal, J., L, & Riley-Tillman, T., Chris. (2004). Positive psychology goes to school: are we there yet? *Psychology in school, 41*(1), 101-110.

Cole, C. M., Waldron, N., & Majd, M. (2004). Academic Progress of Students Across Inclusive and Traditional Settings. *Mental retardation, 42*(2), 136-144.

Convention on the Rights of the Child, United Nations (1989).

Cook, B. G. (2001). A comparisons of teacher's attitudes toward their included students with mild and severe disabilities. *The Journal of Special Education, 34*(4), 203-213.

Council, N. R. (2000). *From Neurons to neighborhoods-the science of early childhood development*. Washington D.C.: National Academy Press.

Cullinan, D., Sabornie, E. J., & Crossland, C. L. (1992). Social mainstreaming of mildly handicapped students. *The elementary school journal, 92*(3), 339-351.

Doctoroff, S. (2001). Adapting the physical environment to meet the needs of all young children for play. *Early Childhood Education Journal, 29*(2), 105-109.

Dudgeon, B. J., Massagli, T. L., & Ross, B. W. (1996). Educational participation of children with spinal cord injury. *The American Journal of Occupational Therapy*, 553-561.

Dunst, C. J., Trivett, C. M., & Jodry, W. (1997). Influence of social support on children with disabilities. In M. J. Guralnick (Ed.), *Effectiveness of early intervetion* (pp. 499-522). Baltimore: Paul H Brookes Publishing Co.

Durrant, J. E., Cunningham, C. E., & Voelker, S. (1990). Academic, social, and general self-concepts of behavioral subgroups of learning disabled children. *Journal of Educational Psychology, 82*(4), 657-663.

Emanuelsson, I. (2004). Integrering/inkludering i svensk skola. [integration/inclusion in Swedish School system] In J. Tössebro (Ed.), *Integrering och inkludering*. Lund: Studentlitteratur.

Eriksson, C. (2001). *Gymnasieelevers skolsituation. relationen mellan elev och miljö.*[High School students School situation, the relation between student

and environment] Unpublished kandidat uppsats, Mälardalens högskola, Västerås.

Eriksson, L., Öhlen, A.-B., & Granlund, M. (in prep). Activity and interaction patterns in preschool.

Eriksson, M., & Mellin, H. (2002). *Bortvalda barn* [rejected children]. Unpublished undergraduate thesis, Mälardalens högskola, Västerås, Sweden.

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

Florian, L., Hollenweger, J., Simeonsson, R., Wedell, K., Riddell, S., Terzi, L., et al. (2006). Cross-cultural perspectives on the classification of children with disabilities: part I. issues in the classification of children with disabilities. *The Journal of Special Education, 40*(1), 36-45.

Granlund, M., & Björck-Åkesson, E. (1999). *Upplevd Interaktions enkät [*percieved interactions, questionnaire]. Västerås: Institutionen för Samhälls- och Beteendevetenskap Mälardalens högskola.

Granlund, M., Björck-Åkesson, E., Åsbrink, M., & Karlsson, M. (2000). *Environmental survey* (questionnaire). Västerås: Mälardalens University, ISB; CHILD.

Granlund, M., Eriksson, L., Almqvist, L., Björck-Åkesson, E., & Luttropp, A. (2004). *Delaktighet: En kort sammanfattning av ett forskningsprojekt.* (No. 4). Stockholm: Institutionen för Samhälls- och Beteendevetenskap, Mälardalens Högskola, Special pedagogiska institutet och stiftelsen **ala**.

Granlund, M., & Olsson, C. (1998). *Familjen och habiliteringen.*[Family and the habilitation] Stockholm: Stiftelsen ala.

Granlund, M., & Roll-Pettersson, L. (2001). The perceived needs of support of parents and classroom teachers-a comparison of needs in two microsystems. *European Journal of Special Needs of Education, 16*(3), 225-244.

Granlund, M., Stéenson, A-L., Roll-Pettersson, L., Björck-Åkesson, E., Sundin, M., & Kylén, A. (1999). *Elever med flera funktionnedsättningar i särskolan - utbildningens effektivitet.* [Students with multiple disabilities in Special schools the effectiveness of education]. Stockholm: FUB:s stiftelse ala.

Grue, L., & Heiberg, A. (2000). Do disabled adolescents view themselves differently from other young people. *Scandinavian Journal of Disability Research, 2*(1), 39-56.

Guralnick, M., J., & Groom, J., H. (1988). Friendship and preschool children in mainstreamed playgroups. *Developmental Psychology, 24*(4), 595-604.

Gustavsson, A. r. (2004). *Delaktighetens språk*. Lund: Studentlitteratur.

Guthrie, J. T., & Davis, M. H. (2003). Motivating struggling readers in middle school through an engagement model of classroom practice. *Reading & Writing Quarterly, 19*, 59-85.

Göransson, K. (2006). Pedagogical traditions and conditions for inclusive education. *Scandinavian Journal of Disability Research, 8*(1), 67-74.

Hall, L. J., & Strickett, T. (2002). Peer relationships of preadolescent students with disabilities who attend a separate school. *Education and Training in Mental Retardation and Developmental Disabilities, 37*(4), 399-409.

Hartup, W. W. (1996). The company they keep: friendship and their developmental significance. *Child Development, 67*, 1-13.

Haug, P. (1998). *Pedagogiskt dilemma: Specialundervisning.* [The pedagogical dilemma: special education]. Stockholm: Skolverket.

Haug, P. (2003). Har spesialundervisninga ein plass i skulen for alle? [has special education a place in a school for all?]. *Nordisk tidskrift för spesialpedagogikk, 81*(2), 81-94.

Heiman, T. (2004). Teachers coping with changes: including students with disabilities in mainstream classes: an international view. *International journal of special education, 19*(2), 91-103.

Hemmingsson, H. (2002). *Student-Environment fit for students with Physical Disabilities.* Doctorial thesis, Karolinska University, Stockholm.

Hemmingsson, H., & Borell, L. (2002). Environmental barriers in mainstream schools. *Child: Care Health and Development, 28*(1), 57-63.

Hemmingsson, H., Borell, L., & Gustavsson, A. (2003). Participation in school: school assistants creating opportunities and obstacles for pupils with disabilities. *OTJR: Occupation, Participation and Health, 23*(3), 88-98.

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.

Holt, L. (2003). (Dis)abling children in primary school micro-spaces: geographies of inclusion and exclusion. *Health and Place, 9*(2), 119-128.

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.

Howes, A., Farell, P., Kaplan, I., & Moss, S. (2003). *The impact of paid adult support on the participation and learning of pupils in mainstream schools.* London: EPPI-Center, Social Science Research Unit, Institute of Education.

Jacobs Sandstrom, M., & Coie, J. D. (1999). A developmental perspective on peer rejection: mechanisms of stability and change. *Child Development, 70*(4), 955-966.

Johnson, J. E., Christie, J.F., & Yawkey, T.D. (1999). *Play and early Childhood Development.* New York, USA: Addisson Wesley Longman.

Jones, F., & Bright, J. (2001). *Stress: Myth, theory and research.* London: Prentice Hall.

Kennedy, C. H., Cushing, L. S., & Itkonen, T. (1997). General Education Participation Improves the Social Contacts and Friendship Networks of Students with Severe Disabilities. *Journal of behavioral education, 7*(2), 167-189.

Kindwall-Fredblad, I. (2004). *Upplevelsen av delaktighet i skolaktiviteter för barn med och utan funktionshinder.* [perceptions of participation in school activities for children with and without disabilities]. Unpublished undergraduate thesis, Mälardalens högskola, Västerås, Sweden.

King, G., McDougall, J., Dewit, D. J., Hong, S., Milller, L., Offord, D., et al. (2005). Pathways to children's academic performance and prosocial behavoiur: roles of physical health status, environmental, family, and child factors. *International journal of disability, development, & education, 52*(4), 313-344.

Kjellberg, A. (2002). *Participation - ideology and everyday life: How to understand the experiences of persons with learning disabilities.* Linköping University, Linköping/Örebro.

Lachapelle, Y., Wehmeyer, M. L., Haelewyck, Y., Courbois, K. D., Keith, K. D., Schalock, R., et al. (2005). The relationship between quality of life and self-determination: an international study. *Journal of Intellectual Disability Research, 49*(10), 740-744.

Lane, K., L, Givner, C., C, & Pierson, M., R. (2004). Teacher expectations of student behavior: social skills necessary for success in elementary school classrooms. *The Journal of Special Education, 32*(2), 104-110.

Larsson Lund, M., Nordlund, A., Nygård, L., Lexell, J., & Bernspång, B. (2005). Perceptions of participation and predictors of perceived problems with participation in persons with spinal cord injury. *Journal of Rehabilitation Medicine, 37*, 3-8.

Law, M., Finkelman, S., Hurley, P., Rosenbaum, P., King, S., King, G., et al. (2004). Participation of children with physical disabilities: relationships with diagnosis, physical function, and demographic variables. *Scandinavian Journal of Occupational Therapy, 11*, 156-162.

Law, M., Haight, M., Milroy, B., Willms, D., Stewart, D., & Rosenbaum, P. (1999). Environmental factors affecting the occupations of children with physical disabilities. *Journal of Occupational Science, 6*(3), 102-110.

Lollar, D. J., & Crews, J. E. (2003). Redefining the role of public health in disability. *Annual reviews of public health, 24*, 195-208.

Lollar, D. J., Simeonsson, R. J., & Nanda, U. (2000). Measures of outcomes for children and adolescents. *Archives of Physical Medicine and Rehabilitation, 81*(12), 46-52.

Lpfö98. (1998). *Curriculum for the preschool LpFö98.* Stockholm: The national agency for education.

Lpo94. (1998). *Curriculum for the compulsory school system, the pre-school class and the leisure-time centre Lpo 94.* Stockholm: The national agency for education.

Magiati, I., Dockrell, J. E., & Logotheti, A-E. (2002). Young children's understanding of disabilities: the influence of development, context, and cognition. *Applied developmental psychology, 23*, 409-430.

Mahoney, J. L., & Bergman, L. R. (2002). Conceptual and methodological considerations in a developmental approach to the study of positive adaptation. *Applied developmental psychology, 23*, 195-217.

Mahoney, J. L., Cairns, B. D., & Farmer, T. W. (2003). Promoting interpersonal competence and educational success through extra curricular activity participation. *Journal of educational psychology, 95*(2), 409-418.

Molin, M. (2004). Delaktighet inom handikappområdet- en begreppsanalys. [participation wihtin the disability field- an analys of concepts]. In A. Gustavsson (Ed.), *Delaktighetens språk* (pp. 21). Lund: Studentlitteratur.

Nirje, B. (2005). *Normaliserings principen*. [The normalization principle]. Lund: Studentlitteratur.

Pavri, S., & Monda-Amaya, L. (2001). Social support in inclusive schools: students and teacher perspectives. *Exceptional children, 67*(3), 391-411.

Perenbloom, R. J. M., & Chorus, A. M. J. (2003). Measuring participation according to the international classification of functioning, disability and health (ICF). *Disability and Rehabilitation, 25*, 577-587.

Persson, B. (2001). *Elevers olikheter och specialpedagogisk kunskap.* [students differences and special educational knowledge] Stockholm: Liber AB.

Persson, B. (2003). Special education competence in school for all-ideals and actualities. *Nordisk tidskrift för spesialpedagogikk, 81*(2), 79-85.

Pramling, I., Samuelsson, I., & Sheridan, S. (1999). *Lärandets grogrund.* [the breeding ground for learning]. Lund: Studentlitteratur.

Ryan, R. M., & Deci, E. L. (2000). Self-determination theory and the facilitation of intrinsic motivation, social development, and well-being. *American Psychologist, 55*(1), 68-78.

The Salamanca statement, UNESCO(1994).

Sameroff, A., J, & Fiese, B., H. (2000). Transactional regulation: the developmental ecology of early intervention. In J. P. Shonkoff & S. J. Meisels (Eds.), *Handbook of early childhood intervention* (second edition ed., pp. 135-159). Cambridge, UK: Press syndicate of the university of Cambridge.

Sand, D., J., & Wehmeyer, M. L. (1996). *Self-determination across the life span.* Baltimore, USA: Paul H. Brookes publishing CO., Inc.

Sandberg. A. (2002). *Vuxnas lekvärld- en studie om vuxnas erfarenheter av lek.* [Adults play, a study of adults experiences of play]. Göteborgs Universitet. PhD thesis. Gothenburg: Acta Universitatis Gothoburgensis.

Sandberg, A., Björck-Åkesson, E., & Granlund, M. (2004). Play in retrospection - play experience form childhood in adults with visual disability, motor disability and asperger syndrome. *Scandinavian Journal of Disability Research, 6*, 111-130.

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.

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

Shonkoff, J. P., & Phillips, D. A. (Eds.). (2002). *From neurons to neighborhoods: The science of early childhood development.* Washington, D.C.: National Academy Press.

Sigafoos, A. D., Feinstein, C. B., Damond, M., & Reiss, D. (Eds.). (1988). *The measure of behavioral autonomy in adolescence: The autonomous functioning checklist* (Vol. 15). Chicago: University of Chicago Press.

Simeonsson, R. (2005). Defining and classifying disability in children. In M. J. Field, A. M. Jette & L. Martin (Eds.), *Workshop on disability in America, a new look* (pp. 67-142). Washington DC: The national academies press.

Simeonsson, R. J., & Bailey, D. B. (1984). *The Abilities Index.* Chapel Hill: Frank Porter Graham Child Development Centre.

Simeonsson, R. J., Carlson, D., Huntington, G. S., Sturtz McMillen, J., & Brendt, J. L. (2001). Students with disabilities: a national survey of participation in school activities. *Disability and Rehabilitation, 23*, 49-63.

Skinner, E. A., & Belmont, M. J. (1993). Motivation in the classroom: reciprocal effects of teacher behavior and student engagement across school year. *Journal of educational psychology, 85*(4), 571-581.

Skinner, E. A., Zimmer-Gembeck, M. J., & Conell, J. P. (1998). Individual differences and the developmental of perceived control. *Monographs of the society for research in child development, 63*(2-3), 232p.

Skolverket. (1999). *Överenskommet! fem internationella överenskommelser som ligger till grund för de nya läroplanerna* (2:a ed.). Stockholm: Liber.

Skolverket. (2005). *Handikapp i skolan, Det offentliga skolväsendents möte med funktionshinder från folkskolan till nutid.* Kalmar: Lenanders Grafiska AB.

Skär, L. (2002a). *Barn och ungdomar med rörelsehinder- deras uppfattningar om roller, relationer och aktiviteter.* [children and adolescents with motor disabilities-their understanding or roles, relations and activities] Doctorial Thesis, Luleås tekniska universitet, Luleå.

Skär, L. (2002b). Disabled Children's Perception of technical aids, assistance and peers in play situations. *Nordic College of caring Science, 16*, 27-33.

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

Skär, L., & Tamm, M. (2000). How children with restricted mobility perceived their technical aids. *Nordisk fysioterapi, 4*(1-9).

Skär, L., & Tamm, M. (2001). My assistant and I: disabled children's and adolescents' roles and relationships to their assistants. *Disability & Society, 16*(7), 917-931.

Sontag, J. C. (1996). Toward a comprehensive theoretical framework for disability research: Bronfenbrenner revisited. *The Journal of Special Education, 30*(3), 319-344.

SOU. (1982). *Integrationsutredningen: Handikappade elever i det allmänna skolväsendet: slutbetänkande från Integrationsutredningen.* Stockholm: LiberFörlag/Allmänna förl.

SOU. (1998:66). *Funkis- funktionshindrade elever i skolan.* [Students with disabilities in school] Stockholm: Skolverket.

Specht, J. A., Miller Polgar, J., Willoughby, C., King, G., & Brown, E. (2000). A retrospective look at the educational experiences of individuals with disabilities. *Exceptionality Education Canada, 10*(3), 25-39.

The standard rules on the equalization of opportunities for persons with disabilities, The Unitied Nation (1993).

Super, C., & Harkness, S. (1999). The environment as culture in developmental research. In S. Friedman & T. Wachs, D. (Eds.), *Measuring environments across the life span* (pp. 279-326). Washington D.C.: American Psychological Association,.

Szönyi, K. (2005). *Särskolan som möjlighet och begränsningar-elevperspektiv på delaktighet och utanförskap.* [The special school as opportunities and restrictions- a student perspective on participation and isolation]. PhD thesis, Stockholm University, Stockholm.

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.

Ueda, S., & Okawa, Y. (2003). The subjective dimension of functioning and disability: what is it and what is it for? *Disability and Rehabilitation, 25*, 596-601.

Wachs, T., D. (2001). *Necessary but not sufficient- the respective roles of single and multiple influences on individual development.* Washington D.C: American Psychological association.

Wehmeyer, M. L. (1995). *The ARC´s Self-Determination Scale - procedural guidelines.* Arlington: Texas: The Arc Of The United States.

Wehmeyer, M. L. (1998). Self-determination and individuals with significant disabilities: Examining meanings and misinterpretation. *Journal of the Association for Persons with Severe Handicaps, 23*(1), 5-16.

Wehmeyer, M. L. (2004). Beyond self-determination: causal agency theory. *Journal of Developmental and Physical Disabilities, 16*(4), 337-359.

Wehmeyer, M. L., Agran, M., & Hughes, C. (2000). A national survey of teachers' promotion of self-determination and student-directed learning. *The Journal of Special Education, 34*(2), 58-68.

Wehmeyer, M. L., Kelchner, K., & Richards, S. (1996). Essential characteristics of self-determined behavior of individuals with mental retardation. *American Journal on Mental Retardation, 100*(6), 632-642.

Wehmeyer, M. L., & Kelchner, M. (1995). *The arc's self-determination scale-adolescent version.* Arlington, Texas: The arc of the United States.

Wehmeyer, M. L., & Palmer, S. B. (2003). Adult outcomes for students with cognitive disabilities three-years after high school: the impact of self-determination. *Education and Training in Mental Retardation and Developmental Disabilities, 38*(2), 131-144.

Wehmeyer, M. L., & Schwartz, M. (1998). The relationship between self-determination and quality of life for adults with mental retardation. *Education and Training in Mental Retardation and Developmental Disabilities, 33*(1), 3-12.

Wentzel, K. R., & Watkins, D. E. (2002). Peer Relationship and Collaborative Learning as Contexts for Academic Enablers. *School Psychology Review, 31*, 366-378.

Westling Allodi, M. (2000). Self-concept in children receiving special support at school. *European Journal of Special Needs Education, 15*(1), 69-78.

Westling Allodi, M. (2002). Children's experiences of school: narratives of Swedish children with and without learning disabilities. *Scandinavian Journal of Educational research, 46*(181-205).

Vetenskapsrådet. (1990). *Forskningsetiska principer inom humanistisk samhällsvetenskaplig forskning.* Stockholm: Elanders Gotab.

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

von Bertalanaffy, L. (1969). *General system theory* (13 ed.). New York: George Braziller, Inc.

Vygotsky, L.S. (1995). *Fantasi och kreativitet i barndomen.* [Fantasy and creativity in childhood]. Göteborg, diadalos.

Vygotsky, L.S. (1980). *Psykologi och Dialektik.* [psychology and dialectics] Malmö, Sweden. P.A. Norstedt & Söner Förlag.

Üstün, T. B., Chatterji, S., Bickenbach, J., Kostanjsek, N., & Schneider, M. (2003). The international classification of functioning, disability and health: a new tool for understanding disability and health. *Disability and Rehabilitation, 25*, 565-571.