

Thesis for doctoral degree (Ph.D.)
2009

Thesis for doctoral degree (Ph.D.) 2009

CHILDREN WITH DOWN SYNDROME IN MAINSTREAM SCHOOLS - CONDITONS INFLUENCING PARTICIPATION

CHILDREN WITH DOWN SYNDROME

Anne-Stine Dolva

Anne-Stine Dolva



**Karolinska
Institutet**



**Karolinska
Institutet**

DEPARTMENT OF NEUROBIOLOGY, CARE SCIENCES
AND SOCIETY
DIVISION OF OCCUPATIONAL THERAPY
Karolinska Institutet, Stockholm, Sweden

**CHILDREN WITH DOWN
SYNDROME IN
MAINSTREAM SCHOOLS –
CONDITIONS INFLUENCING
PARTICIPATION**

Anne-Stine Dolva



**Karolinska
Institutet**

Stockholm 2009

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

Published by Karolinska Institutet.

© Anne-Stine Dolva, 2009
ISBN 978-91-7409-514-2

Printed by



www.reproprint.se

Gårdsvägen 4, 169 70 Solna

ABSTRACT

The overall aim of this thesis was to identify and explore conditions influencing school participation of children with Down syndrome in mainstream elementary schools.

This thesis comprises four studies, and the research was conducted in Norway. **Study I** aimed at describing home and community functional performance in 5-year-old children with Down syndrome, to get insight into the level of performance and variability prior to school entry. In **study II** the aim was to investigate the relation between functional performance skills of children with Down syndrome and the age of their entry into mainstream elementary education. In **study I and II**, data was collected on self-care, mobility and social function with structured interviews with parents using the PED1, and analyzed with descriptive, non-parametric statistics. **Study III** aimed to explore peer interaction in the context of school activities in mainstream classes. Interaction between the pupils with Down syndrome with their peers was studied in order to identify enabling conditions. **Study IV** aimed to explore and describe peer interaction in school activities as experienced by teachers and teachers' assistants, and to identify and explore how they facilitated interaction. **Studies III and IV** used qualitative interviews and observations that were analyzed with constant comparative method followed by interpretations (study IV).

The findings of **study I** provided baseline information about self-care, mobility and social function tasks, indicating a wide range of performance. Mobility appeared as a domain of relative independent performance, and assistance was needed in self-care and social function. Management of bladder and bowel control appeared to be a problem at group level, thus parents expressed a worry regarding school entry. Speech and communication difficulties were found, with higher score on comprehension compared to functional expression. **Study II** identified functional performance skills in relation to children who got a one year postponement of their school entry, which was the case for 40% of the sample. Conditions relating to postponed school entry were found to be lack of bladder and bowel control, low scores in functional comprehension, expressive communication and problem solving. **Study III** identified different patterns of peer interaction in school activities. Instances of equal interaction were found, characterized by the interacting pupils' shared understanding of the activity and tasks within the performance range of those who participated. In unequal interaction, when the activity interest was "shared enough" but tasks too difficult for the pupils with Down syndrome, peers were found to act as a more skilled partner. Peers modified or adjusted activities and tasks, or own behaviour in various ways that in turn enabled participation. Findings of **study IV** revealed support strategies of class staff in order to facilitate peer interaction in school activities. The support strategies seemed to be grounded in their experience of peer interaction as challenging because of diversity among the pupils. Their strategies concerned planning, arranging of activities in groups, pairing the pupil with Down syndrome to more skilled pupils, educating peers to behave supportive, and teachers' assistants' provision of individual support to the pupils with Down syndrome by the role of the "supported ego".

Taken together, the findings of this thesis provide knowledge about conditions influencing school participation of children with Down syndrome in mainstream elementary schools. Findings provide knowledge of performance which may be helpful in planning the children's school entry, knowledge about enabling strategies of peers in order to create opportunities for participation in activities, insight into the planning and organizing of teachers in order to create an including social learning environments, and knowledge about the role of the "supported ego", compensating for the cognitive difficulties of the pupils with Down syndrome in order to facilitate social participation with peers.

Keywords: inclusion, occupational performance, peer interaction in activities, support.

LIST OF PUBLICATIONS

This thesis is based on the following publications, referred to in the text by their roman numerals:

- I. Dolva, A.-S., Coster, W.J., & Lilja, M. (2004). Functional performance in children with Down syndrome. *American Journal of Occupational Therapy*, 58(6), 612-629.
- II. Dolva, A.-S., Lilja, M. & Hemmingsson, H. (2007). Functional performance characteristics associated with postponed elementary school entry among children with Down syndrome. *American Journal of Occupational Therapy*, 61(4), 414-420.
- III. Dolva, A.-S., Hemmingsson, H., Gustavsson, A., & Borell, L. Pupils with Down syndrome in mainstream schools and peer interaction. Submitted.
- IV. Dolva, A.-S., Gustavsson, A., Borell, L., & Hemmingsson, H. Facilitating peer interaction – support to children with Down syndrome in mainstream schools. In manuscript.

Previously published papers (I and II) were reproduced with permission from the publisher. The editor of the journal to which Paper III was submitted have been informed that the papers will be printed in this thesis.

LIST OF ABBREVIATIONS

AOTA	American Occupational Therapy Association
BOTMP	Bruininks-Oseretsky Test of Motor Proficiency
CAOT	Canadian Association of Occupational Therapists
ICIDH	International Classification of Impairment, Disability and Handicaps
ICF	International Classification of Functioning, Disability and Health
ICF-CY	International Classification of Functioning, Disability and Health: Children & Youth version
NETF	Norsk Ergoterapeut Forbund [Norwegian Occupational therapy Association]
PEDI	Pediatric Evaluation of Disability Inventory
PEO	Person-Environment-Occupation model
SSB	Statistisk Sentralbyrå [Statistical Central Bureau]
UNESCO	United Nations Educational, Scientific and Cultural Organization

CONTENTS

ABSTRACT	
LIST OF PUBLICATIONS	
LIST OF ABBREVIATIONS	
CONTENTS	
INTRODUCTION.....	1
BACKGROUND.....	2
An occupational perspective.....	3
Children with Down syndrome.....	7
Social participation of children with Down syndrome.....	10
RESEARCH OBJECTIVE.....	15
METHODS.....	16
Study design.....	16
Participants.....	17
Data collection.....	18
Data analysis.....	26
FINDINGS.....	28
GENERAL DISCUSSION.....	32
School participation of children with Down syndrome.....	32
Development and performance of children with Down syndrome.....	32
Peer interaction; opportunities and challenges.....	36
The provision of adult support.....	39
METHODOLOGICAL CONSIDERATIONS.....	43
ETHICAL CONSIDERATIONS.....	47
CONCLUSIONS AND IMPLICATIONS.....	49
ACKNOWLEDGMENTS.....	51
REFERENCES.....	53

INTRODUCTION

My clinical practice as an occupational therapist has, for many years, been within the field of habilitation, working in a multidisciplinary team at the county hospital with children and adolescents with disabilities. Characteristically, this practice implies working closely with other disciplines, applying a family centered approach, planning for the children in a lifelong perspective and getting to know the individuals and their families over several years. Children with Down syndrome caught my interest for several reasons. I was inspired by the possibilities for these children related to progress in knowledge on their syndrome, changing views on disability and political intentions of inclusion. For me, as for the Norwegian paediatrician Lofterød (1997), Down syndrome became the “syndrome of possibilities”. In clinical practice, one of my tasks was to advice parents through the child’s development. Additionally, I provided supervision to staff of kindergartens and schools for the purpose of promoting participation of children with Down syndrome in mainstream contexts. One common occurrence was that the children’s school entry and participation in regular classes caused anxiety and stress for their parents. The transition from kindergarten to school and school participation is a complex matter. One common area of interest was related to what expectations would be realistic for the children’s performance, and what possibilities there were for the children to participate with peers in school activities in a regular class. With respect to the efforts of those working in kindergartens and school, my experience was that many, both parents and professionals within and outside schools shared an interest in gaining more knowledge on how to succeed in inclusive education of children with Down syndrome. Contributing to the body of knowledge about conditions influencing participation in ordinary life situations for pupils with Down syndrome became my academic interest. My research is grounded in the experiences and knowledge of parents, children with Down syndrome, their class staff and the everyday events in regular classes, and aims at being applicable and useful for clinical practice.

“It takes a village to raise a child”

African proverb

BACKGROUND

Full participation of children with disabilities within inclusive education system is a world wide educational goal (United Nations, 1989; UNESCO, 1994), but many questions regarding *how* to succeed with inclusion still remains to be answered. This thesis concerns conditions influencing school participation of children with Down syndrome. The age range 5 to 10 was chosen to capture the period of entry to elementary school and the children's first years in mainstream elementary school. School participation in this thesis is viewed from an occupational perspective. Children's engagement in occupations is in focus and is believed to be the product of interdependent influences of cultural practice of adults, interpersonal relations with others during participation, and children's effort to do what they find interesting or are expected of them (Coster, 1998; Humphry & Wakeford, 2008).

The child's entry to elementary school is generally described as a key life cycle transition (Pianta & Cox, 1999), with increased academic and social demands, and changes of learning environment (Law, Missiuna, Pollock & Stewart, 2001). The transition to school has traditionally centered on school readiness as indicated by skill development. Such development has commonly being considered a natural consequence of chronological age at which students are determined to be eligible for school entry. This has also been the focus of many practicing occupational therapists (Prigg, 2002). More recently however, a broader view of the transition has been put forth through models that take the influence of contexts into consideration. Pianta and Kraft-Sayre (2003), for example, propose that the transition to elementary school involves different conditions, such as the school environment, teacher attitudes, family expectations and level of support provided. Thus, the transition to elementary school of children with disabilities is not only dependent on knowledge of the children's characteristics, but also on knowledge of and contributions from parents as well as health and educational systems and professionals.

As children enter school, they are expected to participate and adapt to the demands of the school and class context. Successful participation has been defined as being with others and being able to perform tasks (Heah, Case, McGuire & Law, 2007). Further, being with others and being able to achieve in activities that are valued by peers is found to be one key to social participation and friendship in mainstream school for children with Down syndrome (Fox, Farrell & Davies, 2004).

Thus, relationship with class peers take on of considerable importance (Guralnick, 1999). Through performance of, and participation in everyday occupations, children learn and master new skills. From the perspective of children, doing activities together with friends is of the utmost importance (Corsaro, 1998). When children have opportunities to engage in interactions that support and strengthen their skills in naturally occurring ways in everyday life, they develop and flourish (Dunst, Bruder, Trivette, Raab & McLean, 2001). This is also in accordance with the aim of occupational therapy, which is to promote health and participation of people through engagement in occupation (American Occupational Therapy Association [AOTA], 2008; Norsk Ergoterapeut Forbund [NETF], 2007).

In order to promote the school participation of children with Down syndrome in mainstream schools, further knowledge is needed regarding the children's performance of relevant activities as well as the influence of parents, peers, teachers and assistants. Investigation of these contexts for children with Down syndrome around the age of school entry and in elementary school, from an occupational perspective, has been limited. The overall aim of this thesis is to identify and explore conditions influencing participation in mainstream elementary school of children with Down syndrome. I engage in this task from the perspective that interaction between the child and his/her environment varies to a large extent as a result of the characteristics of the developing child and his/her immediate and more remote activities, environmental contexts, and the overall system by which the schools are organized.

In the following, I describe the perspective which underpins this study, as well as the central concepts and conceptual framework that I make use of. I also present a review of literature of concern for this research project.

An occupational perspective

Children's occupation and performance

Occupation involves what people do in everyday life, individually or together with others. The essence of the concept of *occupation* is defined by Christiansen, Clark, Kielhofner and Rogers (1995 p. 1015) as "the ordinary and familiar things that people do every day". Things that people do every day change with age. Throughout childhood, development of skills through different occupations enables the child to engage with the environment in increasingly complex ways. The socially established

and culturally defined occupations of childhood, such as play and self-care, influence the child to perform and change. Thus, when children play and perform activities of daily living, they author their own development through what they do (Kielhofner, 2008). Consequently, development in an occupational perspective can be described as the systematic process of change whereby the individual comes to know the occupational world and becomes competent within it (Davies & Polatajko, 2006).

Pediatric occupational therapy is based on an understanding of the interaction among children, their activities, and their environment (Case-Smith, 2001) and grounded in theories of human development (Hinojosa & Kramer, 1999). For the purpose of this thesis and to capture the ‘world of doing’ of children, occupation is defined as culturally valued, coherent patterns of actions that emerge through transactions between child, environment and activities in which the child wants to do or is expected to perform” (Humphry, 2002). Occupations have a meaning and purpose to the child. Meaning emphasizes an individual value and recognizes the influence of cultural and environmental aspects on doing. Thus, occupation can only be fully understood if we also understand the environment in which it takes place. For the purpose of this thesis, the environment can be defined as the particular physical and social, cultural, economic, and political dimension of one’s context that impact upon the performance of occupations and participation (Kielhofner, 2008). The outcome of a person’s interaction in doing with the environment has been defined as occupational performance (Case-Smith, 2001).

Person-environment model

The Person-Environment-Occupation (PEO) model (Law, Cooper, Strong, Stewart, Rigby & Letts, 1996) has been chosen as a frame of reference for this thesis. The PEO model is acknowledged in pediatric occupational therapy, and it addresses the three transacting concepts (person-environment-occupation) and shows how these concepts fit when performance is optimal or hindered by conditions of one of the concepts.

Several person-environment-occupational performance models were developed during the mid-1990s, which were based on dynamic system theory, for example the Model of Human Occupation (Kielhofner, 1995) and the Canadian Model of Occupational Performance (Law, Baptiste, Carswell, McColl, Polatajko & Pollock, 1998). The PEO model however, is well known and much used as a theoretical framework of clinical pediatric occupational therapy practice. In practice, the PEO

model is used as an analytical tool to identify factors in the person, environment, or occupation that facilitate or hinder the performance of occupations (Law et al., 2001). Occupational therapy intervention can then focus on facilitating change in any of these three dimensions to improve performance. In this model, *task* is defined as a set of purposeful activities in which a person engages, and *occupation* is defined as groups of self-directed, tasks and activities in which a person engages over the lifespan. The model further defines occupational performance as a complex phenomenon, “shaped by the transaction that occurs among person, environment and occupations in which the person engages” (Law et al., 1996, p. 17). Law and colleagues further proposes that the observable qualities of occupational performance can be measured objectively, while the subjective attributes requires self-reports. When occupational therapists use an occupational performance approach, the outcome is increased participation brought about through increases in skills or the elimination of environmental barriers (e.g. Baum & Christiansen, 2005).

Children’s participation

Through participation children develop skills and engage in activities with others (King, Law, King, Rosenbaum, Kertoy & Young, 2003). Skills are embedded in performance, and performance is embedded in participation (Kielhofner, 2008). The first participation context is traditionally within a family, in play and activities of everyday living. Outside the family school is a major influence on children’s participation. Through participation in school activities children gain knowledge and skills for adult life.

Participation is often cited as a goal and a key outcome for children with disabilities. According to Gustavsson (2004) participation has developed as a highly political ideological notion, and the term’s meaning can vary depending on where and when it is used. In relation to health, the concept of participation plays an important role in healthcare, rehabilitation and in occupational therapy. It is one of the key constructs in the International Classification of Functioning, Disability, & Health, in short ICF (WHO, 2001). In the ICF, components of functioning and disability are divided into a Body functions and Body structures component and an Activity and Participation component. Activity is defined as the execution of a task or action by an individual. Participation is defined as “involvement in life situations” (p. 213). Activity and participation are classified within a single list but coded with two qualifiers; the capacity qualifier and the performance qualifier. The performance qualifier describes

what an individual does in his/her current environment. Because the current environment involves the societal context, performance can, according to the ICF (WHO, 2001) also be defined as participation (involvement in life situations). This in turn indicates that participation is not automatically equated with performance on a conceptual level of the ICF. The ICF acknowledges an interactive relationship between person and environment, but has been criticized for not defining life situations (Coster & Khetani, 2008), and for excluding the subjective aspects of participation (Ueda & Okawa, 2003; Hemmingsson & Jonsson, 2005). From the viewpoint of occupational therapy, it is emphasized that participation also included a social aspect such as involvement, engagement, sharing and social interaction (Schenker, Coster, & Parush, 2005; Law, 2002; Kielhofner, 2008).

The concept social participation was recently defined in a literature study of Koster, Nakken, Pijl and van Houten (2009). Their analysis, of 62 articles regarding social participation in inclusive education, revealed that social participation includes four key themes; friendship/ relationships, contacts/interactions, perceptions of pupil with special education needs and acceptance by peers. In this thesis specifically, aspects of peer interaction is in focus with regard to social participation. According to Koster et al. (2009), the key term 'interaction' covers aspects such as playing together, working together on tasks, participation in group activities, (un) acknowledged initiations and social isolation. Further more, 'perception of pupils with special education needs' covers aspects of self-perception, satisfaction or loneliness, and the key term 'acceptance by classmates' covers social preference, social support, bullying and social rejection.

In summary, this thesis focuses on aspects of participation regarding children with Down syndrome in mainstream elementary schools, as an outcome of the transaction between individuals, environments and occupations. Thus, aspects of participation can be viewed as performance while other aspects are rather subjective experiences. The performance component of participation is used in accordance to ICF, and referred to as functional performance or performance. The social dimension of participation is used in accordance with the definition of Koster et al. (2009), and focuses aspects of social participation such as interaction and acceptance by peers.

Children with Down syndrome

Down syndrome

Down syndrome is the most common form of intellectual disability. John Langdon Down (1826-96) described the syndrome in 1866. By 1959, researchers had established that the disability was caused by an extra chromosome. In 94% of cases Down syndrome is caused by a third chromosome 21 in all cells (hence the scientific name for the syndrome, *trisomy 21*). The remaining 6 % of people with Down syndrome have either a form called “translocation,” in which the extra chromosome 21 is acquired in a different way, a form called “mosaic,” in which not all cells are affected, or finally a very rare form called partial trisomy 21 (Annerén, 1997). Down syndrome remains the single largest cause of significant intellectual disability with levels range from profound to mild. Moreover, Down syndrome is the most common birth disorder, and prevalence varies between 1:500 and 1:1000 births (Frid, Drott, Lundell, Rasmussen & Annerén, 1999). The extra chromosome disorder results in significant abnormalities in the structure and functioning of the brain, such as an enlarged third ventricles which with it’s surrounding areas is important in cognitive processing (Schimmel, Hammerman, Bromiker & Berger, 2006), and altered development of the frontal lobe, temporal lobe, cerebellum and the myelination process (Pinter, Eliez, Schmitt, Capone & Reiss, 2001). Common features associated with Down syndrome are a distinctive craniofacial structure and health related issues such as congenital heart defects, hearing and visual impairments, and immune and endocrine system abnormalities (Pueschel & Pueschel, 1992; Annerén, 1997).

The phrase mental retardation is widely accepted in the United States, but is considered offensive to many in the United Kingdom, where the preferred term is learning disabilities (Fernald, 1995). In much of Europe and Canada (Fletcher, Loschen, Stavrakaki & First, 2007), the preferred term is intellectual disability. Intellectual disability is used in this thesis when referring to Down syndrome.

Development and performance in children with Down syndrome

For all children, development is a continuous and interactive process, and it is not wholly determined by genes at birth. Genes may influence a child's capacity to learn but they do not determine opportunities to learn. As for Down syndrome, researchers are divided over whether development is best understood in terms of a slow-down version of typical development or whether it is fundamentally different in nature and progression. Over the last decades, research has begun to converge on a specific

behavioral phenotype or a distinct profile of behavioral outcomes associated with Down syndrome (Fidler, 2005). Hence, there seem reasonable to take into consideration that children with Down syndrome come to function with a different set of biologically-determined “tools” for learning to those held by most developing children. Compared to children without disabilities, researchers have described developmental delays in all areas of functioning, although the degree of delay varies greatly among individuals (Spano, Mercuri, Rando, Panto, Gagliano, Henderson et al., 1999). Development and learning are closely linked to context, such as social and cultural relationships (Tetzchner, 2005), and the culture in which the child lives decides what and how the child learns (Vygotskij, 2004), thus several aspects of the environment may influence the children’s development.

Appropriate expectations and demands are important for planning a child’s transition from kindergarten to elementary school. However, when a child has Down syndrome, it is often difficult for parents to discern the relevant levels of expectations and demands to utilize. What makes planning even more difficult is that the range of phenotype features displayed varies widely. Although it is likely that the child with Down syndrome will display behavior associated with the syndrome, not every child with the disability will exhibit each of the phenotype features (Dykens, 1995).

Skills and performance of children with Down syndrome have been studied by several scholars (Leonard, Msall, Bower, Tremont & Leonard, 2002; Mancini, Carvalho e Silva, Goncalves & Martins, 2003; Dykens, Hodapp & Evans, 1994). Leonard et al., (2002) found that severe functional limitations in children with Down syndrome aged 5 to 17 were rare, but that help and supervision were required for self-care, communication and social skills. Mancini et al. (2003) showed that at the age of two, the capability (how children perform in their own environment) of children with Down syndrome was delayed in comparison to children without disabilities. At the age of 5, significant differences were found between the groups in the domains of self-care and social function.

Developmental trajectories of children with Down syndrome indicating ranges of developmental milestones and when independence can be expected for some skills have been provided to some extent. For example indications of the age range at which children with Down syndrome were undressing independently, was found to be 29 to 72 months of age (Canning & Pueschel, 1990). The age of when a child with Down syndrome can be expected to stop using diapers has been indicated to be around age 4-5 years (Annerén, Johansson, Kristiansson & Lööw, 1997). However, Carr (1995)

reported that only 35% of the children were toilet trained at the age of 4, and at the age of 11 still one third were still enuretic. It is important to note however, that this study was initiated in the 1960's.

Furthermore, a study by Fidler, Hepburn, Mankin & Roger (2005) found praxis deficits to impact activities of everyday living in children with Down syndrome. Praxis was defined as planning, execution and sequencing of movement (Fidler et al., 2005). Praxis is for example involved in the execution of self-care activities such as brushing one's teeth, eating etc.

In general, children with Down syndrome are found to demonstrate a weakness in communication, especially with respect to expressive (i.e. spoken) language (Smith & Tetzchner, 1986; Dykens et al., 1994). A profile of stronger receptive language skills and weaker expressive language skills emerge in early childhood, and means that the children often understand more than the language they can produce. Recent research has showed that children with Down syndrome can make significant progress in speech, language and literacy in inclusive environments. This is possible if they receive interventions from early years related to evidence of the strengths and weaknesses in learning and development of children with Down syndrome (Buckley, Bird & Sacks, 2006).

Social functioning of children with Down syndrome (the ability to engage with a social partner) is found to emerge with competence, albeit in a delayed fashion. Nevertheless, as demands and complexities of social situations increase in middle childhood and beyond individuals with Down syndrome show difficulties with selecting appropriate social strategies (Dykens, Shah, Sagun, Beck & King, 2002). Other aspects of the behavioural phenotype relevant to the influence the children's development are motivation and task persistence (Gunn & Cuskelly, 1991). Research in laboratory settings has shown that children with Down syndrome remove themselves from challenging situations in favour of social interaction. This behaviour may, as a consequence, deprive children with Down syndrome of important opportunities to challenge themselves, and gain new skills through active engagement with the environment (Pitcairn & Wishart, 1994; Cebula & Wishart, 2008).

In summary, there is still limited knowledge about what can be reasonably expected from the child with regard to different skills and performance at the age around school entry and elementary school. More knowledge is needed about the development of children with Down syndrome in general, as well as extended examination of the extent

to which children with Down syndrome follow the same general sequence in development as children without disabilities. The latter information can be useful related intervention, as it will suggest guidelines for the expected timetables for development in particular areas. In addition, profiles of typical strengths and weaknesses can be used to focus intervention efforts, and for example during school entry. There is limited knowledge about the development of skills and performance of children with Down syndrome, and in particular we know little about the influence of environmental factors, as for example cultural expectations.

School participation of children with Down syndrome

Inclusive education

In education, *inclusion* refers to the placement and education of children with disabilities in regular classrooms with children of the same age who do not have disabilities. The underlying premise of inclusion is that all children can learn and belong to the mainstream of school and community life. The concept of inclusion stem from the Salamanca Statement (UNESCO, 1994), which focused on how to support all children's needs for development and participation in school. UNESCO's declaration has become important regarding inclusion, and has been formulated as an ideal for schooling in many countries, for example Norway. The term 'inclusion' has largely replaced 'integration' and is intended to represent a different concept. Thus, 'integration' may be seen as a child adapting to a host setting (regular school) while 'inclusion' refers to the host adapting in order to meet the needs of the pupil with disability (Lindsay, 2007). The term 'mainstream' is used especially in the US, although 'inclusion' is becoming more common internationally (Lindsay, 2007). In this thesis the terms 'inclusion', and 'mainstream' is used interchangeably.

The Norwegian school context

Before 1975, the responsibilities for primary education in Norway were shared between the municipalities and the state, and the state was responsible for running the special schools. From 1975, municipalities became responsible for education of all children. However, some special schools were transferred to municipalities, and in 1992 all state run special schools were closed. Today there are about 16 special schools situated in the most population-rich towns, run by municipalities. However, inclusion policies and ideology have become more prevalent, and the ideology is that special education should take place in a classroom setting with peer at the local school. The terms inclusive

education and “one school for all” were used in the government’s national curriculum reform plans of 1996. These plans specified adjusted or individualized education as a universal right for all children in primary schools, and special education as a right for children with special needs. Municipalities have the responsibility for the education of all children, and the children have a right to be educated in local schools as far as it is possible and justifiable.

The aim of the Norwegian government is an including and adaptive school, where all children will have the opportunity to succeed according to their conditions, abilities and interests (Sosialdepartementet, 2003). In this statement, one can read that personal characteristics of the child with special needs have to be met. However, the statement is also aiming towards “an including and adaptive school”, which reflects the importance of contextual factors and a supportive school environment.

In Norway, most children with intellectual disabilities attend regular kindergartens and preschool groups are traditionally placed in kindergartens. Pupils enter elementary school in the calendar year in which they reach the age of 6, consequently moving to a new educational environment. At this time, parents have a right to apply for a one-year postponement of elementary school entry “*if there is any doubt that the child is sufficiently mature to begin attending school*” (Education Act, §2-1), and have a right to request special education for their child (Education Act, §5.1) (Kunnskapsdepartementet, 2007). An application for a 1-year postponement of elementary school entry is judged by the local pedagogical-psychological service. Children with disabilities are often provided with assistance in school with regard to individual needs.

About 0.5% of pupils with disabilities attended special schools/classes in the mid-1990s in Norway (Vislie, 2003). A recent longitudinal study of Wendelborg and Tøssebro (2008) identified three factors of main impact on school placement in Norway (regular school or special school/classes); size of municipality population, type of disability and degree of impairment. Moreover, they found that few pupils with disability are moved from regular classes in mainstream schools to special schools/classes during the course of primary school. However, a trend seemed to exist in that pupils with disabilities in regular classes gradually were removed from the classroom. Another finding of this study was that children with intellectual disabilities were more likely to attend special school or - class, compared to those with physical disabilities. Further more, when children with intellectual disabilities attained regular

classes they were found to participate less in the classroom, and the more special education they received, the more time they were out of the classroom.

Social participation in school

In the context of mainstream education, interaction with peers between pupils with and without disabilities has become an issue (Flem & Keller, 2000). For pupils with disabilities the social skills of concern are according Gresham (1983) the skills utilized for relating to both their teachers and their peers. The development of children's social competence with peers is highly valued by parents of children with intellectual disabilities (Guralnick, Connor & Hammond, 1995). These parents often state that what they expect is that inclusion will lead to friendship and increased social competence for their children (Sloper & Tyler, 1992) and what they fear is their children becoming socially isolated in mainstream schools (Guralnick et al., 1995; Sale & Carey, 1995).

Available research indicates that children with intellectual disabilities or Down syndrome have considerable difficulty interacting with peers and creating a meaningful social network (Guralnick, 2002; Ytterhus, 2000; Nordstrøm, 2002). These children show an inability to participate in school activities which in turn can lead to marginalization and isolation (Fox et al., 2004). Contrasting these findings, a recent study of Kemp and Carter (2002) investigated the social status of 22 pupils with mild to moderate leaning disabilities in mainstream schools. The results of this study indicate that peer rating for the pupils with disabilities were between "ok" and "really like" which indicate a relatively high level of peer acceptance. The pupils of this study had previously been in early inclusive settings. Kemp and Carter (2002) suggests that future research investigate if early inclusion with social skills training in a mainstream environment better prepare better children for social inclusion in formal schools. Or, whether inclusion is related to more acceptance and inappropriate behaviour is excused in pupils with obvious disabilities. Buckley, Bird, Sacks and Archer (2006) reported results of survey studies conducted in 1987 and 1999 with children with Down syndrome who were placed in either mainstream or "special schools" based upon where they lived. The benefits of children with Down syndrome being educated alongside their peers in mainstream classrooms was related more to their language and literacy skills and less to social participation. Thus, more knowledge is needed in order to understand the social participation of pupil with Down syndrome with peers in regular classes.

Wendelborg and Tøssebro (2008) found, in a Norwegian study, that the removal of pupils with intellectual disabilities from regular classrooms indicated a

barrier to the development of social participation with peers. Flem and Keller (2000) identified the challenge of mainstream education, to be related to the social aspects for children with disabilities. Many children became lonely and isolated in mainstream school by the fifth and sixth grades, and it was difficult to find peers with whom they could communicate and share experiences. This study focused on the importance of promoting social participation by helping the pupils to feel successful; for example by participating in all activities in the classroom, doing the same things as peers, receiving special education service in the classroom and engaging in more group work. Likewise, their findings stressed those teachers who did not have the competence to adjust their training for pupils with intellectual disabilities, had a lack of qualifications.

The role of class staff is central in the implementation of inclusion. Consequently the role and responsibilities of teachers and teachers' assistants are important in promoting social participation among the pupils in the class. The use of teachers' assistants to support children with disabilities in mainstream classes is widely employed as a fundamental mechanism to operationalize inclusive school practises and promote participation (Downing, Ryndak & Clark, 2000; Giangreco & Broer, 2007). Many teachers consider this to be essential support (Wolery, Werts, Caldwell, Snyder & Liskowski, 1995). Recent research (Giangreco & Broer, 2005; 2007) have revealed that pupils with disabilities spend most of their time in close proximity to assistants, and that pupils are unnecessarily and highly dependent on assistants. Also that many assistants are aware that pupils with disabilities think of them as their primary "friend" at school rather than their classmates. Understanding how teachers and teachers' assistants experience peer interaction, and how they try to facilitate the participation of all pupils, can provide useful data about how class staff sees their opportunities to adapt to secure the optimal participation of pupils with a wide range of needs. This is of direct importance as meeting the needs of all pupils is a goal of inclusive education.

In addition to teachers and teachers' assistants, as already mentioned, class peers play a crucial role to influencing school participation of pupils with Down syndrome in mainstream schools. It is reasonable to expect peers to play a considerable role; sometimes as equals, other times by providing different support to a peer with intellectual disability, or even by ignoring or bullying. Peers' acceptance of children with disabilities has often been described according to sociometric nominations (Nabors, 1997). However, researchers have argued that such measures do not correspond to actual shared activities or friendships with peers (Hall & McGregor,

2000). Laws, Taylor, Bennie & Buckley (1996) describe peers' acceptance of classmates with Down syndrome among pupils aged 8 to 11. In their study, pupils with Down syndrome were found to be as popular as their peers in being chosen as a partner for work, but acceptance seemed to be based on the special conditions of those with Down syndrome. This finding has been supported in a more recent study of pupils with mild to moderate intellectual disabilities by Kemp and Carter (2002). They found that these pupils were generally well-accepted by their peers, and had mean measures of social status that were comparable to average peers, but that they rarely formed special friendships with their peers.

In summary, as children with Down syndrome are increasingly educated in mainstream schools, there is a need for enhanced knowledge regarding how to promote their participation in this setting. Data such as descriptive baseline information regarding typical levels of functional performance in children with Down syndrome at age for school entry (age 5 to 7) is needed on individual and group level. Such data can support families in planning the transition from kindergarten to school, and provide the best preparedness for the child with Down syndrome. Enhanced knowledge is also needed to understand the interaction between pupils with and without Down syndrome in activities in class settings. The contributions from teachers and assistants are important to better see the possibilities for, and understand the challenges of, school participation.

RESEARCH OBJECTIVE

Aim of thesis

The overall aim of this thesis was to identify and explore conditions influencing school participation of children with Down syndrome in mainstream elementary school.

Aim of four studies

Study I: To describe home and community functional performance in 5-year-old children with Down syndrome.

Study II: To investigate the relation between functional performance skills of children with Down syndrome and the age of entry into mainstream elementary education.

Study III To explore peer interaction in the context of school activities in mainstream classes that included pupils with Down syndrome together with their peers without disabilities in order to identify enabling conditions.

Study IV To explore and describe peer interaction in school activities as experienced by teachers and teachers' assistants, and to identify and explore how they (teachers and teachers' assistants) facilitate interaction between pupils with Down syndrome and peers.

METHODS

Study design

Study I and II

Study I utilized a cross sectional study design (DePoy & Gitlin, 1998) and covered a cohort of 5-year old children with Down syndrome in Norway, in order to describe a baseline level of performance in everyday activities from a parental point of view. Study II also used a cross sectional approach, but as it was a follow up of study I, it has the character of a longitudinal study design (DePoy & Gitlin, 1998; Benestad & Laake, 2004).

Study III and IV

Study III followed 6 of the pupils from the original cohort from study I and II into their school classes to explore enabling conditions related to peer interaction in school activities, and study IV followed the teacher and teachers' assistants of the six pupils. This multiple-case study design was used for both study III and IV, as case studies have been found suitable for describing persons in-depth and over time in their contemporary context (DePoy & Gitlin, 1998).

An overview of the design and methods of the four studies are presented in Figure 1.

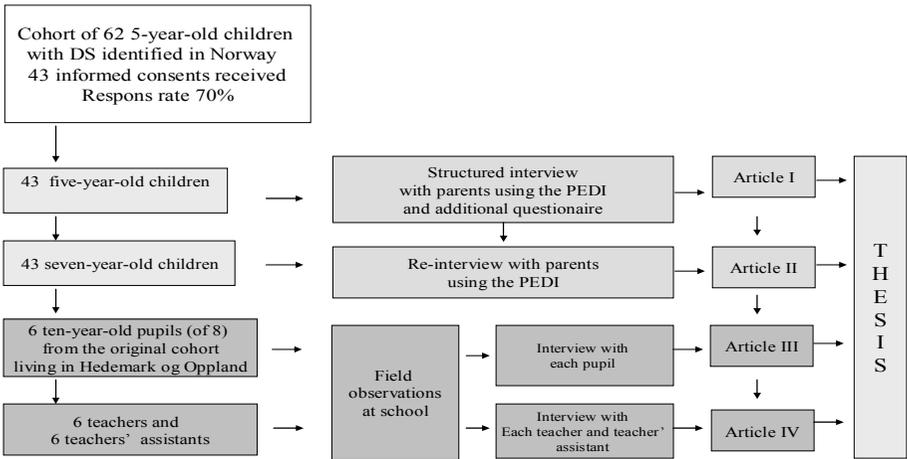


Figure I: Study design

Participants

Selection

In line with the ideology of family-centered service (Rosenbaum, King, Law, King & Evans, 1998), which acknowledges that parents know their child best, the parents were chosen to be the informants for studies I and II. The informants were identified with assistance from local Down syndrome associations and the counties' child habilitations services. All counties in Norway were contacted. From the approximately total population of 50 – 70 children with Down syndrome born yearly in Norway (Folkehelseinstituttet, 2009), 62 were identified. Parents were invited by letter to participate in the study. Forty-three informed consent documents were returned, giving a response rate of 70%. No further information was available for the 19 parents who did not reply, as the invitations were sent through the associations and the habilitation services. The 43 families (child and parents) included in the study were from both rural and urban parts of Norway. Two years later, the participating families from study I were re-invited, by letter, to participate in study II. All of the families agreed to participate again, giving a response rate of 100%.

The children that participated in study III and IV were recruited from the whole sample (n=43) of the first two studies. For practical reasons, the inclusion criteria for study III and IV were children living in the region of Innlandet, and to some extent able to communicate their own experiences of peer interaction, in terms of things done together with peers in class. Eight children fulfilled these inclusion criteria and were invited to participate in the study through letters to their parents. One family did not respond, and the parents of the other child explained that he was in a vulnerable period regarding anxiety, and thus they found it best not to have him participate in studies at that time. Thus, six pupils were included in study III-IV.

Participants in Study I and II

The respondents of study I and II were parents of 43 children with Down syndrome. Those who were interviewed included 38 mothers, two fathers and three couples (interviewed together). Two years later those of the 43 families who were interviewed were 40 mothers, two fathers and one couple together.

Participants in Study III and IV

The respondents of study III and IV were six pupils with Down syndrome, six teachers/special education teachers and 6 teachers' assistants.

Respondents of study III were the six pupils with Down syndrome; two girls and four boys in the context of their classes.

All the six teachers were female, and one of the six assistants was male. The teachers were those who were responsible for the special education of the pupil with Down syndrome, and the assistants were those who were responsible for providing the support to the same pupils.

Demographics

The parents of the 43 children with Down syndrome included in this study lived in diverse parts of Norway. Thirty-seven of the 43 families were two-parent families, and in average the families had three children. Seventy two percent of the respondents had an educational level of high school or beyond. Most families in Norway have two children and 85 % of the population has education at high school or above (Statistisk Sentralbyrå, 2000). The sample (of parents) in this study had more children and a slightly lower level of education. There were no significant correlations found between the study results and the parents' level of education, or between the children's respective birth order rank, or number of siblings. The classes of the six pupils with Down syndrome participating in study III and IV varied in number of pupils from 11 to 26, with a mean of 20, which corresponds well with the mean of all Norwegian primary school classes (Statistisk Sentralbyrå, 2000).

Data collection

Study I and II

In studies I and II data were collected through the assessment Pediatric Evaluation of Disability Inventory (PEDI) (Haley, Coster, Ludlow, Haltiwanger & Andrellos, 1992) and, for study I, an additional questionnaire. This additional questionnaire gathered information regarding medical problems and an overview of previous and recent interventions for the child. Parents were also asked in which situations their child performed well, and what situations were challenging regarding everyday functional performance. This questionnaire was used prior to the PEDI.

The PEDI is a multidisciplinary instrument which is widely used and highly appreciated in pediatric occupational therapy. It was developed as a functional

assessment and an evaluative tool for children with disabilities from six months to seven-and-a-half years of age, and was originally designed for use in the US. The PEDI meets the requirements for valid and reliable outcome measures (Haley et al., 1992), and a number of research reports have supported the internal consistency, inter-interviewer and test-retest reliability and discriminative validity of this instrument (Feldman, Haley & Coryell, 1990; Haley et al., 1992; Nichols & Case-Smith, 1996). The instrument is commonly used in pediatrics and it is described as a “gold standard” assessment for children with disabilities (Ziviani, Ottenbacher, Shephard, Foreman, Astbury & Ireland, 2001; Law, 2003). The PEDI measures capability and caregiver assistance for selected functional activities within the domains of self-care, mobility and social function on three scales: 1) functional skills (current capability of selected tasks), 2) Caregiver assistance (the extent of help provided by the caregiver), and 3) Modifications (environmental or technical aid needed to enable the child’s function). The capability and performance concept as used in the PEDI has been debated (Østensjø, Bjorbækmo, Carlberg & Vøllestad, 2006; Berg, 2008). Østensjø et al. (2006) found that both the PEDI and the ICF use the constructs of capacity and performance, but differ in operationalizing them. Capacity in the ICF refers to standardized environment whereas the concept “what the child can do in its own environment” is not covered in definitions of capacity and performance in the ICF, and the PEDI manual describes capacity as capability and adds “performance in most situations” which reflects performance. Thus, the PEDI lacks a clear distinction between capacity, capability and performance and is at present not in accordance with the ICF (Berg, 2008).

Usually the PEDI is administered as a structural parent interview. The PEDI was translated to Norwegian in 2000 (Jahnsen, Berg, Dolva & Høyem, 2000), and good support for the reliability of the Norwegian version of the PEDI was obtained in a study by Berg, Jahnsen, Frøisli and Hussain (2004). The applicability of the Norwegian version of the PEDI was also investigated (Berg, Aamodt, Stanghelle, Krumlinde-Sundholm & Hussain, 2008). Their results show that the norm referenced scores may need cultural adjustments, but the scaled scores are useful measurements of functional abilities performance in a relevant environmental context.

For study I and II, the PEDI (specifically, the Norwegian version) was chosen to gather information on the children’s performance within the environmental context of home and community, covering the domains of self-care, mobility and social functioning in study I and II, using the Norwegian version. The same researcher

collected all data for study I and II, and was specifically trained in administration of the PEDI. For practical and economical reasons, as the families lived all over Norway, not all interviews could be performed through in-person meetings, although that would have been preferable. Parents' preferences of meeting or phone interviews were met as far as possible within the resources available. Twenty-two interviews were completed by face-to-face meetings and 21 by phone in the first study, and mainly phone interviews (41) were conducted for study II. The interviews lasted approximately 60 to 120 minutes each.

Table I: Content of the PEDI and PEDI scales: Functional Skills Scales (adapted from Haley et al., 1992)

PEDI domains	Subscales	Items
Self-care	Food Textures	4
	Use of Utensils	5
	Use of Drinking Containers	5
	Toothbrushing	5
	Hairbrushing	4
	Nose Care	5
	Handwashing	5
	Washing Body and Face	5
	Pullover/Front-Opening Garments	5
	Fasteners	5
	Pants	5
	Shoes/Socks	5
	Toileting Tasks	5
	Management of Bladder	5
Management of Bowel	5	
	Sum items	73
Mobility	Toilet Transfers	5
	Chair/Wheelchair Transfers	5
	Bed Mobility/Transfers	4
	Tub Transfers	5
	Indoor Locomotion Methods	3
	- Distance/Speed	5
	- Pulls/Carriers Objects	5
	Outdoor Locomotion: Methods	2
	- Distance/Speed	5
	- Surfaces	5
	Upstairs	5
Downstairs	5	
	Sum items	59
Social Function	Comprehension of Word Meanings	5
	Comprehension of sentence complexity	5
	Functional Use of Communication	5
	Complexity of Expr Communication	5
	Problem-resolution	5
	Social interactive play (adults)	5
	Peer interactions: (child of similar age)	5
	Play with objects	5
	Self-Information	5
	Time Orientation	5
	Household Chores	5
	Self-protection	5
	Community	5
	Sum items	65
Format	Dichotomous scale (yes or no; 0 or 1)	

Table II: Content of the PEDI and PEDI scales: Caregiver Assistance Scale and Modification Scale (adapted from Haley et al., 1992)

PEDI Domain	Caregiver Assistance Scale Subscale	Modification Scale Items	Items
Self-care	Eating	1	1
	Grooming	1	1
	Bathing	1	1
	Dressing Upper Body	1	1
	Dressing Lower Body	1	1
	Toileting	1	1
	Bladder Management	1	1
	Bowel Management	1	1
Mobility	Chair/Toilet Transfer	1	1
	Car Transfer	1	1
	Bed Mobility/Transfers	1	1
	Tub Transfers	1	1
	Indoor Locomotion	1	1
	Outdoor Locomotion	1	1
	Stairs	1	1
Social function	Functional Comprehension	1	1
	Functional Expression	1	1
	Joint Problem Solving	1	1
	Peer Play	1	1
	Safety	1	1
Format		6-point ordinal scale	4-point ordinal scale

Table III: The PEDI measurement scales (adapted from Haley et al., 1992)

Functional Skills: Self-care, Mobility, Social Function scale	
0	Unable, or limited in capability to perform items in most situations
1	Can perform: the child is capable of performing the tasks in most situations or behaviors previously mastered but not longer required or used
Caregiver Assistance: Self-care, Mobility, Social Function scale	
5	Independent: Caregiver provides no physical assistance, no direction, rarely adjustments or prompt, child can initiate and complete activity
4	Supervision/Setup/Prompting: Caregiver provides no physical help during the activity, caregiver monitors child's activity to ensure safety
3	Minimal Assistance: Caregiver provides very little assistance, the caregiver makes occasional adjustments
2	Moderate Assistance: Caregiver does less than half the activity, caregiver must frequent direct child's participation, child often initiates appropriate activity
1	Maximum Assistance: Caregiver does more than half of the activity, caregiver makes very frequent adjustments, child provides meaningful assistance
0	Total Assistance: Caregiver does almost all of the activity, caregiver does almost constant adjustments; child rarely participates or provides no meaningful assistance.
Modifications: Self-care, Mobility, Social Function scale	
N	No Modifications
C	Child-Oriented (non-specialized) modifications, commonly used by all children
R	Specialized rehabilitation equipment not normally needed by non-disabled children
E	Extensive modifications such as architectural modifications or wheelchair

Study III and IV

Prior to the data collection phase of studies III and IV, the children's own parents informed their child about their participation in the study. The researcher planned the establishment of contact with the relevant school with the parents by phone. The head of each of the six schools were initially contacted by phone. An information letter was sent, followed by a meeting arranged by the head of each school. The goal of the meeting was to give further information about the research project to the involved class staff. Informed consents were received from all class staff involved. One contact person in each of the six classes agreed to assist with planning the visits, during the data collection. Each class teacher took responsibility for informing the parents of all the pupils in their class about the project in a meeting conducted prior to the beginning of collection of data. At the first visit to each class, the researcher was presented as a

visitor who wanted to learn from what the pupils were doing together in different activities during the school day.

Observations and interviews

Each class was visited intermittently over a period of about four months during a school year. The observer reflected upon her role both prior to observations and repeatedly during the fieldwork. The effect, on subjects, of knowingly having an observer in the environment, is referred to as the “observer effect”. This effect cannot be eliminated. However, it has been shown to be helpful for the observer to reflect and take notes, in order to understand the effect (Bogdan & Biklen, 2003). Reflection notes were written during the process in an attempt to better understand such effects. The researcher collected all data through field observations and interviews (DePoy & Gitlin, 1998; Bogdan & Biklen, 2003). During observations in the classroom, the researcher was placed carefully and purposefully to overlook the pupil with Down syndrome without disturbing any of the pupils. During breaks, the researcher walked around as teachers or teachers’ assistants often do when keeping an eye on the children in the school yard. A time period of several months for data collection was chosen to give pupils and school personnel a chance to get used to the presence of the researcher.

As suggested by Bogdan and Biklen (2003), the researcher used two kinds of field notes; descriptive and reflective. Utilizing descriptive notes the researcher attempted to provide as much detail as possible concerning settings, events, activities, behavior, and dialogues. The reflective field notes emphasized the researcher’s impressions, feelings and ideas. Detailed notes were written during the breaks and after each visit (Patton, 2002). The days in which observation would occur were jointly scheduled by the researcher and a teacher contact. The purpose was to be present in the class for a variety of activities and situations, where the pupils interacted. The observational focus was related to interaction between the pupils with Down syndrome and their peers, with and without the active involvement of adults. The focus of study III the focus was specifically on peer interaction (i.e. when interaction occurred, with whom, on who initiated, how, where, in what activities, etc.). In study IV the focus was shifted towards examining how teachers and assistants arranged for and facilitated peer interaction with two or more pupils (including the pupil with Down syndrome) during the school day. All together the observation resulted in an average of thirteen hours of observations for each class.

The data collection was finalized with interviews. In order to capture a greater understanding of the experiences of the pupils with Down syndrome in their own voices, an interview/conversation was conducted with each of the six children at the end of the study III. The setting of the conversation is especially important when interviewing children because the child's expression and attitudinal preferences are context dependent (Scott, 2000). Group rooms that were well known to the pupils were chosen, in agreement with the children, as a suitable place for the interview-conversations. Of practical reasons, one interview found place in a home with the child's sister present. Cognitive and social development must be taken into account when interviewing children and a less structured method of interviewing has been found appropriate for younger children (Scott, 2000; Mayall, 2000). The interviews were planned to take the form of an interview-conversation, referring to recently observed peer interaction and asking about the subject's favorite activities and friends in class. A teacher or an assistant was present to support communication during the interviews, with one exception. Interviews were tape-recorded and transcribed verbatim (Patton, 2002). The interviews varied in length from 15 to 30 minutes. Recollections of experiences from the children's perspective were scarce in the interviews, as the children were mainly focused on the present time and place in their thinking and speaking.

For the purpose of study IV, final interviews were completed with teachers and assistants. According to Kvale (1996, p. 124) "the purpose of a research interview is to obtain qualitative descriptions of the life world of the subject with respect to interpretation of their meaning". As the interviews were conducted at the end of the observation period of about four months, the respondents were familiar with the research project. The interview was planned semi-structured, following an interview guide (Kvale, 1996; Patton, 2002). According to Kvale it is important to ask the "why" and "what" questions before the "how" question is posed. Consequently, the main questions asked were in this order; 1) What is your experience of the interaction between (name of the subject child) and his/her peer/s? How would you describe the interaction? 2) What do you do to influence peer interaction between the pupils? Why and how? Finally, questions were asked referring to situations observed by the researcher. These last questions were included to ensure that observed situations were understood in accordance with the respondents and to access to their intension and experience (why and how). Each individual interview lasted for 60 to 90 minutes. All

interviews were tape-recorded and transcribed. Unfortunately, for technical reasons, two interviews were lost from the tape-recorder. However, they were consequently transcribed, as well as possible, from the memory.

Data analyses

Study I and II

The data from study I and II were derived from ordinal scales, descriptive and non-parametric methodology were applied in the analysis (DePoy & Gitlin, 1998; Benestad & Laake, 2004). For Study I and II, the items of the questionnaire and the PEDI were summed up, controlled and transferred to the Statistical Package for Social Science (SPSS, version 10.0 & 12.0) for statistical analysis. Descriptive statistics were calculated for mean, medians, standard deviations and range of normative and scaled scores. For between-group analyses (study II) non-parametric statistics; Mann-Whitney test was used (Benestad & Laake, 2004). A p-value less than .05 was considered statistically significant. Between group analyses were used to examine the effects of possible influencing factors such as gender, health impairments, family conditions, and therapy or interventions, etc.

Study III and IV

The aim of study III and IV was to describe and explore peer interaction, and the support provided by class staff in order to facilitate peer interaction between pupils with and without Down syndrome. Based on these aims, data were analyzed using a constant comparative method (Bogdan & Biklen, 2003; Patton, 2002) followed by a second step of interpretation inspired by hermeneutics (study IV).

In study III, analysis of a pilot study was undertaken as a first step (Bogdan & Biklen, 2003) in order to identify the main scope in the analysis. Thus, analysis of one case was conducted after the first fourteen days of observations, involving two of the more experienced researchers. This analysis helped to identify what should be the main emphasis of the study; interaction involving activities in regular school situations. The data for study III comprised of field notes and interviews with the six children with Down syndrome. As the field notes of study III and IV were collected at the same time the analysis started with a process of reading the field notes several times in order to achieve a better overall understanding of the data. The data was separated in two. One set was focusing on peer interaction between the pupil with Down syndrome and their peers. The other data set comprised the support observed offered by class staff, in order

to facilitate interaction among the pupils. After separating the data, the field notes for study III were read several more times in order to get an overview of the content in close connection to the study's aim (Patton, 2002; Bogdan & Biklen, 2003). Each case was individually examined. Coding of the appropriate units of analysis was performed through coding each case individually, and then coding the six cases together (Patton, 2002). In a back and forth process, the codes were constantly compared, with consideration given for developing categories. During the process of coding, two of the researchers, in cooperation, noticed an emerging theme of two different interaction patterns; equal and unequal interaction. Interviews of the six children were analyzed separately, following the same procedure as was used for the field notes. The interviews were found to contain little information directly useful for this analysis, but provided some insights into the interaction with peers from the children's perspective, and were used as supplemental data.

Analysis of study IV followed the same procedure that was used for study III. In these analyses however, the interviews provided rich data, and codes of observations and interviews were compared in a triangulation of data sources (Patton, 2002). Themes emerged from a back and forth process of review between the various categories of all data. The theme "experiences of the peer interaction" and "patterns of support strategies of the class staff" emerged with for example the exploration of the "supported ego". The codes, categories and themes were reanalysed with the aim of reaching an in-depth understanding of how the class staff experienced both peer interaction and the support provided. This process involved the application of interpretations (Gustavsson, 2000), and produced a gradual assembly of individual perceptions and actions into larger bodies of meaning.

To increase the credibility of the analysis, peer examination was conducted throughout the research process. The peer examination was performed by experienced researchers within the field of qualitative methods and school participation among student with disabilities. All findings and interpretations have been discussed from several perspectives to improve trustworthiness of the study (Bogdan & Biklen, 2003). To control and validate the final interpretations specific criteria for the data, structure analysis were used (Gustavsson, 2000). The criteria allows the researcher to combine different types of data, stating that each set of data must be coded, categorized and summarized according to recognized standards for the specific kind of data and consequently interpreted according to the research questions.

FINDINGS

In this chapter the main findings of the thesis will be presented for each of the four studies.

The aim of **Study I** was to describe functional performance in 5-year old children with Down syndrome, prior to elementary school entry. The findings showed a wide range of performance, indicating mobility as a domain of relative independent performance, while assistance was needed in self-care and social function. Within self-care, tasks related to eating and dressing were performed independently except when dressing included management of zippers and buttons, for which assistance was needed. A considerable developmental delay in the management of bladder and bowel control was found, prolonging the use of diapers and causing parents to express worry regarding school entry. Most children were found to do relatively well in playing alone or together with other children, and some individual activities like for example playing computer games were successfully accomplished. Speech and communication difficulties were found, with higher scores on comprehension compared to functional expression. Rules about safety were not within the range of competence for most of the children prior to school entry, which were another source of worry for some of the parents. No gender differences were found in relation to caregiver assistance needs in any of the three domains covered by the PEDI. No significant relationships were found between functional performance and type of Down syndrome, or presence of medical conditions such as heart defects, or impairments of vision or hearing.

Study II investigated the relation between functional performance and the age of entry into mainstream elementary education. Entry into elementary school was postponed for 40% of the sample of the study, resulting in an extra year in kindergarten for those subjects. The results of the study indicated that a certain level of development and independence was required in order for the child to be viewed as 'ready' for elementary school entry. Conditions relating to postponed school entry were found to be lack of bladder and bowel control, and low scores in functional comprehension, expressive communication and problem solving. Information regarding lack of bladder and bowel control was the most surprising finding, and detailed results showed that only about 50% of the children with Down syndrome were 'consistently dry day and night' at the

age of 7. This lack of control brought about special challenges, primarily for the parents. Those of the children whose school entry was postponed showed lower scores in retrospective analysis already at the age of 5, compared to those who entered school at the age of six, but a wide range was found in both groups. In consideration of the pros and cons of postponement, it is noteworthy that delayed school entry was not reflected in self-care and mobility outcomes, but slightly improved social skills were shown for those who started school at age six. In summary, study II found that children who used diapers, and showed speech, communication and problem solving difficulties, were those who seemed to be viewed as not “ready” for school, and consequently had their school entry postponed.

The findings of study I and II provide baseline information regarding typical levels of performance in children with Down syndrome. As the results are based in 70% of the age population in Norway, the results may with some caution be generalized to other Norwegian children with Down syndrome at these ages.

Study III explored peer interaction in play activities for six of the children with Down syndrome with peers in their respective classes in their local schools at their age of ten. This study found two basic conditions enabling peer interaction between the pupils: 1) their understanding of the meaning and doing of the activity 2) the task demands in relation to the pupils’ performance range. These two conditions covered both an individual personal dimension and an activity dimension, which together worked as a joint function; appearing to support each other. The activities in which the pupils (with and without Down syndrome) interacted were different in nature and purpose and included; self-initiated, rather simple play activities and structured games, either indoor in the classrooms or outdoor during breaks. Two main patterns of peer interaction were identified; equal and unequal interaction. When the pupils’ understanding (i.e. of the meaning and the doing) of the activity was shared and tasks were within the performance range of everyone involved, peers were found to interact on a rather equal basis. When, on the other hand, the pupils’ understanding of the activity was limited but still “shared enough” and/or tasks at first were too difficult for the pupils with Down syndrome, different patterns of unequal peer interaction were found. In unequal interaction peers took a more active role, and were often found to divide tasks between them, based on competence, in a complementary way so that activities could be accomplished. Also they were found, alternatively, to adjust tasks, own behavior or

create other tasks in order to better include the pupil with Down syndrome without losing the original meaning of the activity. Peers' competence in coming up with enabling strategies for the facilitation of interaction may be a consequence of knowledge and experience from previous interaction situations. This competence might also be related to knowing the different pupils' strengths and weaknesses as well as to be knowledgeable about suitable activities and their inherent demands. In summary, the findings of study III provided insight into conditions related to activity and task demands, the pupils' shared understanding of the activities and tasks, and finally peers' support, which all together promoted peer interaction.

Study IV aimed to explore and describe peer interaction in school activities as experienced by teachers and teachers' assistants, and to identify and explore how they (teachers and teachers' assistants) facilitate interaction between pupils with Down syndrome and peers. Class staff members (teachers, special education teachers and teachers' assistants) were found to experience interaction between pupils with Down syndrome and peers as challenging, but still possible because of peers' acceptance. The class staff members, depending on their individual role and responsibilities, were found to apply different strategies to facilitate peer interaction in school activities. These strategies included, for example: planning and organising of academic activities, group work, purposefully selecting tasks and pairing children to work together in order for interaction to develop, educating peers to behave supportively and providing individual support to the pupils with Down syndrome. One finding of the study related to individual support was the role of the "supported ego", a role that mainly seemed to compensate for the cognitive difficulties (i.e. perceptions, understanding and agency) of the pupils with Down syndrome. This role tried to be a supportive part of the pupils and thereby aimed to promote peer interaction. In summary, study IV identified and explored class staff's strategies to facilitate interaction between pupils with Down syndrome and peers in mainstream elementary schools. The strategies the class staff utilized to facilitate peer interaction were also understood as an attempt to keep the class together as one unit, with opportunities for participation for all class members.

When the findings of this thesis; conditions influencing school participation of children with Down syndrome, are related to the PEO model (Law et al., 1996), all the three transacting concepts; *person – environment – occupation* are represented. In

short, the main findings related to Person concerns baseline descriptions of the level of performance and assistance needs of the sample studied. The findings relating to Environment concerns peers support strategies and the strategies of class staff in order to facilitate peer interaction in activities. Findings concerning Occupation include knowledge about demands of daily activities and play activities in relation to the pupils. Some findings however, are more clearly results of the three transacting concepts of the model, such as the support strategies of peers that are not characteristics of peers, rather something that occurs in the interaction between the participating pupils during a specific activity, in a specific environment. This will be further discussed in the following chapters.

GENERAL DISCUSSION

School participation of pupils with Down syndrome

As a result of Norway's education policy, children with Down syndrome are among the pupils with disabilities who get their education in regular schools; in "one school for all". According to the government, the general aim of schools is to be including and adaptive, and give all children an opportunity to succeed according to their condition, abilities and interests (Sosialdepartementet, 2003). A vast majority of international studies of school participation of children with Down syndrome (or intellectual disability) show that they have considerable difficulties interacting with class peers. They are increasingly removed from the regular classrooms, individually or in special groups, and are supported by teachers' assistants whose role and responsibilities are unclear. Thus, there is a need for studies that shed light on conditions influencing the school participation of these pupils, in order to better understand the situation and see possibilities for the future. The overall aim of this thesis was to identify and explore conditions influencing school participation of children with Down syndrome in mainstream elementary schools.

The main findings will be discussed under the following themes: 1) Development and performance of children with Down syndrome, 2) Peer interaction; opportunities and challenges, 3) The provision of adult support, and 4) Opportunities for school participation.

Development and performance of children with Down syndrome

The findings of this thesis (study I and II) provided baseline knowledge about the performance of selected activities of everyday life of children with Down syndrome at ages 5 and 7. Such findings may be helpful in order to plan the child's school participation.

Development and performance are largely influenced by context, such as social and cultural relationships (Tetzchner, 2005; Vygotskij, 2004). Thus, these aspects will be discussed in relation to the findings of this thesis in order to better understand how the findings may be interpreted.

Performance of Self care tasks

For the purpose of study I and II, the results were presented according to the US norm of the PEDI, with some caution taken with regard to cultural differences. However, for the purpose of this discussion, interesting comparisons of the results of study I to those of children without disabilities were possible because of a recently published study concerning the validation of the PEDI norms in a randomized Norwegian population (Berg et al., 2008). Berg and colleagues showed that the Norwegian sample (n=174) scored significantly lower compared to the US reference values, especially related to the self-care domain. Thus, for the aim of this discussion, a comparison is made to reflect on the development of the children with Down syndrome aged 5 to that of Norwegian children without disabilities at the same age, to better understand the results of this thesis.

When comparing the normative scores of the sample of 5 year old children with Down syndrome (n=43) of study I to the recently available scores of Norwegian children (without disabilities) from the same age group (n=46; Berg et al. 2008) several interesting factors appeared. The mean scores of the children with Down syndrome are lower and wider compared to the Norwegian sample in all domains both within functional skills scales and caregiver assistance scales. Interestingly however, is the emergence of overlaps in all ranges indicating that some children with Down syndrome score within the range of the children without disabilities, which was not the case when the Norwegian children with Down syndrome were compared to US norm scores of children without disabilities. The ranges with greatest overlaps were found in the self-care and mobility domains, and less overlap was found in social function. This may confirm the cognitive challenges of Down syndrome. First of all, this result addresses a possible cultural influence on the performance of children in daily activities, thus a need to be cautious about using the US PEDI norms. It also addresses a need for age relevant norms in Norway, and in general a use of culturally validated instruments. Without, there is a danger of misinterpreting assessment results when evaluating or identifying strengths and challenges in the development of children with Down syndrome in order to plan for a child's school entry. This comparison will be analyzed in more details in a planned future study.

Findings showed that by the age of 5 and 7, tasks within the domains of self-care and social function were most demanding, while mobility was less demanding or relatively good. An interesting find within self-care was significant challenges due to the

children's use of diapers, in that 3 of 4 of the Norwegian 5-year-olds with Down syndrome used diapers daily and half of the sample still used them at the age of 7. This finding indicated a considerable delay of bladder and bowel control of children with Down syndrome. A similar finding was reported in a study of Carr (1995) based on findings in a study initiated in the 1960's, thus it was likely that early intervention services were not as available as might be the case currently. What has been reported however is a one year delay compared to most children (without disabilities). Scandinavian literature indicates that most children with Down syndrome stay dry day and night by ages 4 to 5 (Annerén et al, 1997; Lofterød, 1989). However, no specific references are provided for this estimate. The literature of Annerén et al. (1997) and Lofterød (1989) were popular references for parents and professionals in Norway, thus parents expected their children to have bladder and bowel control prior to school entry.

Berg and colleagues (2008) found that the achievement of bladder and bowel control occurred between 4 and 5 years of age, which is 12-18 months later compared to the normative sample used in the development of the PEDI in the US. This result is in agreement with a similar trend found in a recent longitudinal study of bladder control in Swedish children (without disabilities) (Jansson, Hanson, Sillen, & Hellström, 2005). Berg and colleagues suggest that these differences may reflect a trend due to more comfortable diapers compared to earlier times combined with a Scandinavian culture value of not stressing the child with early toilet training, and an earlier start of toilet training in the US. Given that most children are typically toilet trained at a later age, a one year delay for children with Down syndrome would still not influence their time for school entry. As already mentioned above, according to the results of this thesis half of the children used diapers at the age of 7. To sum up, there appears to be an agreement between the different studies in that Norwegian (and Swedish) children are toilet trained later compared to US children. Norwegian children with Down syndrome show a considerable delay in these skills. The reason for the delay in Norwegian children with Down syndrome seems hard to explain based on existing knowledge. This thesis suggests a need for more research to understand why bladder and bowel control are considerably delayed in some children with Down syndrome.

Until we know more, what is important however, is to inform parents of children with Down syndrome in Norway not to expect their child to be dry day and night by the age of 4-5, as it probably will vary and may happen later. Consequently, toilet training programs before school start may be an option for some children while for others the schools need to handle children with diapers in a respectful way.

Within the self-care domain, we also found children's performance to be challenged by fine motor skills in the managing of for example zippers and buttons when clothing, thus assistance was needed in many self-care tasks. Some studies have concluded that fine motor skills might be less affected than gross motor skills in Down syndrome (e.g. Connolly, Morgan, Russell & Fulliton, 1993), while others (Spano et al., 1999; Volman, Visser & Lensvelt-Mulders, 2007) found the opposite. One explanation for this difference may be related to methodology. The study of for example Connolly et al., (1993) used the Bruininks-Oseretsky Test of Motor Proficiency (BOTMP), measuring quality of motor development in a standardized environment, and compared the fine and gross motor development of children with Down syndrome with a normative sample. The PEDI, measuring the child's performance in their own environment, was used by both Volman and colleagues (2007) and for this study. One explanation for the contradictory results might also be that what a child can do in a standardized environment may differ from what the child does on an everyday basis in its own environment. Thus, the results must be understood within the frames of what was measured. It is possible that gross motor development in quality may be more impaired with for example reduced balance and speed compared to that of children without disabilities. However, these qualities may not cause disabling situations for the children in every day activities. However, fine motor skills as measured with the PEDI, caused the children some problems in their daily activities. An additional consideration may be whether the children understood the complex tasks in which fine motor skills were involved, and that cognition plays a significant role.

Speech and communication

Findings of all the four studies indicate that speech and communication (language) difficulties of children with Down syndrome influence school participation. For example, Study I and II indicate that speech and communication difficulties were influencing conditions to a postponed school entry. Study III, identified that peer interaction between a child with Down syndrome and peers was successful when based on nonverbal communication rather than the spoken language. Study IV found that the class staff provided a role of "supported ego" to the children with Down syndrome based on a need to compensate for the communication difficulties of the pupils with Down syndrome interacting with their peers. Thus, speech and

communication difficulties were found to influence school participation in different ways.

Literatures consistently suggest that children with Down syndrome present with deficits in expressive speech and language, accompanied by strengths in vocabulary comprehension compared to their nonverbal mental age (e.g. Chapman, 2006). Complex relationships between underlying deficits and language skills seem to exist (Laws & Bishop, 2004). The main focus of intervention at the level of deficits in Down syndrome has been on training short term memory aiming at teaching the children a rehearsal strategy (Laws & Bishop, 2004). Buckley (1995) argues that it is a need for intervention programmes to be evaluated, and she reports promising results of language (phonography and grammar) intervention in a small sample of adolescents with Down syndrome. The findings of this thesis confirm the speech and communication problems of pupils with Down syndrome, and it is timely to question what attention these problems are given in mainstream schools and if intervention programmes are provided. It is also relevant to question if and how participation in mainstream school influence speech and communication skills of pupils with Down syndrome? The results of study II indicate a positive trend for those children who started at the age of 6 compared to those with postponed school entry. This is in agreement with Buckley et al., (2006a) who reported language improvements in pupils with Down syndrome being educated in mainstream school. Thus, it is possible that attending school and interacting with school aged children who have a more developed language compared to children in kindergarten positively influence the language development of children with Down syndrome. This is a question that needs to be addressed specifically in future studies.

Peer interaction; opportunities and challenges

The findings of this thesis showed that environmental aspects play a considerable role in creating opportunities for social participation of pupils with Down syndrome.

Firstly, class peers were found to create opportunities for promoting their interaction with the peer with Down syndrome in activities at school, thus facilitating interpersonal interactions (Study III). Most studies of interaction between children with and without disability report few instances of interaction on equal terms. Often children with disabilities have a more passive role, while children without disabilities act more dominantly (Nordstrøm, 2002; Ytterhus, 2000; Tamm & Skär, 2000). Findings in this thesis partly support previous research. However, this thesis revealed some instances of

equal interaction, based on conditions of shared understanding of the activity and tasks within the performance range of each participant. Most often however, the interaction could not be described as equal, but on such occasions peers were found to apply strategies to facilitate interaction. Interestingly peers divided tasks between them and the pupil with Down syndrome so that the tasks performed by each part complemented each other; here called complementary interaction. Or, peers were found to adjust everybody's tasks or their own behavior; named adjusted interaction, in order to interact in a joint activity. Thus, on one hand, the dominant role of peers was supported in our findings, but we also found that they in their 'dominating' role created opportunities for interaction with pupils with Down syndrome as well as achieving a cooperatively accomplishment of school tasks. The findings of this thesis indicate a need for more research on the interaction taking place in activities between children with Down syndrome to further understand peers' role in inclusive education.

The dynamics of ongoing activities between children with disabilities and more experienced peers have been investigated in occupational therapy research (Humphry, 2002; Humphry & Wakeford, 2006; 2008). This research describes the participating children's simultaneously organizing of their performances around the activity. Also it describes how the children challenge one another to do things differently in order to have the interaction on track and/or accomplish the tasks. The findings of this thesis related to the adjustments of tasks, activities and peers behaviour seem in agreement with this suggestion. However, one more aspect by our findings was that the pupils appeared to have realistic expectations of each others contributions in an activity. By having realistic expectations of each counterpart contribution they could modify the activity to include the pupil with Down syndrome. Thus, findings indicate that realistic expectations might be one explanation to the success of peer facilitating strategies. In turn, their realistic expectations may be founded in their interactional history in school; being in the same class for years and for some children since kindergarten.

Peer interaction in activities organized by children themselves and by children who know each other well has been described as "situated activities", and defined as "games that are produced in real settings with real children who often have long interactional histories" (Corsaro, 1998, p. 172). Thus a crucial factor in situated activities is that the children share an interactional history. For that reason, when pupils with Down syndrome attend regular classes, they must be given the opportunity to build an interactional history with class peers. Many children with

Down syndrome in regular classes spend part of their school day outside the classroom with support of an adult assistant (e.g. Lorenz, 1999), with restricted opportunities to build an interactional history with peers and with that fewer chances to develop enabling strategies for interaction. Based on the results of this study one recommendation is to limit the occasions children with DS spend outside the classroom to optimise children's opportunities to build an interactional history with each other which in turn will increase peers' opportunities to develop facilitating strategies for peer interaction.

The findings concerning pupils tendency to withdraw from peer interaction (Study III, IV) are in agreement with previous research suggesting that pupils with Down syndrome show less frequent participation with their peers compared to most children (Guralnick, 1997). These studies (Study III, IV) however, did not aim at measuring frequencies of interaction but rather aimed at identifying facilitating conditions to peer interaction – when interaction occurred in order to find opportunities and in this peer strategies to facilitate interaction seemed to be one important condition. Interpersonal interactions underpin intellectual growth and can also play a role in determining quality of life, and restricted peer interactions may impact negatively on later mental health (Collacott, Cooper, Branford & McGrother, 1998). As many children with Down syndrome experience significant difficulties at an interpersonal level, knowledge about facilitating opportunities for interaction with peers when attending regular classes is most important for inclusive education. Thus, the findings of this thesis point to this possibility that interaction history may be of importance, but more knowledge is needed in order to understand the influence of school participation on pupils with Down syndrome and peers.

Activity opportunities for peer interaction

Study III and IV revealed that shared activity interest was crucial for peer interaction to occur. For example, one explanation of the withdrawal from peers or failure to find a playmate during breaks for children with Down syndrome might be related to the pupils' different activity interests. The results revealed that successful self-initiated interaction with peers appeared mostly in play activities that attracted both parts equally.

At preschool age children (in general) are found to enjoy simply being and doing things together and choosing friends for playing certain games (see Corsaro,

1998). At that age, the activity interest by children with Down syndrome is not very different from other children (Freeman & Kasari, 2002). However, for most children, verbal activities gradually replace nonverbal play by the age of 7 (Corsaro, 1998). Peer interaction was in this thesis mainly found to occur in activities that were fairly simple and less verbal, such as football, sledging, board games etc. These activities were not as complex as could be expected of children at the age of 10. In order to facilitate peer interaction teachers' assistants tried to arrange activities in the breaks which they were hoping could be of common interest for both the child with Down syndrome and peers. Facilitating peer interaction in activities requires some knowledge not only about the activity interest of the pupils, but also of demands inherent in the activities in order to see the possibilities. The concept of interest in occupational therapy literature is defined to address ideas connected to likes and dislikes, preferences, and willingness to engage in specific occupations and closely linked to meaning and motivation (Reed, 2005), and depends upon the opportunities available and skills to carry out the activity. In occupational therapy, the therapist makes use of activity analysis in order to find suitable activities or tasks for each individual. Activity analysis is the process in which one determines the performance demands of the activity and breaking the activity down to tasks and analyzing each task in terms of its contextual, temporal, psychological, social, cultural and meaning dimensions (Christiansen & Baum, 2005). Considering the important task of facilitating peer interaction in school activities one may reflect however, if not enhanced knowledge about the use of activities and activities' inherent demands would be beneficial also for teachers' assistants working with children with disabilities.

The provision of adult support

Findings of this thesis revealed that children with Down syndrome received various support from class staff including both environmental adaptations and individual support (Study IV). Findings of this thesis specifically gave insight into the individual support provided to pupils with Down syndrome during peer interaction in school activities, by the role of the "supported ego" (Study IV). This role was mainly provided by teachers' assistants and intended to facilitate participation by coaching, guiding or compensating for the cognitive difficulties of the pupils with Down syndrome. The role required close proximity to the pupils.

Teachers' assistants are offering a valuable contribution in promoting participation and learning for pupils with disabilities (Wolery et al., 1995), but

unintended effects of the role have been found by several (Egilson & Traustadottir, 2009; Hemmingsson, Borell & Gustavsson, 2003; Skär & Tamm, 2001; Giangreco, Edelman, Luiselli & MacFarland, 1997), in relation to pupils with both physical and intellectual disabilities. The vast majority of these studies show the assistants' close proximity to the pupil with disability, their possible interference with peer interaction, and how assistants are found to influence the pupils' personal control. At the same time pupils may become dependent on adults' help.

Concerning the role of the assistant with respect to pupils with physical disabilities an optimal assistant may be viewed as being the persons "arms and legs" (Askheim, 1999) compensating for the persons motor impairments. The finding of the role of the "supported ego" in this thesis, is, on the contrary described as an attempt to be the pupils "head, ears and eyes" illustrating the special needs of children with intellectual disabilities. This is confirmed in Study I and II, which showed how children needed less assistance with mobility compared to assistance with self-care and social functioning. Hence, the support needs of children with intellectual disabilities are different compared to those having physical disabilities, and therefore different forms of assistance or support are needed. While children with physical disabilities require basic tasks to be performed by an assistant, children with intellectual disabilities may look for support in understanding or in communication.

The role of the "supported ego" trying to be the pupil's "head, ears and eyes" in order to compensate intellectual disabilities appeared to be a very complex and difficult task, and whatever the intention is, the role may be considered to influence on the person's agency and self-determination. Self-determination is a complex concept, but according to Wehmeyer (2007) it concerns becoming a causal agent in one's life and components comprise the developing of choice making skills, decision making skills and problem solving skills. On one hand, influencing and partly taking over a persons' agency may conflict with the view of autonomy and self-determination as a goal and desirable outcome of child development. On the other hand, the role of the "supported ego" may be understood as adaptation to the needs of the pupils with Down syndrome in order to provide them "opportunities according to their conditions, abilities and interest" in accordance with the aim of the Norwegian school system. It may also be timely to question which opportunities that would have been provided for the pupils with Down syndrome without the support from the "supported ego"? Based on the results of this thesis it could be concluded that careful, knowledgeable assistance, which compensate pupils intellectual disabilities might be

needed for school participation of children with Down syndrome. The pressing question is how such assistance can be provided in a way that also promotes, or at least do not hinder, the development of the growing child's self-determination. This question is of utmost importance and further research is urgently needed.

Opportunities for school participation

School participation of children with Down syndrome was studied from age 5, prior to school entry, until age 10. By school entry, school readiness has traditionally been considered in relation to maturity, and this is reflected in the Educational Act §2-1 mentioned earlier. The point is however, how to understand this paragraph in relation to children with disabilities, children who do not fit the normative expectations of what is considered as mature. Findings of this thesis showed that 40% of the sample got their school entry postponed. It is relevant however, to question what constitutes school readiness for children with disabilities, as developmental delays (or not sufficiently mature) are characteristics both prior to and during school years. Delayed bladder and bowel control, cognitive difficulties and language were conditions that this thesis found to influence the question of postponement. Such conditions are traditionally viewed as signs of immaturity in children without disabilities. The point is, that time for school entry for each individual with Down syndrome should be based on the best interest of the child rather than relating to normative expectations. Findings of study II indicated a slight improvement in social skills for those who started school at the age of 6, compared to the children who remained in kindergarten one more year. This may indicate that school participation has a positive influence on the social functioning of children with Down syndrome. Thus, the pros and cons of postponed school entry need to be more closely examined as pupils with Down syndrome attend regular schools. This will be a topic for further examination.

The vision of "one school for all" sets the stage for expecting the schools to adapt to the different need of all pupils. Within the frames of its focus and limitations, the findings of this thesis showed incidents of successful school participation in regular classes for children with Down syndrome. First and foremost, class peers in their own way were found to include peers with Down syndrome. That is, they seemed to adapt themselves and the activities or tasks to the needs and interests of the pupils with Down syndrome which opened for opportunities for them to interact in activities. Teachers' planning and organizing of activities and special educators' contributions

were also found to be inclusive in the same meaning, as was much of the support provided by the teachers' assistants. However, opportunities for peer interaction in activities were found to be challenged by a growing difference among the pupils with regard to interest and range of performance. This growing difference became demanding for class staff in their strive to create opportunities for the whole class as a unit. The findings of study III and IV related to the pupils aged 10. Previous research indicates that children with disabilities become more lonely and isolated in regular school from the age of 10 as it becomes more difficult to find peers with whom they can interact (Wendelborg & Tøssebro, 2008; Flem & Keller, 2000). It may be that the interactions witnessed in these studies are close to the limit of what is possible without extensive support.

METHODOLOGICAL CONSIDERATIONS

The findings of this thesis must be seen in light of several methodological limitations which may have influenced the results and conclusions drawn. Some of the main methodological considerations are discussed and critically reflected upon in this chapter.

The sample of this thesis warrants reflection on possible selection bias. Was the sample of 43 children truly representative of the total of originally identified for inclusion? Since the invitations to the research study were sent through the organizations, the researcher had no names or other information related to the pool of possible subjects until the informed consents were received. Based on the numbers of letters sent to the different counties, most of the 19 who did not reply lived in the most densely populated areas of Norway. One explanation for the lack of responses from this group could be that those living in the biggest towns already had offers to or were included in other projects. Various kinds of studies often take place in urban areas, thus the parents may not have chosen to participate in this study. However, since no information about these 19 families was available, there are no reasons to expect that these children were different compared to those that did participate. It seems therefore reasonable to believe that the study's sample, which includes 70% of the age population in Norway, represents the age group as a whole. Thus, with some caution, the findings based on this population may be generalized to other Norwegian children with Down syndrome at these ages.

A second question relates to the contexts of study III and IV. Were the six schools representatives of Norwegian schools in general? The six schools were relatively small, three in small towns and three in small villages in the country side. The pupils with Down syndrome were each the first at their school with this disability. None of the teachers, special education teachers or teachers' assistants had any previous experience teaching pupils with Down syndrome. This fact may influence the results of this study, as more experienced staff probably would have had different knowledge and experiences from different pupils with Down syndrome. One goal of this study, however, was to focus on pupils in rural districts. This focus was deemed important because those pupils commonly have different opportunities, compared to pupils living

in urban areas. For example, in the more densely populated areas of Norway, special schools, or at least special classes, are often available. In the six schools studied, few opportunities for special schooling existed outside of the regular classroom. In conclusion, the context of the studies III and IV is consequently rather narrow, as there are a low number of pupils with Down syndrome participating in rural districts studied.

The small number of participants in study III and IV may be regarded as a limitation. In qualitative studies the aim of the research is to increase the depth of understanding of the subject that is studied (Patton, 2002). This research approach does not search for generalizations, but rather, analytical generalizations can be utilized considering the extent to which the findings in one study can be used as a guide to what might occur in other studies (Kvale, 1996). Consequently, the findings of study III and IV cannot be generalized to include all individuals with Down syndrome.

The thesis applied a combination of methods. Triangulation is an approach by which information is collected using a variety of methods, including quantitative and qualitative study designs (Patton, 2002). One implication of this approach is that different kinds of data may reveal somewhat different results, because different methods are sensitive to different nuances of what is studied.

Study I and II applied the PEDI (Haley et al., 1992) for collecting data. Research has found that while applying the PEDI, reliability is secured when the same interviewer interviews the same respondent (e.g. Berg et al., 2004). There may be a risk however, that being interviewed more than one time may influence the results of the study. Parents who have been interviewed twice have been found to focus on functional skills which in turn increase the child's performance in the second interview (Berg et al., 2004).

Traditionally, interventions designed for children with disabilities have focused on body function and structures rather than on interventions related to dimensions of activities and participation. Consequently, few instruments have been developed to measure the dimensions related to activity, participation and contextual factors. However, the PEDI (Haley et al., 1992) was developed in accordance with the World Health Organization's (WHO) International Classification of Impairments, Disability and Handicaps (ICIDH) (WHO, 1980). A Norwegian version of the PEDI was linked to the ICIDH classification by Bjorbækmo (2002), and showed that 96% of the items within the area of self-care, all items related to mobility, and 83% of items in the area

of social function of the PEDI were classified as Activity and Participation components. Østensjø and colleagues (2006) investigated the conceptual basis of the PEDI scales in relation to the ICF and found that the PEDI primarily was measuring activity and participation. Furthermore, the construction of the PEDI, which originally was developed in accordance with the ICIDH, is found to fit even better with the recently developed International Classification of Functioning, Disability and Health – Children and Youth (ICF-CY) (WHO, 2007) (Berg, 2008). Thus, the PEDI seems to be a relevant assessment instrument for measuring conditions influencing school participation of children with Down syndrome.

In studies III and IV field observations were conducted. With the role of an observer, the researcher's intension was to be "a fly on the wall"; the less the pupils and the class staff were aware that they were studied the better. Observers are advised to minimize the influence they are likely to have on the behavior of their subjects, and mingling with the respondents before the actual conduct of the study has been suggested as a strategy to achieve this (Christensen & James, 2000). Thus, information meeting with the class staff at each school, including a visit in the class room and mingling outdoors during breaks, initiated the visits at each school.

Study III included interviews with each of the six pupils with Down syndrome. Interviews with children in general are found to be possible once children have reached the age where they are able to process and respond to standard questions (Scott, 2000). Context, such as where the interviews are carried out, is found to be of importance and is likely to influence the way children respond. Motivation is rarely a problem (Scott, 2000). Thus, interviews were carried out in group rooms that were familiar to the children, and a teacher or teacher' assistant was present to secure the pupils and for assisting the researcher in the communication with the child. There are several problems with interviewing children, which became evident in interviewing the children with Down syndrome. Structured questions are found not to be appropriate for younger children because of cognitive and language limitations (Scott, 2000). Instead, conversations have been suggested to be beneficial (Mayall, 2000). Likewise, conversations with short concrete questions referring to concrete situations were applied. Some of the pupils responded with one or two words sentences only. Although the researcher was experienced in relating to children with disabilities the interviews came out differently than expected, and, in some cases, useful information was sparse. Conducting the interviews while children interacted with peers in activities would have been more beneficial. Also, the influence of power of two adults being

present during interviewing may have affected the access to the children's personal experiences as they may have tried to please the adults with their answers. Thus, alternative ways of getting access to their perspective might have been through concrete situations or by the use of pictures that related to situations in the class room or outside during breaks. Such situations would probably have opened for a more spontaneous access to their world as the children seemed to prefer to talk about concrete situations and reflecting on past situations was sometimes challenging.

One more and important concern to be discussed is how the choice of focus in studies III and IV may have influenced the results of this thesis. The studies focused on peer interaction when it occurred. Thus, by leaving out initiations and unsuccessful attempts, refusals and solitary activity, this thesis may provide a positive impression of peer interaction that is not representative of the situations as a whole. Neither did we count how often successful interaction occurred. Our intention however, was to study more in detail what peer interaction actually consisted of when it occurred. By applying this approach in addition to an occupational perspective, results, such as the strategies that peers used to include pupils with Down syndrome, were explored.

Finally, there is always a risk that the results are colored by assumptions held by the researcher, such as pre-understanding of the topic, professional background and perspective. For example, the researcher's professional background may have influenced the meaning of the activities of the pupils through a pre-understanding of activities and activity analysis. Thus, self-awareness and to some extent self-analysis is required in qualitative inquiry, and this has been referred to as reflexivity (Patton, 2002; DePoy & Gitlin, 1998). To increase the trustworthiness of the study, reflections and evaluations were made with two more highly qualified scholars on the researcher's own thinking, understanding and possible biases (DePoy & Gitlin, 1998). To strengthen the credibility of the results, three highly qualified researchers were involved in parts of the analysis and in the final interpretations (Gustavsson, 2000; Patton, 2002).

ETHICAL CONSIDERATIONS

All the studies, I-IV, were approved by the Regional Ethical Committee (Eastern Region) and the Norwegian Social Science Data Service (Personverneombudet).

The first ethical dilemma of this study occurred during the planning phase of the research. The Ethical committee that approved the study questioned if the aim of the study was to construct a norm for the skills of children with Down syndrome as they regarded such a norm to be stigmatizing. The intention of the study was never to produce a norm, but rather to enhance the knowledge base related to skills development of children with Down syndrome. By enhancing such knowledge, the goal is to optimize intervention through formulating realistic expectations, providing environmental support and forming a better understanding of the child's potential. Thus, knowledge about functioning on group level was needed in order to understand the variability and what it consisted.

Parents were chosen to be informants. Parent confidentiality was maintained by having the letter of invitation sent through the associations that identified parents of children with 5-year old children with Down syndrome in Norway (study I). The parents who participated in study I were re-invited to study II by letter, and those who met the inclusion criteria of study III and IV were again invited in those studies. For all the studies, the parents were informed that they (or the child) could withdraw from the study at any stage. To confirm their participation, the parents returned the informed consent form. There was one ethical dilemma that was related to the participation of the children with Down syndrome in study III and IV. As mentioned above, the Regional Ethical Committee approved the studies. Still, the researcher reflected upon the fact that the parents were the ones to agree upon the participation of their children, and inform the child. It was not possible to know exactly what information had been given to the children. Also it was uncertain to what extent the children understood that they could refuse to participate, or withdraw from the research.

Another ethical dilemma was related to the reporting of the results. When significant extracts from interviews were quoted from a small number of participants, was the identity of these participants sufficiently protected? Confidentiality in research implies that data identifying the subjects will not be used (Kvale, 1996). Thus, in order to more fully protect the children's identity, fictive names and small changes in the

children's characteristics were used without making major changes of meanings in the substance of the reports.

As written by Antoine de Saint-Exupéry in his book *The little prince* (1962), adults cannot on their own understand the world from a child's point of view and therefore need children to explain it to them. When reflecting on his advice, it seems reasonable to have included interviews with class peers of the pupils with Down syndrome. This thesis tried to understand peer interaction between pupils with Down syndrome and their peers, but findings (besides observations) are based on information from adults and the children with Down syndrome only. The perspective of peers is missing. Thus, in retrospect, interviews with peers would have been beneficial in order to capture a broader understanding of the pupils' social participation. However, this would have required a broader ethical approval and more time in order to obtain informed consent from pupils and /or their parents. Because of time limitations, this was not pursued.

To reduce the risk of stigmatisation of the pupil with Down syndrome, the researcher planned all observations for study III and IV in cooperation with the teacher, in an attempt to optimise the timing and to secure the integrity of the pupils as well as of teachers and assistants. Today's classes are accustomed to regular visits from students and other adults for limited periods of time, and neither pupils nor school personal seemed bothered or distracted by the researcher's presence. As suggested by Bogdan and Biklen (2003), researchers would do well to reflect on the effects of their own role in the research environment. The researcher thus aimed at being open-minded to the experiences of the teachers and teachers' assistants and to the idea that they might have differing insights and competencies.

CONCLUSION AND IMPLICATIONS

The findings of this thesis have contributed with new knowledge and insights related to school participation of children with Down syndrome in elementary mainstream schools. The findings have clinical implications and provide knowledge useful to occupational therapy, as well as to other professionals. Staff in kindergartens and school and to authorities that plan and evaluate practice and services for children with Down syndrome will benefit from this knowledge. The findings may also have implications and provide knowledge to parents of children with Down syndrome.

Study I and II provided knowledge about baseline performance and variability of performance of children with Down syndrome at age 5 and 7. Such knowledge may be useful for parents and professionals for the planning for school entry and school participation of children with Down syndrome. These results may also be helpful in a more general discussion of the pros and cons of postponed school entry for children with Down syndrome.

Study findings also provided knowledge about a general delay regarding bladder and bowel control in children with Down syndrome, which can have implication for parents' expectations. These findings give information to parents blaming themselves for not succeeding in getting their child with Down syndrome toilet trained prior to the child's school entry. In consideration of the noted delays, intensive training methods might be provided before school start as one possible solution. In addition, class staff needs to be prepared to handle diapers and /or to take part in toilet training procedures in a respectful way.

Findings of this thesis (studies I-IV) showed that speech and communication difficulties of the children with Down syndrome influenced on their school participation; their postponement of school entry, their interaction in activities with peers and they needed support provided by the class staff and teachers' assistants in particular. More efforts to alleviate such communication difficulties need to be provided in schools. Also, a follow-up examination of the methods applied in the respective kindergartens should be conducted.

Study III provided insight into the strategies used by peers in order to enable peer interaction in activities with a less capable peer. This insight may, in turn, indicate opportunities for participation in unequal conditions, such as complementary interaction in activities. Interaction was enabled through the use of adaptations by peers in order to meet the needs of the pupils with Down syndrome in a shared or shared enough understanding of the activities and to provide tasks within the performance range of the less competent participant. This study also provided knowledge about some characteristics of activities found suitable for peer interaction, such as self-initiated, rather simple activities or structured games, with low demands on for example verbal communication. Such activities may have a potential for structured use, in order to provide opportunities for social participation. Study III and IV indicated that an interaction history of the pupils may provide opportunities for the pupils' social participation. This finding indicates the need for the pupils to have regular opportunities to do activities together, in order to get to know each other and build an interactional history.

Study IV provided information about the kinds of support delivered by teachers' assistants in the role of the "supported ego". These findings point to the need for support that compensates for the cognitive difficulties of the pupils with Down syndrome in interaction with peers. However, trying to be somebody's "head, ears and eyes" is a difficult task, and one implication of this finding is to suggest a critical examination of this role in order to understand what training and knowledge that is necessary in order to perform this role well.

ACKNOWLEDGEMENTS

This thesis was been made possible through generous support of a bunch of great people. I wish to express my warm and deep thanks:

Firstly, the families, children, and class staff who took part in this research. Thank you for welcoming me, believing in the project and for participating by generously sharing your time and experiences!

A warm and special thanks to my four supervisors; Helena Hemmingsson, Margareta Lilja, Lena Borell and Anders Gustavsson.

First *Helena*, my main supervisor, thank you for your patience and availability, and for your invaluable support and guidance during my research education.

Margareta, my co-supervisor, thank you for encouraging me to take this journey and for your warm support and pointy remarks.

Lena, my other co-supervisor, thank you for your warm support and sharing of your enormous knowledge.

Anders, my co-supervisor, thank you for sharing your enormous experience and knowledge of disability research.

I would also like to highlight and thank other key persons:

Wendy Coster, co-author of one of the studies, for your interest and encouragement of the project, for your support and thoughtful comments.

Jo Kleiven, for statistical guidance, for you pedagogical skills in introducing me into statistics and for thoughtful comment and engagement.

Ole Petter Askheim, my local supporter at the Lillehammer University College, for warm support and for introducing me to the Norwegian disability research group.

Marie Berg, friend and colleague for inspiration, knowledge, support and joy.

Margit Aalandslid for engagement and support.

Kristin, Jason, Rosemary and *Ingvild* for language support.

Sigbjørn Hernes for reference editing, and all the librarians at Lillehammer University College for always being helpful.

Thanks to all colleagues and fellow doctoral students at the division of Occupational Therapy at Karolinska Institutet, Stockholm for an including friendly atmosphere, for inspiring seminars and high quality knowledge!

A warm thanks to my *colleagues* at department for Health and Social work, Lillehammer University College, for making the day at work so positive. And a special thank to *Astrid Smedsrud Johansen* for warm support and for always seeing possibilities. *Astrid, Inger Marie, Liv* and *Randi* for additional physical enjoyments.

Thanks to *Lillehammer University College* for financially support to this research and my research education.

Thanks to *Sykehuset Innlandet* and *Habiliteringstjenesten for barn*, for support and for providing me with the opportunities that lead to this research journey. A special thank to *Olav Renolen* for believing in the project.

Thanks to *Norsk Nettverk for Down syndrome; NNDS* for interest and encouragement. Thanks to *Norsk Ergoterapeut Forbund* for financial support to data collection.

Thanks to *all my supportive friends*.

And, finally, my dearest *Ketil* for your patience, encouragement, support and love on an everyday basis. At last, our dearest children and favourite youngsters *Christiane, Frederik* and *Nicolai* for love, laughter, and enthusiasm, and to my dear mother, *Gerd* for warmly engagement.

REFERENCES

- Annerén, G. (1997). Den genetiska bakgrunden till Downs syndrom [Genetical background for Down syndrome]. In G. Anneren, I. Johansson, I.L. Kristiansson, & L. Lööv (Eds.), *Downs syndrom* (p. 20-36). Stockholm: Liber.
- Annerén, G., Johansson, I., Kristiansson, I.L., & Lööv, L. (Eds.), (1997). *Downs syndrom*. Stockholm: Liber.
- American Occupational Therapy Association. (2008). Occupational therapy practice framework: domain & process (2nd ed.). *American Journal of Occupational Therapy*, 62(6), 625-683.
- Askheim, O.P. (1999). Personal assistance for disabled people – the Norwegian experience. *International Journal of Social Welfare*, 8 (2), 111-119.
- Baum, C. M., & Christiansen, C.H. (2005). Outcomes: the results of interventions in occupational therapy practice. In C.H. Christiansen, C.M. Baum, & J. Bass-Haugen (Eds.), *Occupational therapy: performance, participation, and well-being* (3rd ed., p. 522-534). Thorofare, NJ: SLACK Incorporated.
- Benestad, H.B., & Laake, P. (2004). *Forskningsmetode i medisin og biofag* [Research method in medicine and biology]. Oslo: Gyldendal Akademisk.
- Berg, M. (2008). *Norwegian validation of the Pediatric Evaluation of Disability Inventory (PEDI)*. Unpublished doctoral dissertation, University of Oslo, Norway.
- Berg, M., Aamodt, G., Stanghelle, J., Krumlinde-Sundholm, L., & Hussain, A. (2008). Cross-cultural validation of the Pediatric Evaluation of Disability Inventor (PEDI) norms in a randomized Norwegian population. *Scandinavian Journal of Occupational Therapy*, 15(3), 143-152.
- Berg, M., Jahnsen, R., Frøisli, K.F., & Hussain, A. (2004). Reliability of the Pediatric Evaluation of Disability Inventory (PEDI). *Physical & Occupational Therapy in Pediatrics*, 24(3), 61-77.
- Bjorbækmo, W. (2002). *Kartlegging et spørsmål om perspektiv og projeksjon: En innholdsanalyse av kartleggingsinstrumentene GMFM og PEDI* [Assessment: a question of perspectives and projection: content analysis

- of the instruments GMFM and PEDI]. Unpublished master's thesis, University of Oslo, Norway.
- Bogdan, R.C., & Biklen, S.K. (2003). *Qualitative research for education: an introduction to theory and methods*. Boston: Allyn and Bacon.
- Buckley, S., Bird, G., & Sacks, B. (2006a). Evidence that we can change the profile from a study of inclusive education. *Down syndrome Research and Practice*, 9(3), 51-53.
- Buckley, S., Bird, G., Sacks, B., & Archer, T. (2006b). A comparison of mainstream and special education for teenagers with Down syndrome: implications for parents and teachers. *Down syndrome Research and Practice*, 9(3), 54-67.
- Buckley, S. (1995). Improving the expressive language skills of teenagers with Down's syndrome. *Down syndrome Research and Practice*, 3(3), 110-115.
- Canning, C.D., & Pueschel, S.M. (1990). Developmental expectations: an overview. In S.M. Pueschel (Ed.), *A Parent's guide to Down syndrome: toward a brighter future*, (p. 97-99). Baltimore, MD: Paul Brookes.
- Case-Smith, J. (2001). An overview of occupational therapy for children. In J. Case-Smith (Ed.), *Occupational therapy for children* (4th ed., p. 2-20). St. Louis, MO: Mosby.
- Carr, J. (1995). *Down's syndrome. Children growing up*. Cambridge: University Press.
- Cebula, K.R., & Wishart, J.G. (2008). Social cognition in children with Down syndrome. In L. Glidden (Ed.), *International review of research in mental retardation* (p. 43-86). New York: Academic Press.
- Chapman, R.C. (2006). Language learning in Down syndrome: the speech and language profile compared to adolescents with cognitive impairment of unknown origin. *Down syndrome Research and Practice*, 10(2), 61-66.
- Christensen, P., & James, A. (Eds.), (2000). *Research with children*. London: RoutledgeFalmer.
- Christiansen, C., Clark, F., & Kielhofner, G. & Rogers, J. (1995). Position paper: occupation. *American Journal of Occupational Therapy*, 49(10), 1015-1018.
- Christiansen, C.H., & Baum, C.M. (Eds.). (2005). *Occupational Therapy: performance, participation, and well-being*. Thorofare, NJ: SLACK Incorporated.
- Collacott, R.A., Cooper, S.A., Branford, D., & McGrother, C. (1998). Behaviour

- phenotypes of Down syndrome. *British Journal of Psychiatry*, 172, 85-89.
- Connolly, B.H., Morgan, S.B., Russell, F.F., & Fulliton, W.L. (1993). A longitudinal study of children with Down's syndrome who experienced early intervention programming. *Physical Therapy*, 73(3), 170-179.
- Corsaro, W.A. (1998). *The sociology of childhood*. Thousand Oaks, CA: Pine Forge Press.
- Coster, W., & Khetani, M.A. (2008). Measuring participation in children with disabilities: Issues and challenges. *Disability and Rehabilitation*, 30(8), 639-648.
- Coster, W. J. (1998). Occupation-centered assessment for children. *American Journal of Occupational Therapy*, 52(5), 337-344.
- Davies, J., & Polatajko, H. (2006). The occupational development of children. In S. Rodger & J. Ziviani (Eds.), *Occupational therapy with children* (p. 136-157). Victoria: Blackwell Publishing.
- DePoy, E., & Gitlin, L.N. (1998). *Introduction to research*. (2nd ed.) St. Louis, MD: Mosby.
- Downing, J.E., Ryndak, D.L., & Clark, D. (2000). Paraeducators in inclusive classrooms. *Remedial and Special Education*, 21(3), 171-181.
- Dunst, C.J., Bruder, M.B., Trivette, C., Raab, M., & McLean, M. (2001). Characteristics and consequences of everyday natural learning opportunities. *Topics in Early childhood special education*, 21(2), 68-92.
- Dykens, E.M. (1995). Measuring behavioral phenotypes: provocations from the "new genetics". *American Journal of Mental Retardation*, 99(5), 522-532.
- Dykens, E.M., Hodapp, R.M., & Evans, D.W. (1994). Profiles and development of adaptive behavior in children with Down syndrome. *American Journal on Mental Retardation*, 98(5), 580-587.
- Dykens, E.M., Shah, B., Sagun, J., Beck, T., & King, B.H. (2002). Maladaptive behavior children and adolescents with Down syndrome. *Journal of Intellectual Disability Research*, 46(6), 484-492.
- Egilson, S.T., & Traustadottir, R. (2009). Assistance to pupils with physical disabilities in regular schools: promoting inclusion or creating dependency? *European Journal of Special Needs Education*, 24(1), 21-36.
- Feldman, A.B., Haley, S.M., & Coryell, J. (1990). Concurrent and construct validity of

- the Pediatric Evaluation of Disability Inventory. *Physical Therapy*, 70(10), 602-610.
- Fernald, C.D. (1995). When in London: Differences in disability language preferences among English-speaking counties. *Mental Retardation* 33(2), 99-103.
- Fidler, D.J. (2005). The emerging Down syndrome behavioral phenotype in early childhood. *Infants & Young Children*, 18(2), 86-103.
- Fidler, D.J., Hepburn, S.L., Mankin, G., & Roger, S.J. (2005). Praxis skills in children with Down syndrome and other developmental disabilities, and typically developing children. *American Journal of Occupational Therapy*, 59(2), 129-138.
- Flem, A., & Keller, C. (2000). Inclusion in Norway: a study of ideology in practice. *European Journal of Special Needs Education*, 15(2), 188-205.
- Fletcher, R., Loschen, E., Stavrakaki, C., & First, M. (Eds.), (2007). *Diagnostic manual – intellectual disability: a clinical guide for diagnosis of mental disorders in persons with intellectual disability*. New York: NADD Press.
- Folkehelseinstituttet. (2009). Statistics. Retrieved April 28, 2009, from <http://www.fhi.no/dav/C90877FAE7.pdf>
- Fox, S., Farrell, P., & Davies, P. (2004). Factors associated with the effective inclusion of primary-aged pupils with Down's syndrome. *British Journal of Special Education*, 31(4), 184-190.
- Freeman, S.F.N., & Kasari, C. (2002). Characteristics and qualities of the play dates of children with Down syndrome: emerging or true friendship? *American Journal on Mental Retardation*, 107(1), 16-31.
- Frid, C., Drott, P., Lundell, B., Rasmussen, F., & Annerén, G. (1999). Mortality in Down's syndrome in relation to congenital malformations. *Journal of Intellectual Disability Research*, 43(3), 234-241.
- Giangreco, M.F., & Broer, S.M. (2005). Questionable utilization of paraprofessionals in inclusive schools: are we addressing symptoms or causes? *Focus on autism and other developmental disabilities*, 20(1), 10-26.
- Giangreco, M.F., & Broer, S.M. (2007). School-based screening to determine overreliance on paraprofessionals. *Focus on autism and other developmental disabilities*, 22(3), 149-158.
- Giangreco, M.F., Edelman, S.W., Luiselli, T.E., & MacFarland, S.Z.C. (1997). Helping

- or hovering? Effects of instructional assistant proximity on students with disabilities. *Exceptional Children*, 64(1), 7-18.
- Gresham, F.M. (1983). Social skills assessment as a component of mainstream placement decisions. *Exceptional Children*, 49(4), 331-336.
- Gunn, P., & Cuskelly, M. (1991). Down syndrome temperament: the stereotype at middle childhood and adolescence. *International Journal of Disability, Development and Education*, 38(1) 59-70.
- Guralnick, M.J. (1997). The peer social networks of young boys with developmental delays. *American Journal on Mental Retardation*, 101(6), 595-612.
- Guralnick, M.J. (1999). Family and child influences on the peer-related social competence of young children with developmental delays. *Mental Retardation and Developmental Disabilities Research review*, 5, 21-29.
- Guralnick, M.J. (2002). Involvement with peers: comparisons between young children with and without Down's syndrome. *Journal of Intellectual Disability Research*, 46(5), 379-393.
- Guralnick, M.J., Connor, R.T., & Hammond, M. (1995). Parent perspective of peer relationships and friendships in integrated and specialised programs. *American Journal on Mental Retardation*, 99(5), 457-476.
- Gustavsson, A. (2000). *Tolkning och tolkningsteori 1: Introduktion* [Interpretations and theory of interpretation 1: Introduction]. Stockholm University: Department of Education.
- Gustavsson, A. (2004). (Ed.) *Delaktighetens språk* [Language of participation]. Lund: Studentlitteratur.
- Haley, S., Coster, W.J., Ludlow, L.H., Haltiwanger, J.T., & Andrellos, J.P. (1992). *Pediatric Evaluation o Disability Inventory (PEDI)*. Version 1.0. Boston: New England Medical Centre Hospitals.
- Hall, L.J., & McGregor, J.S. (2000). A follow-up study of the peer relationships of children with disabilities in an inclusive school. *The Journal of Special Education*, 34(3), 114-126.
- Heah, T., Case, T., McGuire, B., & Law, M. (2007). Successful participation: The lived experience among children with disabilities. *Canadian Journal of Occupational Therapy*, 74(1), 38-47.
- 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.

- Hemmingsson, H., & Jonsson, H. (2005). The issue is – an occupational perspective on the concept of participation in the International Classification of Functioning, Disability and Health – some critical remarks. *American Journal of Occupational Therapy*, 59(2), 569-576.
- Hinojosa, J., & Kramer, P. (1999). Developmental perspective: fundamentals of development theory. In P. Kramer & J. Hinojosa (Eds.), *Frames of reference for pediatric occupational therapy* (2nd ed., p. 3-8). Baltimore: Lippincott, Williams & Wilkins.
- Humphry, R. (2002). Young children's occupations: explicating the dynamics of developmental processes. *American Journal of Occupational Therapy* 56 (2), 171-179.
- Humphry, R., & Wakeford, L. (2006). An occupation-centered discussion of development and implications for practice. *American Journal of Occupational Therapy*, 60(3), 258-267.
- Humphry, R., & Wakeford, L. (2008). Development of everyday activities. A model for occupation-centered therapy. *Infants & Young Children*, 21(3), 88-98.
- Jahnsen, R., Berg, M., Dolva, A.-S., & Høyem, R. (2000). *Norwegian supplement version to Pediatric Evaluation of Disability Inventory*. Oslo: Norsk Psykologforening.
- Jansson, U., Hanson, M., Sillen, U., & Hellström, A. (2005). Voiding pattern and acquisition of bladder control from birth to age 6 years – a longitudinal study. *Journal of Urology*, 174(1), 289-293.
- Kemp, C., & Carter, M. (2002). The social skills and social status of mainstreamed students with intellectual disabilities. *Educational Psychology*, 22(4), 391-411.
- Kielhofner, G. (1995). *Model of human occupation: theory and application* (2nd ed.). Baltimore: Williams & Wilkins.
- Kielhofner, G. (2008). *Model of human occupation: theory and application* (4th ed.). Baltimore: Lippincott Williams & Wilkins.
- King, G., Law, M., King, S., Rosenbaum, P., Kertoy, M., & Young, N. (2003). A conceptual model of the factors affecting the recreation and leisure participation of children with disabilities. *Physical and Occupational Therapy in Pediatrics*, 23(1), 63-90.
- Koster, M., Nakken, H., Pijl, S.J., & Houten, van E. (2009). Being part of the peer

- group: a literature study focusing on the social dimension of inclusion in education. *International Journal of Inclusive Education*, 13(2), 117-140.
- Kunnskapsdepartementet. (2007). *Opplæringslova* [Education Act]. Oslo: Cappelen Akademisk.
- Kvale, S. (1996). *Interviews. An introduction to qualitative research interviewing*. Thousand Oaks, CA: Sage Publications.
- Law, M. (2002). Participation in the occupations of everyday life. Distinguished Scholar Lecture. *American Journal of Occupational Therapy*, 56(6), 640-649.
- Law, M. (2003). Outcome measure in pediatric rehabilitation. *Physical & Occupational Therapy in Pediatrics*, 23(2), 1-4.
- Law, M., Baptiste, S., Carswell, A., McColl, M., Polatajko, H., & Pollock, N. (1998). Canadian occupational performance measure (3rd ed.). Ottawa: CAOT Publications ACE.
- Law, M., Cooper, B., Strong, S., Stewart, D., Rigby, P., & Letts, L. (1996). The person-environment- occupation model: a transactive approach to occupational performance. *Canadian Journal of Occupational Therapy*, 63(1), 9-23.
- Law, M., Missiuna, C., Pollock, N., & Stewart, D. (2001). Foundations for occupational therapy practice with children. In J. Case-Smith (Ed.), *Occupational therapy for children* (4th ed., p. 39-70). St Louis, MO: Mosby.
- Laws, G., Taylor, M., Bennie, S., & Buckley, S. (1996). Classroom behaviour, language competence, and the acceptance of children with Down syndrome by their mainstream peers. *Down syndrome Research and Practice*, 4(3), 100-109.
- Laws, G., & Bishop, D.V.M. (2004). Verbal deficits in Down's syndrome and verbal language impairment: a comparison. *International Journal of Language & Communication Disorders*, 39(4), 423-451.
- Leonard, S., Msall, M., Bower, C., Tremont, M., & Leonard, H. (2002). Functional status of school aged children with Down syndrome. *Journal of Pediatrics and Child Health*, 38(2), 160-165.
- Lindsay, G. (2007). Educational psychology and the effectiveness of inclusive education/mainstreaming. *British Journal of Educational Psychology*, 77, 1-24.
- Lofterød, B. (1989). *Barn og unge med Down's syndrome* [Children and adolescents

- with Down syndrome]. Drøbak, Norway: Trine Suphammer AS
- Lofterød, B. (1997). Down syndrom – mulighetenes syndrom. In E. Ruud & B. Nilsson (Eds.), *Hver for seg små – sammen store* [Each one small – together bigger] (p. 89-97). Oslo: Frambu and Rikshospitalet.
- Lorenz, S. (1999). Making inclusion work for children with Down syndrome. *Down syndrome News and Update* 1(4), 175-180.
- Mancini, M.C., Carvalho e Silva, P., Goncalves, S.C., & Martins, S. (2003). Comparison of functional performance among children with Down syndrome and children with age-appropriate development at 2 and 5 years of age. *Arquivos de Neuro-psiquiatria*, 61(2b), 409-415.
- Mayall, B. (2000). Conversations with children: working with generational issues. In P. Christensen & A. James (Eds.), *Research with children* (p. 120-135). London: RoutledgeFalmer.
- Nabors, L. (1997). Playmate preferences of typically developing for their classmates with special needs. *Mental Retardation*, 35(2), 107-113.
- Nichols, D.S., & Case-Smith, J. (1996). Reliability and validity of the Pediatric Evaluation of Disability Inventory. *Pediatric Physical Therapy*, 8(1), 15-24.
- Nordstrøm, I. (2002). *Samspell på jämlika och ojämlika villkor* [Interaction on equal and unequal terms]. Unpublished doctoral dissertation, Stockholm University, Sweden.
- Norsk Ergoterapeut Forbund (2007). *Barns helse og oppvekst* [Children's health]. Retrieved April 28, 2009, from <http://www.netf.no/Netf/Fag-ogyrkesutovelse/Fagomroder/barn-helse>
- Patton, M.Q. (2002). *Qualitative research & evaluation methods* (3rd ed.). Thousand Oaks, CA: Sage Publications.
- Pianta, R., & Cox, M.E. (1999). *The transition to kindergarten*. Baltimore, MD: Paul Brooks.
- Pianta, R., & Kraft-Sayre, M. (2003). *Successful kindergarten transition*. Baltimore, MD: Paul Brooks.
- Pinter, J.D., Eliez, S., Schmitt, J.E., Capone, G.T., & Reiss, A.L. (2001). Neuroanatomy of Down syndrome: a high resolution MRI study. *American Journal of Psychiatry*, 158(10), 1659-1665.
- Pitcairn, T.K., & Wishart, J.G. (1994). Reactions of young children with Down's

- syndrome to an impossible task. *British Journal of Developmental Psychology*, 12(4), 485-490.
- Prigg, A. (2002). Experiences and perceived roles of occupational therapists working with children with special learning needs during transition to school: a pilot study. *Australian Occupational Therapy Journal*, 49(2), 100-111.
- Pueschel, S.R., & Pueschel, J.K. (1992). *Biomedical concerns in persons with Down syndrome*. Baltimore, MD: Paul Brookes.
- Reed, K.L. (2005). An annotated history of the concepts used in occupational therapy. In C.H. Christiansen and Baum, C.M. (Eds.), *Occupational therapy: Performance, participation, and well-being* (p. 567-626). Thorofare, NJ: SLACK Incorporated.
- Rosenbaum, P., King, S., Law, M., King, G., & Evans, J. (1998). Family-centered service: A conceptual framework and research review. *Physical & Occupational Therapy in Pediatrics*, 18(1), 1-20.
- Saint-Exupéry, A. (1962). *Den lille prinsen* [The little Prince]. Oslo: Aschehoug.
- Sale, P., & Carey, D.M. (1995). The sociometric status of students with disabilities in a full-inclusion school. *Exceptional Children*, 62(1), 6-19.
- Schenker, R., Coster, W.J., & Parush, S. (2005). Neuroimpariments, activity performance, and participation in children with cerebral palsy mainstreamed in elementary schools. *Developmental Medicine and Child Neurology* 47(12), 808-814.
- Schimmel, M.S., Hammerman, C., Bromiker, R., & Berger, I. (2006). Third ventricle enlargement among newborn infants with trisomy 21. *Pediatrics*, 117(5), e928-e931. Retrieved April 28, 2009 from <http://pediatrics.aappublications.org/cgi/content/full/117/5/e928>
- Scott, J. (2000). Children as respondents: the challenge for qualitative methods. In P. Christensen & A. James (Eds.), *Research with children* (p. 98-119). London: RoutledgeFalmer.
- Skär, L., & Tamm, M. (2001). My assistant and I: disabled children's and adolescents' roles and relationships to their assistants. *Disability and Society*, 16(7), 917-931.
- Sloper, T., & Tyler, S. (1992). Integration of children with severe learning difficulties in mainstream schools: evaluation of a pilot study. *Educational and Child Psychology*, 9(4), 34-45.
- Smith, L., & Tetzchner, S. von. (1986). Communicative, sensorimotor, and language

- skills of young children with Down syndrome. *American Journal of Mental Deficiency*, 91(1), 57-66.
- Sosialdepartementet. (2003). *Nedbygging av funksjonshemmende barrierer* [Removing disabling barriers]. St.meld. nr. 40 (2002-2003). Oslo: Sosialdepartementet.
- Spano, M., Mercuri, E., Rando, T., Panto, T., Gagliano, A., Henderson, S., et al. (1999). Motor and perceptual-motor competence in children with Down's syndrome: variation in performance with age. *European Journal of Paediatric Neurology*, 3(1), 7-14.
- Statistisk Sentralbyrå. (2000). *Statistisk årbok* [Statistical yearbook]. Oslo/Kongsvinger: Statistisk sentralbyrå.
- 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(4), 174-182.
- Tetzchner, S. von. (2005). *Utviklingspsykologi* [Developmental psychology]. Oslo: Gyldendal Akademisk.
- Ueda, S., & Okawa, Y. (2003). The subjective dimension of functioning and disability: what is it and what is it for? *Disability and Rehabilitation*, 25(11-12), 596-601.
- UNESCO. (1994). *The Salamanca statement and framework for action on special needs education, adopted by the world conference on special needs education: access and quality*. Paris: UNESCO.
- United Nations. (1989). *Convention on the rights of the child*. New York: UN.
- Vislie, L. (2003). From integration to inclusion: focusing global trends and changes in western European societies. *Journal of Special Needs Education*, 18(1), 17-35.
- Volman, M.M.J., Visser, J.J.W., & Lensvelt-Mulders, G.J.L.M. (2007). Functional status in 5 to 7-year-old children with Down syndrome in relation to motor ability and performance mental ability. *Disability and Rehabilitation*, 29(1), 25-31.
- Vygotskij, L.S. (2004). *Tenkning og tale* [Thought and language]. Oslo: Gyldendal Akademisk [Original work published 1934].
- Wehmeyer, M.L. (2007). Promoting self-determination in students with developmental

- disabilities. New York: Guilford Publications. [Electronic version]. Retrieved April 28, 2009, from <http://site.ebrary.com/lib/hilhmr/docDetail.action?docID=10201015>
- Wendelborg, C., & Tøssebro, J. (2008). School placement and classroom participation among children with disabilities in primary school in Norway: a longitudinal study. *European Journal of Special Needs Education*, 23(4), 305-319.
- WHO. (1980). *International classification of impairments, disability, and handicaps: ICDH*. Geneva: WHO.
- WHO. (2001). *International classification of functioning, disability and health: ICF*. Geneva: WHO.
- WHO. (2007). *International classification of functioning, disability and health: children & youth version: ICF-CY*. Geneva: WHO.
- Wolery, M., Werts, M., Caldwell, N., Snyder, E., & Liskowski, L. (1995). Experienced teachers' perceptions of resources and supports for inclusion. *Education and Training in Mental Retardation, and Developmental Disabilities*, 30(1), 15-26.
- Ytterhus, B. (2000). "De minste vil, og får det kanskje til..." ["The youngest may wish, and probably manage..."]. Unpublished doctoral dissertation, Norwegian University of science and technology, Norway.
- Ziviani, J., Ottenbacher, K.J., Shephard, K., Foreman, S., Astbury, W., & Ireland, P. (2001). Concurrent validity of the Functional Independence Measure for children (WeeFIM) and the Pediatric Evaluation of Disability Inventory in children with developmental disabilities and acquired brain injuries. *Physical & Occupational Therapy in Pediatrics*, 21(2-3), 91-101.
- Østensjø, S., Bjorbækmo, W., Carlberg, E.B., & Vøllestad, N.K. (2006). Assessment of everyday functioning in young children with disabilities: an ICF based analysis of concepts and content of the Pediatric Evaluation of Disability Inventory (PEDI). *Disability and Rehabilitation*, 28(8), 489-504.

