Mona Asbjørnslett

“Ordinary Kids”–

Everyday life experiences of children with disabilities

DISSERTATION FROM THE NORWEGIAN SCHOOL OF SPORT SCIENCES • 2015

ISBN 978-82-502-0513-0

Sammendrag

Målet med denne studien er å anvende kunnskap fra barn i alderen 11-14 år som har fysiske funksjonsnedsettelser. Avhandlingen relaterer til barnas erfaringer rundt deltakelse i eget hverdagsliv og med fokus på overgangsfasen fra barne- til ungdomsskole. Avhandlingen ønsker også å belyse viktigheten av å ta barns perspektiver inn i forskningen og å rette fokus mot barns deltakelse i profesjonelle praksiser. Denne avhandlingen er en del av et større tverr- profesjonelt forsknings samarbeid ved Høgskolen I Oslo og Akershus som har handlet om «Barns deltakelse og profesjonelle praksiser». Barn, foreldre og profesjonsutøvere i skolen har deltatt som informanter i studien og til sammen har tre forskere intervjuet femten barn, deres foreldre (mor, far eller begge), ni lærere og tre assistenter i skolen. Forskerne har brukt livsforms- intervjuer som metode for å innhente erfaringer fra informantene. Barna ble intervjuet en til fire ganger i perioden fra barne- og overgang til ungdomsskole, foreldre og skole personell ble intervjuet en til to ganger i samme periode. I tråd med denne avhandlingens hensikt har de empiriske analysene hatt mest fokus på barnas egne erfaringer. Forsknings- spørsmålene tar utgangspunkt i barnas egne perspektiver og funnene er operasjonalisert gjennom fire temaer; vennskap; 2) Om å være et «vanlig barn» med merkelappen funksjonshemmet; 3) Barns engasjement i aktiviteter og i en overgangsfase mellom barne- og ungdomsskole; 4) Inkludering og deltakelse i skolen. Konklusjonen er at barna i større grad enn å snakke om sin funksjonsnedsettelse fokuserer på sine mange ressurser. I hverdagen bruker de sitt engasjement til å utvikle sine mange og varierende interesser og relasjoner for å kunne leve et aktivt liv. Barna påvirkes i stor grad av ulike normer og forventninger om «normalitet» i skole og hverdagsliv som de både tilpasser seg til og utfordres av. Barna uttrykker at venner, profesjonsutøvere i skolen og andre som de møter i sin hverdag skal se og anerkjenne at de er «vanlige barn» for å kunne føle seg inkludert. Når barna i denne studien gis muligheter og innflytelse til selv å kunne utforme sin hverdag i samarbeid med andre, vil de i større grad kunne bruke sine evner og ressurser til å tilpasse seg sin livssituasjon.

Contents

ARTICLES 1-4
APPENDIX

Abstract

The aim of this thesis was to obtain knowledge about the everyday life experiences of some Norwegian children with disabilities who were in a transitional phase between primary and secondary school. This thesis is a part of broader inter-professional research project at Oslo and Akershus University College of Applied Sciences researching children`s participation and professional practice. This research group used purposive sampling to recruit children, parents and school personnel to participate in the study. Altogether, they interviewed 15 children, their parents (mother, father or both), nine teachers and three school aides. The researchers used a life mode interview design to elicit their experiences. They interviewed the children over time and conducted between one and four interviews with each of them. During the same period, they interviewed their parents and school personnel once or twice each. For the purposes of this thesis the data analysis focused on the children`s own experiences of everyday life. Research questions related to their perspectives were operationalized through four themes, which are presented in four papers. 1) “Friendships in all directions” -- How Norwegian children with physical disabilities experience friendship; 2) "Being an ordinary kid"-- demands of everyday life experienced by children labelled with disability; 3) How children with disabilities engage in activities during a transitional phase, 4) Inclusion and participation in everyday school life: experiences of children with physical disabilities. The conclusion of this thesis is that the children who took part in this study live active lives; they have a variety of interests, take part in a range of activities and form many different kinds of relationships. These children are influenced by and adapt to the many norms and expectations of what is considered “normal” in everyday life. Consequently, they want their friends, school personnel and other people they encounter in the course of this life to view them as “normal” and treat them like “mainstream” children. If these children are given opportunities to help shape their everyday life experiences in collaboration with others they will use the many abilities they possess to adapt to their life situation, responding to both challenges and opportunities.

Acknowledgements

This thesis and my own interest in the field have developed over many years of work experiences and encounters with children and their parents as an occupational therapist and now as an assistant professor in the Department of Occupational Therapy at Oslo and Akershus University College (OAUC). My first work experience as an occupational therapist was at the Trondsletten Rehabilitation Center, from 1987 to 1994, which I remember with gratitude. After moving to Drøbak, Akershus in 1994, I continued my work in rehabilitation services through community work in Ås. As a professional, I often met children in a medical and institutional context; these encounters also informed my knowledge of the subject. Since the year 2000, I have been employed at OAUC, where my primary responsibility has been teaching occupational therapy students about children, disability and participation in everyday life. My initial experience in research came through a Master's program in which I had an opportunity to interview children with a variety of diagnoses and related challenges. These encounters proved to be both interesting and inspiring. My PhD research offered an opportunity to deepen my investigation and knowledge of children`s everyday life experiences when living with impairments. I was fortunate to get the opportunity to follow up my research interest in collaboration with the multidisciplinary project "Talk with us": Children`s participation and professional practice.[1] This interdisciplinary research group was established in 2005 at Oslo and Akershus University College of Applied Sciences.[2] Liv Mette Gulbrandsen initiated the project and has served as its principal director. Based on their shared interest in "children`s participation and professional practice," the participants divided themselves into research groups on different aspects of this theme. This particular study was further developed in one of these research groups, which in addition to me included my co-researchers, Bennedichte Rappana Olsen and Kari Opsahl, as well as my supervisor at Oslo and Akershus University College, Sølvi Helseth. The latter is one of my two co-authors in the four articles attached to this thesis.

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[1] Professional Practice and Children's Participation, "Talk with us" is a six-year interdepartmental project at the Oslo and Akershus University College Health, Care and Welfare (HOV) research program on the participation of children with disabilities in everyday life activities and relations, and in professional practice related to child welfare and rehabilitation. The goal of the project is to develop professional expertise that includes and supports children's participation.

[2] Professor of Psychology, Oslo and Akershus University College of Applied Sciences, Faculty of Social Sciences, Department of Social Work, Child Care and Social Policy.

I would like to thank my advisors Sølvi Helseth and Gunn Helene Engelsrud. Sølvi and I started out on this project in 2005, based on our common interest in children`s participation. I have benefited greatly from the knowledge and steadfast support that both she and Gunn have provided. I am also grateful to Liv Mette Gulbrandsen for her advice on choosing a research design and her support and extremely valuable supervision throughout this entire process, as well as for all the stimulating, challenging experiences and social events that we have shared. I would also like to thank the colleges at Trenings and Rådgivnings-sentret (TRS) at Sunnaas Hospital, which first introduced me to this field of research.

Kari Opsahl and Bennedichte Rappana-Olsen, my co-researchers on this project, have enriched this thesis through their contributions of empirical material and discussions. I am also grateful to the research group/PhD students in my PhD Program at Norges Idrettshøgskole and at Høgskolen i Oslo and Akershus for giving me opportunities to discuss my work, as well as for sharing their knowledge, care, and humor with me.

I am grateful to Mona Dahl at the Department of Occupational Therapy and Nina Waaler at the Faculty of Health at Oslo and Akershus University College, who believed in the project and supported me from the start. I would also like to thank my colleagues at the Department of Occupational Therapy. Special thanks to Kari Opsahl and Grete Alve, whose willingness to discuss relevant theories and ideas was invaluable. Simply for being there – as well as for providing thoughtful comments, humor, feedback and support -- I am grateful to my colleagues Cecilie Krüger, Dorte Lybye Norenberg, Mali Melhus, Vigdis Holmberg, Tore Bonsaksen, Brian Ellingham, Kjell Emil Granå, Lena Andersson, Else Britt Bruseth, Lisebet Skeie Skarpaas, Anne Lund, Gunvor Lilleholt Klevberg, Jorid Grimeland, Unni Sveen, Goro Skou, Ratna Hussain, Kari Weum, Helen Bull, Ingvild Kjeken, Randi Wågø Aas, Irma Pinxsterhuis, Ellen Gabrielsen Hjelle and John Erik Berg. Halvor Hanisch, Hilde Sylliaas and Tone Dahl-Michelsen - I thank you for interesting conversations, valuable advice and support. I am also grateful for support and encouragement from my colleagues at NMBU, Ruth Kjærsti Raanaas and Grete Patil.

This dissertation is part of the project "Talk with us": Professional practice and children`s participation. The entire research group has been extraordinarily important to me. I am grateful to all of them: Liv Mette Gulbrandsen, Sissel Seim, Oddbjørg Skjær Ulvik, Karin Haarberg Aas, Kari Opsahl, Bennedichte Rappana Olsen, Kari Sjøhjelle Jevne, Emad- Al Rozzi, Pernille Skotte, Mari Dahlen Herland, Ingeborg Marie Helgeland, Ingvil Øien, Bjørg

Fallang, Sigrid Østensjø and Sølvi Helseth. I give special thanks to Wenche Bekken for her support, encouragement and valuable discussions all these years.

I would like to thank Kristin Røijen, Andrè Bialk and Anett Kristin Kolstad at the library for their courteous and helpful service. I am also grateful for the expert feedback from my peer reviewers, who have been of great help in validating the published articles that have emerged from this study.

Family and friends have been important contributors to this thesis, providing social breaks and personal support. I thank my daughters Ida and Anna, the most important people in my life; and Lotte, the most adorable addition to my family. I am grateful to Magne and my mother Kari Bakke Asbjørnslett. My closest friends -- Anne Schäffer, Laila Ryen, Bente Arnesen, Nina Levin, Grete Korbi, Grethe Haga Jensen, Elin Jensen Langaard, Trude Mathiesen, Tone Kjenstad, Kirsti Gjeldnes, Eli Lang- Ree, Sara Strøm and Hege Schive Dahl– all provided valuable support.

Finally, and most importantly, I would like to thank all the children, as well as their parents, teachers and school aides, who participated in this project with so much generosity and interest. My special thanks go to the children. The knowledge they have shared with me has been the most vital contribution to this project. It’s a cliché, but I have been deeply impressed by their insights into their life experiences, their bravery and their wisdom. This study is, above all, a tribute to them.

1 Introduction

This thesis is concerned with the everyday life experiences of Norwegian children with disabilities. This concern is consistent with a general argument and assumption that our knowledge of the everyday life experiences of children, whether viewed from a social level or seen from their own world and context, has been both limited and undervalued (Greene & Hill, 2006; Corsaro, 2011; Scott, 2008). A related argument is that childhood and children`s lives have been explored solely from the perspectives of their caretakers, who claim to speak for the children (Christensen & James, 2008). Both of these arguments reflect an increasing recognition that children`s views differ from those of adults. Consequently, in recent years research focusing on children`s own experiences and exploring their own perspectives has increased (Sloper & Beresford, 2014). This research is based on a recognition that the perspectives of children are not only important, but should influence arrangements of their individual situations, as well as the formation of school, community and social policy. This requires their collaboration in many different situations in everyday life contexts.

Children`s perspectives are to a great extent influenced by their participation in everyday life, including school and leisure time activities, and usually linked to their local community. Among children with disabilities, research shows that particular challenges -- for example, access to common activities meant for all children, and the practices and attitudes they encounter while taking part in these activities – have a significant effect on their participation in everyday life. Their perspectives and experiences have particular significance for assisting them in meeting any challenges that participation entails, but also in revealing their abilities and potential. Consequently, understanding disability and impairment from a children`s perspective can benefit professionals in the children`s local environment and (re)habilitation process who encounter, view and collaborate with them and wish to take their perceptions into account. This is also consistent with the argument of Garth & Aroni that knowledge derived from a children`s perspective can contribute to creating a more accurate evidence basis for clinical practice, as well as better policy (Garth & Aroni, 2003). In an attempt to develop a deeper understanding of children`s perspectives, this research project was designed to elicit their experiences and clarify their significance.

1.1 Purpose of this study and research questions

The purpose of this study is to develop knowledge of the everyday life of some children with disabilities during their transitional phase between primary and secondary school by exploring;

- How these children engage in and adapt to everyday life demands, relations and activities during this transitional phase
- How the perspectives of these children can contribute to the field of knowledge in disability research

1.2 Context of the study

The context of this study is the transitional phase between primary and secondary school. In their everyday life, the children in this study participate with other children and adults in their local communities, particularly in school and leisure time activities. For children, everyday life is the most significant context for experiences. It is regulated by their individual engagement and meaning, as well as social and cultural meanings that influence them in their specific environments, including the attitudes and expectations of the children themselves and of others. The influences and determinants of the everyday life of children with disabilities also include political and international guidelines, legislation and conventions, all of which reflect broader social and cultural perspectives. In illuminating the perspectives of these children on their everyday life experiences, this thesis presents four papers:

1.3 List of papers

1. Asbjørnslett, M.; Engelsrud, G. H. & Helseth, S.(2011). "Friendship in all directions": Norwegian children with physical disabilities experiencing friendship. *Childhood* (19) (4), 481- 494. DOI:10.1177/0907568211428093
2. Asbjørnslett, M.; Helseth, S. & Engelsrud, G.H. (2013). "Being an ordinary kid"--demands of everyday life when labelled with disability. *Scandinavian Journal of Disability Research* .16 (4), 364-376. DOI:10.1080/15017419.2013.787368.

3. Asbjørnslett, M.; Engelsrud, G.H. & Helseth, S. (2014). How children with disabilities engage in occupations during a transitional phase. *Journal of Occupational Science.* DOI**:**10.1080/14427591.2014.952365
4. Asbjørnslett, M.; Engelsrud, G.H. & Helseth, S. (2014). Inclusion and participation in everyday school life: experiences of children with physical (dis)abilities. *International Journal of Inclusive Education,* 1-14. DOI:10.1080/09687599.2010.505744

1.4 Structure of the thesis

Chapters Two through Six constitute the body of this thesis. In Chapter Two, I offer a literature review and a summary of what is known about children with disabilities and their everyday life based on research eliciting their own experiences, as well as the perspectives of their parents and caretakers. I also describe how children with disabilities see themselves in relation to others and discuss their own understanding of disability and impairment.

In Chapter Three, I provide a broader socio-cultural understanding of children`s everyday life and elaborate on the themes presented in the four papers. I introduce current theory and guidelines of participation and inclusion in society and offer some reflections on the contemporary understanding of children as “beings” and agents in their own lives. This perspective is crucial to how professionals in institutions like schools or in community and (re)habilitation services meet and collaborate with children. The chapter also introduces several different understandings of disability and impairment that I believe are relevant to children`s participation in various aspects of everyday life -- education, community life and relationships. This chapter also discusses key legislation and rights concerning participation, inclusion and non- discrimination in society for people with disabilities.

Chapter Four outlines the research material and qualitative research approach and methods applied in this study. It also describes how the study was planned, performed, analyzed and completed. First, it explains the life mode interview design, the primary method used in this study for interviewing children. It then discusses the participants in this project and the interpretational process I used in in creating and analyzing the material, including my own research position, experiences and learning process. This description of the analytic process also describes my process of analyzing the text material and writing articles together with co-authors. I also consider and discuss the ethical and methodological considerations associated with this research process.

In Chapter Five I list the research questions following each paper and provide a brief synopsis of all four, as well as a summary of the main findings of the study.

In Chapter Six I discuss some of my main findings concerning children with disabilities and their participation in everyday life, drawing on the literature review and theoretical perspectives presented in this thesis. I also explore how disability and impairment can influence the everyday life of these children and consider the implications that this study might have for current practice and further research. In the conclusion of this chapter, I offer an argument for the importance of this study and final thoughts.

2. The everyday life of children with disabilities; literature review

The aim of this literature review was to systematically examine relevant published articles exploring the everyday life of children with disabilities. Specifically, we addressed two questions: How do children perceive their everyday life experiences? How do parents and school personnel consider and understand the everyday life situation of children with disabilities?

2.1 Procedure

The review considered studies based on children`s accounts of their own experiences, primarily interview studies. It also included explorations of the everyday life of children with disabilities from the perspectives of parents and school personnel, based on a variety of research designs -- observations and/or interviews with parents and/or teachers, and assessment scales. The literature that was perused was published in the Nordic countries, the UK, Australia and the US.

Language: English

<u>Inclusion criteria</u>

All of the relevant quantitative and qualitative peer-reviewed articles published in scientific journals in sociological fields, including disability and disability research, as well as in health and medicine was reviewed. The articles included focused on children with physical disabilities/impairments and learning disabilities/impairments in primary and/ or secondary school. The issues they investigated included social participation/inclusion at school and in learning activities, social participation with peers/friends (with and without disabilities) in the community and other contexts, and disability from the perspective of the children themselves.

<u>Exclusion criteria</u>

The literature review did not include articles concerning children with severe disabilities, rare disorders, autism, asthma, mental health, Attention Deficit Disorder and Hyper-activity (ADHD), developmental disabilities, deaf children, preschool children, special school education and rehabilitation; articles from Asian and African countries; articles focusing on skill-training or specific health care and (re)habilitation intervention programs; or articles published more than 10 years ago.

Search strategy and results

A systematic search using the following six databases was conducted:

International databases:

- Educational Resource Information Clearinghouse (ERIC). Covers pedagogy, school-related research on children`s participation in everyday life and at school and inclusion/exclusion at school.
- Psychinfo, covers psychiatry and psychology, behavioral sciences and mental health
- SocIndex. Covers sociological studies, including children`s social participation with friends, local participation and leisure-time activities
- Occupational Therapy (OT-seeker), covers occupational therapy literature
- Medline. Covers medicine and nursing, as well as health-related issues

Nordic database:

- Svemed+ (Karolinska Institutet). Covers Nordic journal articles in medicine, odontology, nursing and physiotherapy

The search was conducted in ERIC and PsycInfo, Medline, SocIndex and OT-seeker using a combination of subject headings from a controlled vocabulary and self- selected keywords. The databases have different controlled vocabulary e.g medical subject headings (MeSH) in Medline and Thesaurus in Eric. In the international databases it was conducted a systematic search. In smaller databases e.g Swemed+ and Norart some of the controlled vocabulary and the key words were used, but without the same systematic combination.

The search in the databases was conducted systematically like this:

Eric

(Children/ thesaurus) OR child* AND (disabilities/thesaurus) OR severity of disability/ thesaurus) OR disability* OR severit* AND (social integration/ thesaurus) OR social integration* OR social particip* OR social inclusion* OR life satisfaction/ thesaurus OR life satisfact*

The searches resulted in 215 articles. The procedure was repeated in the following databases; Psychinfo, SocIndex and OT- seeker. The searches in Psychinfo generated 91articles, the searches in SocIndex resulted in 38 articles. In addition the search in OT- seeker identified 70 articles with themes related to the terms children, disability and participation. In line with the exclusion criteria, articles that did not accommodate with the issue, age and diagnostic relevancy and were not included

Medline

(Disabled children/MeSH OR disabled child* AND (social participation/MeSH OR leisure activities/ MeSH OR friend/MeSH OR interpersonal relations /MeSH OR social identification/MeSH OR everyday life OR social integration* OR social identificat* OR social participat* OR social inclus* OR leisure activit* OR friend*) AND (adaptation/MeSH OR personal satisfaction/MeSH OR adapt* OR experienc* OR life satisfact* OR personal satisfact*. This search resulted in 319 articles.

Selecting the literature

The analysis of the literature focused on three themes and areas of inquiry: friendship and children with disabilities/disabled children; children with disabilities, self-identity and self-awareness; participation at school of children with disabilities/physical impairment/Special Educational Needs. 46 articles were selected and found relevant for this review.

Table 1. Overview- selected literature

References	Type of study	Nationality	Disability/ diagnosis	Number of participants (age)
Almqvist & Granlund, 2005	Questionnaires	Sweden	Disability	472 children (7-12 and 13-17), 103 special educational consultants, parents, teachers
Antle et. al., 2009	In depth interviews with parents & youths	Canada	Spina bifida	21youth (9-15) and 21parents
Bedell et al., 2013	Cross sectional, descriptive & exploratory	US & Canada	Disability	576 parents of children (5-7) with (n=282) and without (n=294)disabilities
Asbjørnslett & Hemmingsson, 2008	Focus group, individual interviews	Norway	Physical disabilities	14 children(13-18)
Bourke & Burgman, 2010	Interviews	Australia	Disability	10 children (8-10)
Connors & Stalker, 2007	Interviews	England	Disability	26 children (7-15)
Curtin & Clarke, 2005	Interviews	Australia	Physical disability	9 children (10-13)
De Schauwer et. Al., 2009	Interviews, observations	Belgium	Disability	15children (5-17)
Egilson & Traustadottir, 2009	School Functioning Assessment; observation	Iceland	Physical disability	14 children (6-12), 17 parents, 18 teachers
Eriksson, Welander & Granlund, 2007	Comparing observations between children with and without disabilities, interviews	Sweden		66 children, 33 with disabilities and 33 without disabilities
Estell et al., 2009			Learning disabilities	55
Fitzgerald & Stride, 2012	Interviews	United Kingdom	Disability	3 (12,13,13)
Gantschnig et al. 2011	Qualitative design; Interviews	Austria	Physical and cognitive disabilities	5 (8-12)
Harding et al., 2009	Case study, semi-structured interviews, assessment Out of School Time (OST)	Canada	Disability	6 children (8-13)
Heah. et al, 2007	Semi-structured interviews	Canada	Physical disability	8 children/8 parents
Hughes et al., 2013	Literature review			
Imms, 2008	Literature review		Cerebral palsy	
Khadka et al., 2014	13 focus groups	England	Visual impairments	81 children (5-18)

King et al., 2010	Longitudinal design: Home interviews and self-administered standardized questionnaires.	Canada	Physical disability	426 families/ 229 boys/ 198 girls (age 6-8, 9-11, and 12-14)
Koster et al., 2009	Literature review			
Lindsay & McPherson, 2012	Group discussion	Canada	Cerebral palsy	15 children
Lowe & Chapparo, 2010	Survey, written open-end response questionnaire	Australia	Disability/difficulty with learning	50 teachers, 44 parents
McArthur & Sharp, 2007	Ethnography	New Zealand	Disability	7 children (11-14)
McArthur, 2013	Examples from research case studies, ethnography and action research	New Zealand	Disability	11 children (7-15) + teachers and family
McCoy & Banks, 2012	Survey, interviews, children, parents (growing up in Ireland- study)	Ireland	Special educational needs	8578 (9 year olds)
McMaugh, 2011	Interviews	Australia	Physical disability or chronic illness	24 children (mean age 12.4)
Morrison & Burgman, 2009	Interviews	Australia	Disability	10 children (8-10)
Mundhenke et al., 2010	Interviews	Sweden	Physical, intellectual or neuro-psychiatric disability	33 children (7-13)
Raghavendra et al., 2013	Multi-method	Australia	Disability	18 children (10-18)
O`Rourke & Houghton, 2008	Measurement-- The Student Perception of Classroom Support Scale	Australia	Mild disability	60 children (8-12)
Rutherford, 2012	Semi-structured meetings with children and aides	New Zealand	Disability	10 children (8-17) 18 aides
Seymour et al., 2009	Semi-structured interviews, children with and without disabilities	Canada	Physical disability	8 children with disabilities(9-13) 8 children without disabilities (9-12)
Shah, 2007	Interviewing	England	Disability	30 children (13-19 and 16-25)
Schenker et al., 2005	School Function Assessment	USA		
Shikako- Thomas et al., 2009	Children`s assessment of participation and enjoyment (CAPE)	Canada	Cerebral palsy	63 children (mean age 9.7)
Spencer-Cavaliere & Watkinson (2010)	Semi-structured interviews, field notes	Canada	Disability	11 (8-12)
Stewart et al., 2012	Semi-structured interviews	Canada	Cerebral palsy	10 adolescents (17-20)
Svendby & Dowling, 2012	Narrative design, interviews	Norway	Disability	10 children (age 10-19), 16 parents, 6

				teachers in physical education
Sylvester et al., 2014	KIDSCREEN, measure	Scotland	Disability	91 children (5-18)
Ward, A., 2010	Narrative interviews, children, parents, siblings	New Zealand	Disability	4 children
Wendelborg & Kvello, 2010	Longitudinal design, questionnaires	Norway	Disability	85 children (11-13) and parents
Wendelborg & Tøssebro, 2010a	Interviews and questionnaires	Norway	Disability	Parents of 26 children
Wendelborg & Tøssebro, 2010b	Survey, parents and children	Norway	Disability	
Wendelborg & Tøssebro, 2011	Survey, parents of children with disabilities	Norway		262 parents
Woolfson et al., 2007	1) Questionnaires 2) 5 focus groups	Scotland	Multiple disabilities	1) 290 children (9-14), 2) 30 children (10-13)
Ytterhus, 2012	Qualitative Longitudinal fieldwork	Norway	Disability	1)56 children, 9 disabled (3-7), 2)100 children, 7 disabled (9-12), 3)120, 8 disabled 13-16)

My summary of this selected literature first examines perspectives on friendships and peer-relations, focusing primarily on topics the children themselves considered significant. It will then introduce perspectives on social participation and inclusion in general everyday life situations. I then look at what the articles contain concerning children`s self- identity and awareness of disability in everyday life, particularly at school. Finally, I will present perspectives of children with disabilities related to their participation and inclusion at school.

2.2 The everyday life of children with disabilities

The everyday life of children is embedded with both individual and social significance, as well as a desire to be with peers and have “best friends.” From a children`s perspective, best friends care about each other and show concern; they listen, encourage and do not ignore you (Seymour, Read & Bloom, 2009). Best friends look beyond disability and show acceptance of who you are, including “differences” such as being in a “walker” or doing things differently (Seymour et al., 2009). Like any other children, those with disabilities long for close and long-lasting friendships and like to spend a lot of time with their friends (Morrison & Burgman, 2009; Bourke & Burgman, 2010; Seymour et al., 2009). They enjoy and engage in activities like “hanging out,” going to the movies and communicating on the phone or computer (Seymour et al., 2009; Stewart et al., 2012). Friends also connect by visiting each other’s houses, or by participating together in organized sports or other activities (Seymour et al., 2009; Bourke & Burgman, 2010). As doing things together indicates, strong friendships are often based on similar interests, engagement in shared activities, but they may also be based on a shared sense of humor and shared academic goals (Seymour et al., 2009; McMaugh, 2011). Online friends have also begun to play an important role in everyday life, as evidenced by positive experiences related by Australian children with disabilities who used the Internet, including Facebook and Twitter, to facilitate social participation (Raghavendra, Newman, Grace & Wood, 2013).

For children with disabilities, friends who care and actively express their caring play an important role in protecting them from being “othered” in everyday social life. Being “othered” can include enduring comments on looking “different” by using adaptive equipment such as a wheelchair, and sometimes overt bullying (Seymour et al., 2009; Morrison & Burgman, 2009; McMaugh, 2011; Lindsay & McPherson, 2012). These children are also vulnerable to confronting physical barriers that can hinder their ability to socialize with peers, such as limitations on physical access to each other’s houses and barriers in the school environment (Seymour et al., 2009; Ward, 2010). In some cases, these children lack sufficient funds to engage in the same activities as their peers. One reported consequence is a sense of sadness that comes from lack of friendships and an inability to engage in social activities with other children (Sylvester, Donnell, Gray, Higgins & Stalker, 2014). As suggested above, friendships are complex and establishing strong relationships can be challenging (Antle, Montgomery & Stapleford, 2009).

In everyday social life, children with disabilities typically self-identify with other children and often describe themselves as similar to their peers – “like all the other children” and “being like everybody else” (Connors & Stalker, 2007; MacArthur, Gaffney & Sharp, 2007; Mundhenke, Hermansson & Nätterlund, 2010). They also want to be ”treated” like anyone else (Antle et al., 2009). A key point is that for these children, their abilities, capacities and interests rather than just their difficulties or disabilities play a huge influence on determining their lives (De Schauwer, Van Hove, Mortier & Loots, 2009). At the same time, these children are aware of their limitations, differences and challenges although they tend to view them as manageable and are confident that they can meet the challenges they face in everyday life (Shikako- Thomas et al., 2009; Gantschnig, Hemmingsson & La Cour, 2011). Even so, they are considered more vulnerable to non-participation than “mainstream” children, and run a greater risk of social isolation and less frequent participation, than peers without disabilities (King, Law, Hurley, Petrenchik & Schwellnus, 2010; Bedell et al., 2013). In the study by King et al. (2010), the authors concluded that children with disabilities participated in significantly fewer physical, social and skill-based activities than their peers. When they did join in, it was with less intensity. This is also supported by the study of Bedell et al. (2013), reporting that children with disabilities get less social support and participate less in social activities than their peers.

It has been argued that children with disabilities believe participation in everyday life means being where things “actually happen” – meaning, they want to be together with the other children and engage in the same activities (Asbjørnslett & Hemmingsson, 2008). It has also been argued that the perception of social acceptance and peer intimacy strongly depends on the child’s social participation with peers during leisure time (Wendelborg & Kvello, 2010). To achieve this in a particular activity, ability to engage in it and social support are both important (Mundhenke et al., 2010). Successful participation in everyday life activities includes experiences of fun, well-being, doing the same things as others and being with others, but also doing things independently, as well as participating without assistance (Heah, Case, McGuire & Law, 2007). When children are afforded opportunities to participate in valued activities that they choose themselves and join in with supportive friends and/or family, their quality of life is enhanced (Shikako-Thomas et al., 2009). Their participation is also facilitated by accessible buildings, mobility aides, assistive devices and social support from friends, family and their school -- including the ability to make choices in school, such as getting help only when they ask for it (Stewart et al., 2012). Family support is also crucial -- assistance with dressing, for example, or driving the child to activities (Antle et al., 2009). The most significant barriers to participation are environmental, such as restricted physical access to buildings and mobility, including transportation (Shikako-Thomas et al., 2009; Stewart et al., 2012). In addition to restricted physical access, children with cerebral palsy frequently experience attitudinal barriers in recreational, educational and social domains (Imms, 2008; Stewart et al., 2012). These attitudes also intensify feelings of sadness in some children, especially when they cannot participate with their peers, either in school or elsewhere (Mundhenke et al., 2010).

Participation at school holds particular significance in the organization and experience of children’s everyday life. The importance of being part of a regular school life has been reported in a study from Austria (Gantschnig et al., 2011). At the same time, for children with disabilities, inclusive education provides many opportunities as well as challenges. In a study by Almqvist & Granlund, a high degree of participation correlated with high scores on autonomy and perceived interrelationship with peers and teachers, as well as an internal locus of control (Almqvist & Granlund, 2005). Feeling and being involved with the others, as well as mastery of scholastic activities facilitate sense of participation at school (Gantschnig et al., 2011). A similar conclusion was reached in the study by De Schauwer et al. (2009). The children reported that they preferred doing things their own way as much as possible. Such studies suggest that inclusive education for children with special educational needs should be based on three concepts: friendships/relationships, interactions/contacts and classmate perception and acceptance of the pupil (Koster, Nakken, Jan Pijl & Houten, 2009). At the same time it is necessary to acknowledge some children`s need for an individual approach to learning (O`Rourke & Houghton, 2008).

In everyday school life, particular challenges have been identified in learning new activities, which children with disabilities can find difficult and time consuming. They may also tire easily, experience pain and have difficulty completing schoolwork -- a challenge that occasionally leads to disengagement or withdrawal (Woolfson, Harker, Lowe, Sheilds & Mackintosh, 2007; Egilson & Traustadottir, 2009). Some children with visual impairments have reported enjoying a lifestyle similar to their classmates’, but they also encounter more restrictions in various activities – reading, for example -- which some of them may then try to avoid (Khadka, Ryan, Margrain & Woodhouse, 2014). When they are viewed as “different,” some children have reported that their impairment can generate taunts or bullying, leaving them feeling rejected and worthless (Shah, 2007; MacArthur et al., 2007; Bourke & Burgman, 2010). The problematic of being treated and viewed as “an outsider” in social situations can also lead to a sense of loneliness (MacArthur & Sharp, 2007; De Schauwer et al., 2009).

Children report that they dislike structures that make them feel “different” at school, rather than full social participants. Examples cited include withdrawal from class for specialist support and teachers’ aides who sit too close and restrict their “space” to be part of their class or with peers (Curtin & Clarke, 2005; MacArthur, 2013). Other studies support that working in groups support positive social outcomes (O`Rourke & Houghton, 2008). The role of school aides in supporting children`s participation is complex and sensitive. Children depend on some help, but believe that having a school aide “sitting beside” them can be a hindrance to social participation (McArthur et al., 2007). Some children express frustration that they are not getting enough support from school aides, while others perceive that their aides’ help is not a support to learning, and sometimes actually interferes with it (Shah, 2007). Similarly, children in a Swedish study complained that some school personnel have only limited knowledge and understanding of how having a disability can affect their schoolwork (Mundhenke et al., 2010). At the same time, many children rely on extra support. Some researchers have found that when teacher`s aides are available in classroom situations and do not provide more support than the child desires, the results can be positive (Rutherford, 2012).

Some children have said that they are uncomfortable receiving extra support and adaptations because their classmates react negatively (De Schauwer et al., 2009). Thus, although adequate access to a shared curriculum is very important to these children, they want to minimize modifications that make this possible (Woolfson et al., 2007). The transitional phase between primary and secondary school can bring particular challenges in this regard.

Many of these children also reported that being labeled as requiring “special education” associates them with “others with impairments” and threatens their sense of inclusion in the broader school community (McArthur, 2012). That children with special educational needs are more likely to dislike school compared with their peers is reported as a problem for inclusive education (McCoy & Banks, 2012). Similarly, some researchers have suggested that special education arrangements in which teacher aides take children out of the classroom may hinder their social participation with peers and reduce their classroom participation (Wendelborg & Tøssebro, 2010a). These researchers have expressed concern that children with intellectual disabilities in particular can miss out on the social benefits of classroom participation available to their peers (Wendelborg & Tøssebro, 2011). Their study also found that the amount of special education provided in Norwegian primary schools expands significantly as children become older (Wendelborg & Tøssebro, 2010 b). This leads to their increasing marginalization, according to some parents (Wendelborg & Tøssebro, 2010a).

Researchers in Sweden report that children with disabilities are at risk of lower participation in structured and unstructured activities than other children (Eriksson, Welander & Granlund, (2007). They also had fewer friends and rated their autonomy lower (Eriksson et al., 2007).

School participation of children with disabilities can also be hindered by the institution's social and physical arrangements. Unstructured activities such a recess soccer games can present particular challenges (Egilson & Traustadottir, 2009). Even structured physical education can produce anxiety and trepidation. In some instances, children have described feeling conflicted about whether to do their physical education with an aide instead of with their class (Fitzgerald & Stride, 2012). Children with disabilities also experience segregation or other forms of alienation in physical education. It has been suggested that they feel that they are malfunctioning and lack "ability" in this area (Svendby & Dowling, 2012). In a physical activity means having a sense of belonging, acceptance and peer support is essential to feeling included. The children in one study explained that they get this when they encounter a welcoming attitude, and positive gestures by other participants -- for example, being asked to join in play (Spencer-Cavaliere & Watkinson, 2010).

The review of the literature revealed that going from primary school to middle school is particularly challenging for children with special educational needs (SEN) due to learning difficulties. They believe that after they make this transition they will be receive reduced social support and suffer greater peer victimization than other children (Hughes, Banks & Terras, 2013). Children with intellectual impairments are often marginalized in this phase of childhood. In fact, peer interactions are typically most fraught with difficulties during the years from 10 to 14 for children in general, according to a Norwegian study (Ytterhus, 2012). Junior high school has different structural practices; the social context of schooling and individual beliefs of teachers and peers lead to new everyday attitudes (McMaugh, 2011). Sometimes, the principal problem for children with an intellectual disability is a failure to grasp the nuances in implicit rules governing social relations, which increase in the teenage years (Ytterhus, 2012).

Children`s participation and individual needs have also been explored from the perspective of institutional collaboration. In one study, the researchers found that children with disabilities complained that teachers made decisions about their participation without consulting them and isolated them from their peers during physical education (Khadka et al., 2014). In another, the authors concluded that teachers often fail to seek the views of the students on how much support they need, simply assuming that the level provided was adequate and appropriate. The children themselves expressed a strong desire to have a say in the amount and type of help they received (Woolfson et al., 2009).

2.3 The literature review; summary

Researchers have explored the everyday life of children with disabilities in numerous studies, noting a variety of perspectives and results, opportunities and challenges. Nonetheless, they tend to agree that for children with disabilities, participation means being with friends and peers and doing things together with them. Positive friendships play a significant role in the mutual interactions and shared interests that these children engage in, both at school and in their local environment. Supportive friends also provide protection from the bullying and "othering" that children with disabilities sometimes experience. However, how qualities of friendships influence children with disabilities and how they adapt to different friendships in everyday life, including how it changes in transitional phases in everyday life appear as a knowledge gap and can be better explored.

Children with disabilities self-identify with other children and describe themselves as "similar" to other children. Typically, they do not problematize their situation – they tend to view it as manageable. At the same time, physical and other challenges inevitably constrain the participation of some children in a variety of activities; these barriers are frequently intensified by negative attitudes in their peer group and lack of support in the environment, including at school. How children with disabilities experience and adapt to their many everyday life situations, including their relationships with others and the challenges they encounter can however be better explored in research addressing disability and impairment in everyday life settings.

The literature review indicated that it is important for all children – with and without disabilities -- to be with differently abled peers and participate in activities with them based on shared interests. On the most fundamental level, participation means being part of the broader community. This literature review provides strong evidence that the prevailing concept of participation used to characterize how children with disabilities make choices and influence decision-making in school and rehabilitation programs is too narrow. Often, it leads to insufficient recognition of the abilities and desires of these children, as well as to a culture in which they have little opportunity to be heard and have a say in their situation. More positively, school professionals frequently view self-determination as an important value for children to learn and exercise. At the same time, it can be considered a gap in the literature using children`s experiences in examining how they prefer to take part in self- determination, in particular at school, also considering transitional phases in the school system.

3 Theory and frames of reference

This chapter presents this study's theoretical context, which is based on a socio-cultural perspective that incorporates a theory of children`s participation and inclusion. Frames of reference also include laws and declarations covering both social and individual aspects of children`s rights to participation, and in particular the rights of people with disabilities. This chapter also includes a discussion of the theoretical frameworks regarding disability and impairment that inform this study.

3.1 Children`s participation in everyday life

Theory of participation is a broad term, but generally refers to what people do and their relationships with others in everyday life. Social anthropologist Marianne Gullestad (1989) has observed that the term "everyday life" itself is a diffuse concept with many dimensions. She argues that two dimensions are most important: the daily organization of subjects and activities as a "life world" and as experience. The concept "life world" has been defined as the "lived everyday world" that can be described based on subjective experience (Kvale & Brinkmann, 2009: 29). Gullestad claims that experience connects everyday life with culture, defined as how reality, attitudes and symbols are interpreted in a particular society (Gullestad, 1989, p.18). Applying this definition to the perspective of children with disabilities, their everyday lives are typically organized around participation in school and leisure time activities, as well as spending time with their family and friends. Children`s subjective experience of the "lived world" has various dimensions, including experiences of a variety of attitudes expressed by the people they encounter in various social contexts. In line with Gullestad (1989) for children with disabilities, subjective reality as experienced and interpreted can be viewed as socio-cultural, varied, broad and comprehensive.

The premise of participation in activities and events in a particular social context and culture is naturally embedded within the concepts of everyday life and lived experiences. One way of understanding children's participation is that they take part in some type of social arrangements in arenas such as family life, leisure time activities and school (Kousholt, 2012). Although children`s participation in everyday life can be viewed from an individual and personal perspective, it is always subject to social and cultural influences, particularly those related to social activities. Mariane Hedegaard argues that even though participation can be viewed from the perspective of what children themselves find meaningful and important, it is always influenced by and linked to their particular environment and context (Hedegaard, 2012). As noted earlier, all children are both individual and social; they represent themselves in a broader context, and, William Corsaro suggests, based on their particular childhood experience – which, he observes, must be regarded as social. He extends this argument to assert that we need a "new sociology of childhood," recognizing that an understanding of children and childhood must focus on their interactions and collective actions (Corsaro, 2011).

Theory of participation and theory of inclusion are overlapping concepts. Participation means that children take part in an activity. Inclusion means that they have the abilities or opportunities they need or require to take part in everyday life and society on equal terms with their peers (Davis & Hill, 2006). For children to take part and be included, they must be social actors and active citizens. Social actors are individuals who contribute to a variety of everyday life settings and activities, and use their abilities to take action in them (Percy-Smith & Thomas, 2010). Sociologist Allison James dates the shift to viewing children as social actors to the 1970s, reflecting the changing awareness of children` s place and position in society during those years (James, 2009).

Another central tenet in contemporary theory regarding children`s participation in everyday life is the concept of children`s agency: viewing children as individual and social agents (Oswell, 2013). It has been suggested that participation is a precondition for children`s agency (Sancar & Can Severcan, 2010). Viewing children as social agents and subjects is a sharp departure from earlier conceptual frameworks that viewed children as a "category" or "object" (James, 2009). In the new framework, instead of being considered as "emerging adults," children are viewed as "being children," who represent and can represent their own childhood, including their own experiences of participation in everyday life. Thus, viewing children as agents presumes that they are individuals who interact socially with others and have the power to influence their own lives as well as the lives of others. Regarding children as social individuals challenges the assumption in traditional developmental psychology, exemplified by the work of Jean Piaget, that they begin as unsocial beings and gradually become social (Oswell, 2013). A related conceptual approach viewed childhood as "preparation for adulthood," rather than a stage of life that is social in itself (Corsaro, 2011). In contrast, the new socio-cultural perspective presumes that children are agents who can never be understood as autonomous; they must be considered in their broader context of power, structure and culture (Oswell, 2013; White & Choudhury, 2010).

As noted earlier, interdependency between people is a presumption for agency and children are in many ways influenced by their peers and friends -- and, in turn, influence them. Peers and friends are extremely important to children in their everyday life; children with disabilities make great efforts to use the abilities and capacities at their disposal to interact with peers in their local environment and other environments, such as the Internet. They consider friendships to be essential to social participation in everyday life – which, for them, involves contacts with other children of the same age (Ytterhus & Tøssebro, 2006). According to Ben-Arieh (2014) children`s friendships are regarded as being based on close, interdependent relationships, which are often freely chosen. Sometimes these friendships involve children with a shared history, in which case the friends are likely to have similar levels of power. Such friendships are voluntary, which can make them both hard to establish and fragile (Asher, Guerry & McDonald, 2014). Even though friends may be considered to have more or less equal power, they frequently involve members of a particular group that plays a strong role in child culture, such as a football team or class (Corsaro, 2009).

Throughout the world, the participation of children in society, as well as their use of time, have become more and more institutionalized. Their schedule is often organized and controlled by adults; school and schoolwork in particular absorb an increasing number of years in children`s lives (Qvortrup, 2008). Schools and other institutions largely organize how and what children do, influence children`s relationships with others (both children and adults) and without doubt influence the agency of children (James, Jenks & Prout, 2012). Schools, for example, can facilitate children`s agency in learning by doing (Oswell, 2013) and ensure that the professionals who work in them listen to children with disabilities, learn from them and take their perspectives seriously. As a precondition for children to have an impact on themselves and others, agency is also encouraged when children are given the power to act -- for example, by playing an active role in determining school policy or the shaping of other institutions in which they participate (Oswell, 2013). At the same time, schools are strongly influenced by normative ideals of what and how to learn, and children are assessed based on this understanding. They are expected to conform to institutional standards and fit the “ideal” that allows the school structure and organization to function as effectively as possible (Oswell, 2013). One consequence is that some children receive segregated education, which carries an implicit message that they require treatment that is “different” from what children considered “mainstream” receive. Recognizing the value of inclusion, a Norwegian government report recommended that it should replace special education wherever feasible, and be supplemented by individual approaches and adaptations to meet each child’s needs (Kunnskapsdepartementet, 2003). The report was based on the premise that participation and inclusion are the ideal, and all children should be together at school as much of the time as possible. This is in line with a clear connection that children`s social participation is found to increases in line with their participation in the classroom together with peers (Engan & Tøssebro, 2006).

3.1.1 Children`s participation from a rights perspective

From a rights perspective, the ideal is that social participation should be inclusive to ensure that all people, including all children, feel that they are recognized as active participants in their society. This is a significant issue since many people with disabilities experience barriers to participation in society, but at the same time they are embedded with many opportunities (WHO, 2011). People’s rights to participation and principles of participation and inclusion must include full access to material, economic and physical conditions in society (Ridge, 2006; Read, Blackburn, & Spencer, 2012). In a society that takes a rights perspective, government officials, as well as professionals at school and leisure time and (re)habilitation services, have a particular responsibility to support inclusion by, for example, by ensuring that children with disabilities are able to participate fully in mainstream everyday life and being aware of potentially discriminatory policies or physical arrangements in institutions such as schools or in local communities. Children`s specific rights to participation, to enjoy life and be treated as active subjects, instead of passive objects are supported by the United Nations Convention on the Rights of the Child (UNICEF, 1989). Norwegian legislation and constitutional reports also clearly states that children are entitled to access to and equal opportunities for participation and self- realization in society and that they are legally protected from discrimination (Barnelova, 1981; Opplæringslova 1998, Diskriminerings- og tilgjengelighetsloven, 2008; NOU 2001:22). Thus, when children are not guaranteed the same opportunities as others, including access to shared spaces in their communities, they are at risk of experiencing a sense of social exclusion (Gallagher, 2006), not to say actual exclusion, from activities that are related to their interests or simply socially valued.

Equal participation and inclusion of all children from access to education at school are rights established in the UN Convention on the Rights of the Child, article 23 and 28 (UNICEF, 1989). The ideal of inclusive education and access to education for was also stated in the Salamanca declaration (UNESCO, 1994; Tøssebro, 2006). Norwegian legislation and governmental reports, meaning that they have the right to equal opportunities and facilitation of individual adaptation, responsibility, better inclusion and participation in learning programs and in society has also been secured and further developed (Meld. St. 18 2010/2011; NOU 2009: 18; Oppll, 1998). It has also been suggested for children`s future learning that communication and collaboration with other pupils in the classroom are central to their learning (NOU 2014:7).

The rights of children to participation can also be viewed from a broader perspective. Recognition of their rights to be heard has increased in tandem with the global attention to promoting children`s overall civil rights (Qvortrup, 2008; Read et al., 2012). Specifically, they should have an opportunity to be involved in making choices and decisions on matters that concern them -- for example, their educational and (re)habilitation programs. Involvement presumes that they are able to take part in decision-making processes (Sancar & Can Severcan, 2010; James et al., 2012) and have both the competence and the capacity to do so, including competence in the art of making judgments and the ability to orient themselves in a life situation (Hedegaard et al., 2012; Percy-Smith & Thomas, 2010; Strandbu, 2011). It stands to reason, then, that their rights to participation should also be respected when ground rules are being established for professional practices and research involving children (Ulvik, 2009).

In summary, children`s social participation in everyday life is based on both what they do and their relationships to other people. From a research perspective, children`s interests and engagement in what they do must be seen as embedded with social and cultural values. In research as well as in practice, understanding their participation and inclusion in everyday social life requires that they be viewed as social actors who take part in everyday life and as agents who play a part in their own life and the lives of others. From a rights perspective, children`s social and individual participation has been established in legislation and declarations that affirm their right of access to social spaces and to equal opportunities to participate in society. It is also based on their right to be heard in everyday life matters that concern children at school, for example, or in (re)habilitation services.

3.2 Disability in the context of children`s everyday life

Disability is a concept that appears in many different traditions, historical periods and mandates. Moreover, different societies and cultures view and understand it in a variety of ways. Thus, understanding children’s disability in contemporary society requires an understanding of how it is experienced in practice. In our society, the primary context in which disability has been viewed is medical. Disability theorists have offered considerable evidence that 21st century efforts to rebrand and relocate disability outside the body notwithstanding, it is still primarily viewed through the lens of diagnostic, individual medical conditions and issues (Depoy & Gilson, 2011; Siebers, 2011; L.Grue & Rua, 2013).

Tobin Siebers, a professor of English Language and Literature, has illuminated how the medical approach to disability frames it as a particular defect lodged in an individual; something that must be cured or eliminated before s/he can achieve full human capacity (Siebers, 2008). Similarly, disability scholar Dan Goodley argues that being engaged in disability through the gaze of medicalization is problematic because the neurological or psychological language and synonyms it employs have an inherent bias toward special education and rehabilitation sciences (Goodley, 2014). Other scholars have suggested that an individual, medicalised approach to disability implicitly equates it with “dependency,” suggesting that medical personnel should take “administrative control” over some people`s lives (Finkelstein, 1980; in Thomas, 2007).

Despite these criticisms, it is true that surgery and adaptations such as technical aids can make life easier for many children with disabilities. Some may benefit greatly from medical treatment. For many of them, (re)habilitation services are required to achieve the best possible functionality. Still, as Goodley suggests, medical thinking can limit our thinking and narrow our understanding of disability. In (re)habilitation services, for example, an individual understanding of disability puts children at risk of being perceived and treated as “objects” whose everyday life concerns are not accorded full attention in consultations (Bekken, 2014). Inclusive schools are another arena in which generally beneficial intervention can have negative consequences if the children’s perspective is not given the respect it merits. In an inclusive school system, children with “special needs” are given services that are often considered essential and beneficial to learning (Shakespeare, 2014). However, the concept of normative schooling can be problematic if it defines children as impaired through what Goodley refers to as labeling. He warns that a “hostile” attitude towards difference is still a significant danger in the school system (Goodley, 2011). As I have documented in this study, children with disabilities frequently find school norms and expectations challenging.

The critique of the medical understanding of disability began emerging in the 1960s, when American sociologists such as Erving Goffman (2000) and Roger Scott (1969) challenged what they referred to as stigmatization and discrimination against disabled people (Grue, L. & Rua, M., 2013). Based on this theoretical work, the British Union of Physically Impaired against Segregation (UPIAS) called in the 1970s for making a clear distinction between impairment and disability. UPIAS members campaigned for participation in society, as well as their right to independence and control over their life-situation (Tøssebro, 2010). Disabled Peoples International (DPI), a worldwide organization established in Canada in1981, issued a declaration echoing their position and making a clear distinction between impairment and disability:

> IMPAIRMENT is the functional limitation within the individual caused by physical, mental or sensory impairment
>
> DISABILITY is the loss or limitation of opportunities to take part in the normal life of the community on an equal level with others due to physical and social barriers
>
> (DPI, 1982)

Over the past three decades, the DPI movement has won widespread acceptance and helped shape global policies regarding children with disabilities and their families (Read et al., 2012). Its influence can be seen in the UN Convention on the Rights of Persons with Disabilities (UNRCPD) (UN, 2006), which establishes rights to dignity and participation in society, accessibility and independent community living (Read, Blackburn & Spencer, 2012). Many people with disabilities, disability scholars, researchers and politicians regard acceptance of the distinction between disability and impairment as an important step in reducing societal discrimination. Advocates of this position also point out that making a distinction between disability and impairment draws attention to the physical and social challenges faced by some members of society without denying the existence of bodily impairment, suffering or the need for medical treatment (Wendell, 1996; L. Grue & Rua, 2013).

The most prominent work exploring disability as a form of social oppression faced by members regarded as a minority group has been the British “social model of disability”

(Thomas, 2007). This approach was originally suggested by UK activist Michael Oliver, the first Professor of Disability Studies, who began applying British social model theory to disability in the early 1980`s (Oliver, 1996; Shakespeare, 2006). Seen through the lens of the social model, disability is the set of attitudes, barriers and exclusion faced by some individuals regardless of their embodied characteristics (Depoy & Gilson, 2004, 2011). Within this model "society" or the "social" has been defined for political and strategic reasons as a domain where personal, collective and scientific interests meet (Schillmeier, 2010). In addition to its influence in the social and political spheres, the social model of disability has had a significant impact on the field of disability research.

Theoretical debate on the constructs "disabled" and "disability" has become a cross-disciplinary space for critical disability studies, straddling the humanities and the social sciences (J. Grue, 2011; Hanisch, 2012; Thomas, 2007). Through its work in support of a commitment to assisting individuals in achieving their right to full equality and social inclusion, critical disability studies has introduced terms such as inclusion, participation and non-discrimination into the literature, along with critiques that challenge stigma, prejudice, marginalization, segregation and exclusion (Depoy & Gilson, 2004; Thomas, 2004).

The socio-cultural perspective on disability has stimulated important research exploring why some people experience exclusion and the negative representation and ambiguity of disability in society (Shildrick, 2012; Shakespeare, 2014). As both a term and a concept, disability often has negative connotations in society. It is seen as contrary to "normal" -- the "ideal" way of living (Thomas, 2007). According to Goodley, the category "normal" exists not only as a simple, fixed position of humanity, but as a register, a subject position; a phenomenon established as a preferred way of living by able-ist cultures (Goodley, 2014). The very term disability, he argues, signifies the opposite of ability, which is understood to refer to natural gifts, talents, intelligence, capacity and eagerness to strive—a set of characteristics considered to form the essence of ability and the human spirit (Siebers 2011). Consequently, as a term and concept, "disability" signals that some people are situated apart (deviance), from other members of society ("normal" people), and also from cultural norms. Grue asserts that acquiescing to these negative cultural associations by referring to oneself as disabled signifies accepting a marginalized position. Recognizing this, many people with chronic diseases and lasting impairments strenuously resist the label "disabled" (J. Grue, 2010).

Sociologist Per Solvang has pointed out that although from one perspective the concept of “normal” is a subjective position and a preferred way of living, from another, it can appear -- and be used -- as a form of suppression by the dominant social order in society. Within that social system, “normality” signifies the ideal; those who embody it are regarded culturally and socially as essential to a well-functioning society, while those who do not are considered inessential, if not actually detrimental (Solvang, 2000, 2006). Other ways of being human are considered to be of less value than the “normal.” It could also be argued, Solvang observes, that “normality” is a necessary component of social order in society. Integration policy, for example, uses the concepts of ´”normality” and “normalization” in formulating its strategies for including individuals in society. In this sense, it is a component of the solution, rather than a “problem.” (Solvang, 2000).

Another problematic assumption regarding disability has been suggested by gender reader Margrit Shildrick, who argues that the category “disabled” denigrates and devalues those who do not conform to problematic normative standards in society; it isolates them from the pervasive normative structures of thought. Shildrick posits the urgent need for a way of engaging with difference that transcends the binary simplicity of sameness or difference, ability and disability (Shildrick 1997, 2012). She points out that using dichotomous understandings to classify other people narrows our views and thinking. Following her argument, any use of the term “disability” should always raise the question of who constitute the “non- disabled” (Shildrick, 2009).

These ideas and arguments in what is referred to as the post-modern trajectory of deconstruction and destabilization of the concept of disability open up new ways of thinking. Recently, several scholars have suggested that challenges to exclusionary models and the deconstruction of binary concepts could have a salutary influence on normative assumptions regarding what it means to be disabled and non-disabled (Shakespeare, 2014; Shildrick 2002, 2012). Shildrick has even suggested that repositioning dis/ability could alter our concept of all human beings/becoming, and enable us to recognize that we exist in multiple variations and varieties and are inherently unstable and labile (Shildrick, 2009).

While scholars in cultural disability studies have done important work in identifying and deconstructing negative social and cultural stereotypes of disability in general and regarding children in particular, some of them have gone on to argue that their field can play an active role in asserting the potential of people with disabilities, as well as the positive values that they can contribute to society (Siebers 2008).

In most sections of this study, I have employed the term “children with disabilities,” based on the disability theory premise that this usage signifies children as first understanding. It is also consistent with the prevailing terminology in the global disability rights field, based on the argument that because “people” is the dominant word in the term “people with disabilities,” it expresses our common humanity (Shakespeare, 2014). In Paper III, however, we have used the term (dis)ability to suggest that we view children as having both disabilities and abilities that affect their everyday life. This study has also been influenced by different understandings and changes in understandings of disability, along with relevant experiences and theoretical perspectives. For example, as noted earlier, disability scholar Tom Shakespeare has argued that when we use the term “people with disabilities” we are inevitably adopting a “medical model” (Shakespeare, 2014). My own argument is that aside from whatever abstract theoretical significance the terms “disabled children” and “children with disabilities” may possess, the perspective of the children in this study is that these are labels that they may experience, and often do experience, as uncomfortable, damaging and socially alienating.

Although usage of some labels can have multiple consequences and the word “disability” is particularly fraught with meaning, as researchers we have to rely on terminology that makes our arguments clear and explicit. As Shildrick observes, in studies involving children, understanding them as subjects and trying to understand how they view themselves is essential. Shildrick points out that subjectivity and self- identity are powerful concepts in this context. Once the concept of embodied self- identity is introduced, disability cannot easily be absorbed through normative standards, and binary categories such as abled/disabled no longer make sense (Shildrick, 2009, pp. 78, 128, 161). The concept of self-identity addresses how children view themselves, which is always related to how other children view them. Thus, their self- identity must also be understood within its complex social and cultural context. In a research context that considers the subjective experiences and self- identity of children, as well as in a school or (re)habilitation context, eschewing dichotomous understandings of disability can minimize the deleterious effects of our own prejudices and broaden our understanding.

Once the self-identity of children is understood to be socially embedded with the ideas and actions of other children in their environment, Shildrick suggests, it can be defined as the totality of the embodied beings and never regarded as stable or fixed. In this study, my working premise is that self-identity is, or could be, influenced by the situation and context, as well as by relationships that vary according to the context.

Another useful definition of self- identity, proposed by the British sociologist Anthony Giddens, is the self as reflexively understood by the individual in terms of his or her biography (Giddens, 1991, p. 53). For children with a disability, their history of disability or illness will always be a central part of their biography or narrative. Similarly, UK sociologist Carol Thomas asserts that in making sense of who they are, people with impairments are highly affected by their biography and their experiences (Thomas, 2007). Their experiences of everyday life and their self-identity inevitably include their encounters with dichotomous understandings of ability/disability – or, most crucially, understandings of normal/not normal. Their self-identity and individual narratives are also influenced by public and cultural narratives that they are exposed to, such as them/us (positive/negative). This can explain why particular individuals self-identify with or reject the designation “disabled” (Thomas, 2007).

Thomas goes on to argue that disability exists simultaneously within each person`s experience, within a social context that includes our everyday language, and as a category. People experience their disability both in the form of social oppression in society and, through its biological dimension of limitations and incapacity that require medical treatment. She and other scholars have criticized some post-structuralist approaches for being concerned with texts and discourse to the exclusion of understanding the ordinary lives of disabled people, including their experiences with an impairment that significantly affects their life (Shakespeare, 2014). Thomas goes on to warn against understanding the “impaired body” as only “socially structured.” She does not find the arguments for refusing to categorize and group people particularly persuasive. In rebutting them, she emphasizes that disability embodies incorporated physical experiences, such as pain and illness, which disability studies often fail to explore. Other disability scholars have been more concerned with the danger of focusing on negative experiences to the exclusion of positive and forgetting that living in the world with others also includes experiences of ability and a “good human life” (Bickenbach, Felder & Schmitz, 2014).

To summarize, children with a disability are typically viewed from a medical and individualized perspective. In the context of everyday life, including schools and (re)habilitation services, these children are characterized as having individual “problems and deficits” that should be “cured” or “treated.” This view is associated with practices such as medical services and special education. From a socio-cultural perspective, disability often has negative connotations; it is regarded as a misfortune and the opposite of “normal.” This perspective can explain why many people who have a disability resist the label. Like other “normal” people, they have resources and abilities that enable them to participate in society. The ways in which they see themselves, their self- identity, may differ considerably from the ways in which others see them. Developing an accurate understanding of people with a disability or impairment requires eliciting their subjective views.

4 Materials and methods

This chapter outlines the methodological approach applied in this study and the methods used in investigating and interpreting everyday life from the perspectives of children with disabilities. It introduces the study participants, with a main focus on the children who were the primary informants for this thesis. This chapter also introduces and discusses methodological and ethical concerns involving interviews with children and the use of children`s experiences in research.

4.1 A qualitative approach

Based on a shared interest in following a group of Norwegian children with disabilities in a phase of transition between primary and secondary school[3], Kari Opsahl, Bennedichte Rappana Olsen, Sølvi Helseth and I established a research group and began planning a joint research project. As few prior studies had examined children`s own experiences in this particular phase of development, we chose to employ qualitative research. Kvale & Brinkmann describe a qualitative approach as research focusing on the cultural, everyday and situated aspects of human thinking, learning, knowing, acting, and ways of understanding ourselves as persons, as opposed to taking a "technified" approach to the study of human life (Kvale & Brinkmann, 2009, p. 12). More precisely, we decided to investigate the everyday life of children by interviewing them about their experiences. To supplement their perspectives, we interviewed their parents, teachers and school aides and observed some of the children in their school environment. Choosing the transitional phase between primary and secondary school enabled us to explore the children's own expectations, concerns and worries, as well as those of their parents and teachers/school aides, at a critical point in the complex and sensitive process of becoming a teenager.

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[3] Bennedichte Rappana Olsen, associate professor, Oslo & Akershus University College of Applied Sciences, Department of social work, child welfare and social policy, Faculty of social sciences
Kari Opsahl, Oslo & Akershus University College of Applied Sciences, Department of Occupational therapy, prosthetics & orthotics, Faculty of health sciences
Sølvi Helseth, professor, Oslo & Akershus University College of applied sciences, Department of nursing, Faculty of health sciences,

4.2 Participants; recruitment procedures, methodological and ethical considerations

This section presents the procedures we followed in recruiting informants and ethical considerations that arise in recruiting children for research. It also discusses methodological issues that our approach involved and the methodology we used to explore children`s experiences.

4.2.1 Participant recruitment and ethics

The primary participants in this study were 15 children with disabilities. We employed a purposive sample strategy to select children who were able to understand and inform us about the phenomena addressed in the study (Creswell, 2007). The sample was also selected based on convenience (Creswell, 2007). Since we planned to conduct life mode interviews with children in their homes or at school and all three interviewers were living and working in or near the city of Oslo, we limited our sample to children living in its metropolitan area. Because we wanted to follow the children during their transition from primary to secondary school, we selected children who were in their final year of primary school at the time of their first interview. They also had to be enrolled in a "mainstream" school; none of the participants were in a "special school" at the time of our study.

Methodologically, 15 children is a small number of respondents. However, in qualitative research, any experience and situation is regarded as unique; the emphasis is on the context of the knowledge gained (Kvale & Brinkmann, 2009, 262). The children in this study shared many relevant and unique experiences they had in an everyday life context as children with disabilities. They also shared their knowledge of being children in a variety of different communities and settings, both with adults and with other children, involving their many interests and their engagement in a wide range of activities.

According to Kvale & Brinkmann, in qualitative research, the emphasis should be on analytical generalization – that is, determining whether findings from the situation under study can be transferred to other, relevant situations – rather than formulating statistic generalizations (Kvale & Brinkmann, 2009, p.262). From a socio-cultural perspective, a child`s individual situation living with impairments and/or experiencing disability in society is always embedded with social and cultural influences and thus is relevant and transferable to the situation of many other children. The knowledge gained from children`s experiences can also be considered as transferable and relevant in efforts to improve professional practices that can facilitate participation and inclusion in schools, communities, (re)habilitation services and other aspects of society.

Although our primary aim was to elicit children`s perspectives we decided to interview parents (mother, father or both) to obtain their view on the everyday life of their children. We also conducted interviews with school professionals who knew and worked directly with children participating in the study to gain their perspectives on the everyday school life of a particular child.

To identify children who could be informants, all three interviewers made contact with and telephoned school nurses and professionals, such as occupational and physiotherapists, in a number of communities. We also contacted a variety of interest-group organizations that we believed could identify children with various physical impairments. After the children were recruited, we approached the professionals, in collaboration with the parents and individual children who had a relationship with them. Because we intended to explore “best practices” from children`s perspectives, we only recruited professionals whom children had spoken of positively and whom we believed could supplement the perspectives of the children and their parents with largely positive examples of children`s participation and inclusion at school.

Altogether, our sample consisted of 15 children, 15 parents, 9 teachers and 3 school aides. Fourteen of the children were classified as born with physical (motor) impairments; one had a severe visual impairment. Two of the informants were also classified as having specific learning impairments. All of the participating teachers and/or school aides were working with one of our child informants at school and knew her or him quite well. We conducted the study from the spring of 2009 through the spring of 2011. The children were between 12 and 14 years old at the time. In spring 2009 we were able to recruit nine children. In an effort to expand our material, two of us recruited a second sample; we followed this group of six children from spring 2010.

My own contribution to this study was following 9 children. This required 26 interviews with them, supplemented by 16 interviews with parents (mother, father or both). I also interviewed five teachers and one school aide. My colleagues Kari Opsahl and Bennedichte Rappana Olsen followed the other six children, completing a total of 13 interviews with them and 10 with their parents. They also interviewed two school aides and four teachers, in a total of six sessions.

4.2.2 Ethics; formal procedure

The study was approved by the Regional Committees for Medical and Health Research Ethics (REC) and the Norwegian Social Science Data Services (NSD) (Appendix 1-2). It followed all legal requirements to protect personal information and prevent any of the children from being recognizable through a diagnosis. In addition to the formal requirements from REC and NSD the study was based on respect for informed consent; confidentiality; and anonymity; which included that the consequences for the participants, including after the study has been published (Brinkmann & Kvale, 2008). For the purpose of confidentiality and anonymity it has been important not to reveal specific diagnosis in the written papers, as well as being sensitive to not reveal some specific ´personal´ or ´intimate´ information that some children and parents talked about, the question of what is too ´personal` or ´intimate´ to reveal however have sometimes been issues for discussion.

Research ethics also required that we explain the overall purpose of our study to potential participants, both adults and children, in the process of soliciting their informed consent/assent (Brinkmann & Kvale, 2008; Helseth & Slettebø, 2004). The letter of consent/ assent covered the aim of the research; commitments required of participants, in terms of the timing and number of interviews; who would learn the results and how; and confidentiality and anonymity (Hill, 2006). The letter was accompanied by a brochure we had created describing the project. Before we sent the letter of consent/assent, we called the parents to explain the purpose of the study and asked them to share this information with their child. A copy of the letter was sent to each child`s parents and a copy was given to them for their child (Appendix 4). The parents, in collaboration with their child, could then refuse or allow their child to participate in the study. Teachers and school aides were also asked to read and sign an information letter that described the aim and the commitments involved in the project (Appendix 5). At our initial meeting with participants we asked them if they had read the information brochure and the assent/consent letter. We also tried to explain the purpose of the study in our initial meeting with each child. Nevertheless, the extent to which a child was interested in and understood the purpose of the study was sometimes unclear. We also gave each child an assent letter to read and sign (Appendix 3). Assent is a process whereby a child is legally permitted to enter into a contract. In addition, we observed the moral requirement to acquire the closest approximation of consent one can achieve within the child`s capacity to understand (Helseth & Slettebø, 2004). From an ethical standpoint, by reading and signing the assent letter and voluntarily choosing to participate in the study, the children exercised a form of self- determination. That said, we suspect that in many, if not most, cases, the parents had a role in convincing their child to participate in this study, based on their own conviction that it was an important and valuable project. From a research perspective, this raises questions about how self-determined the children`s participation actually was, and suggests that their written assent did not necessarily mean that they were motivated or engaged in the research process.

4.2.3 Sample overview; number of conducted interviews and interviewees

In the following table, blue denotes the first sample of children (spring 2009 -- summer 2010) and red the second sample (spring 2010 -- summer 2011). The final column indicates the interviewer; MA, Mona Asbjørnslett; KO, Kari Opsahl BOL, Bennedichte Rappana Olsen.

Table 2 Overview of informants, number of interviews, interviewees

				Number of interviews with each respondent				
	Children	**Physical status**	**Age at time of interviews**	**Child**	**Teacher**	**Aide**	**Parent**	**Initials**
	Boy 1	Walks with aids/or wheelchair	12, 13	4			1	MA
	Boy 2	Wheelchair	12, 14	2			1	MA
	Girl 3	Visual impairment	12, 13	3	1		2	MA
	Girl 4	Wheelchair	12,13	3	1		2	MA
	Boy 5	Walks/uses aids	13	3	2		3	MA
	Girl 6	Wheelchair	12,13,14	4	3	1	1	KO
	Girl 7	Walks	12	1		1	1	KO
	Boy 8	Wheelchair	13,14	3	1		3	KO
	Boy 9	Wheelchair	13	2			2	BOL
	Boy 10	Walks/uses aids	13	1			1	BOL
	Boy 11	Walks/uses aids	12,13	3			2	MA
	Boy 12	Walks/uses aids	13	3			2	MA
	Boy 13	Walks/uses aids	12,13	3			1	MA
	Girl 14	Walks/uses aids	12,13	2	1	1	2	MA
	Girl 15	Walks/wheelchair	12,13	2			2	KO

4.3 Interview design; conducting and considering life mode interviews

Kvale & Brinkmann refer to the use of qualitative interviews to obtain empirical data as descriptive interview design. This method encourages participants in a study to express what they experience and feel as precisely as possible; the interviewer also observes how they act (Kvale & Brinkmann, 2009, p.30). Adopting this approach, we used a descriptive interview design -- more precisely, a life mode format – to explore children`s experiences of common everyday life through conversations with the children themselves. In these conversations and through adopting a socio-cultural perspective, we anchored the children`s descriptions in a social and cultural context, placing the analytical focus on everyday life relations and social events (Gulbrandsen, 2007). The next section discusses the life mode format and how the interviews with children were conducted, including ethical and methodological issues that we considered.

4.3.1 The life mode interview

The life mode format, introduced by psychologist Hanne Haavind (1987), has been found to be particularly suitable for interviewing children about their everyday life. Rather than following a standard questionnaire or semi-structured format in interviews, the life mode format is based on a conversation between the child and the interviewer about what has happened in an ordinary day. The children are invited to talk about what they did and how they related to other people on a particular day -- for example, their parents, teachers, peers and friends they met in various situations and the common activities they engaged in. In addition, the researcher and the child could talk about and investigate regular patterns in the child's life -- for example, a regular Wednesday afternoon swim accompanied by an aide. Within this format, the interviewer asks the child about specific everyday life events and daily routines, including leisure time activities and relationships with others (Gulbrandsen, 2012; Haavind, 2007). The intent is to obtain descriptions of social interactions that illuminate the child`s perspectives on a variety of everyday life experiences (Andenæs, 1991). The life mode format elicits children's descriptions of their experiences that can be explored as lived and experienced within a particular social and cultural understanding. The children participating can be considered to represent a broader group of children at a particular age and phase of life.

Using an ordinary day as a framework makes it easier for the interviewer to encourage the child to relate specific events in detail and share her/his reflections on specific and various activities, events and relationships (Gulbrandsen, 2010, 2012). In addition, it can provide many opportunities to follow up on topics the child considers significant -- a particular interest or leisure time hobby, for example. To allow the interviewer to take advantage of these opportunities, the interview design should include open-ended questions like, “What happened then?” and, “Is that what usually happens?” Three researchers, Kari Opsahl, Bennedichte Rappana Olsen and I, conducted the study’s interviews with children (see the overview on page 35).

4.3.1.1 Conducting interviews

In the interviews with children we followed the framework of a particular ordinary weekday, which was usually the day prior to the interview if it was not a Saturday or Sunday. We usually started out by asking, “When did you get up yesterday morning?” “Is that when you usually get up in the weekdays?” We followed up by asking, “What happened after you got out of bed that morning?” The children might respond by saying that they liked getting up early in the morning, and usually watched television. They sometimes cited a particular channel, such as Disney or an animal channel. They then typically told the interviewer how they got dressed -- for example, that their clothing had been laid out on the sofa, the bed or in the bathroom. Some of the children told us that they made their own breakfast, while others said they depended on their parents to make and serve it. We got many different descriptions of how a particular child got to school, including driving an electric wheelchair, walking or waiting for a taxi (some recounted irritating experiences waiting for the taxi to arrive). Through these descriptions we also learned whether or not the child was accompanied, just on that particular day or usually and by whom, as well as whether the child considered those companions to be friends.

We used this format repeatedly during the interview to prompt detailed descriptions of the entire day, until bedtime. Whenever the children talked about specific interests, we took the opportunity to follow up the subject in depth to learn more about their level of engagement, their struggles and the meaning they attached to their interests. We might say, for example, “Can you tell me a little bit more about [the interest] and/or what happened the last time you were there?” In one instance, a child who played in a marching band described the experience of “getting a rhythm inside you.” In another, a child described a happy experience playing for the king. In addition to eliciting detailed descriptions of everyday life events and giving us broader insight into the children`s interests and social relationships, the interviews provided information about how children felt in particular situations -- for example, that they did not like English as a subject or found it boring to sit on the bench watching others during school play periods and not have anything else to do.

We wanted to follow the children in the transitional phase between primary and secondary school to investigate their expectations and the particular challenges, advantages and disadvantages they perceived after entering a new environment and school – which sometimes meant acquiring new peers and friends. To accomplish this, we decided to interview the same children several times over a period of approximately 1½ years. In the first interview, which took place when the children attended primary school, we asked them how they felt about the transition. The children responded in a variety of ways, including that they were looking forward to having more people to talk to, or that they were worried about grades and making or keeping friends. Usually, they made it clear that they felt both excited and anxious. In the next interview, which took place when the children were attending secondary school, we asked questions about what had happened since our previous encounter and their experiences during this transitional period, including what had happened during their summer vacation. We also interviewed the children`s parents, teachers and school aides around the same time. These interviews were more thematically flexible; we tried to elicit their perspective on the particular child’s participation in the broader context of everyday life. We usually began by asking what an ordinary day looked like for the child, and for them in relation to the child.

4.3.1.2 Interviews with children; Ethical and methodological concerns;

Conducting a research interview with a child requires a variety of skills. According to Brinkmann & Kvale (2008), they include being sensitive and attentive and at the same time professionally distant (Brinkmann & Kvale, 2008). Some of the many children we interviewed had difficulty expressing themselves verbally. Being attentive in the interview situation sometimes required that parents be present to assist their children with communication challenges. On other occasions, the child signaled that s/he wanted to have a parent present for other reasons, such as feeling uncomfortable being interviewed by a "stranger" without direct parental support. In most cases, however, even though the children did not know the interviewer at all or had only met her once or twice, they usually declared that meeting her alone was fine. Since many of the interviews took place in the child's home, the family often offered us coffee or tea. By the second or third interview, the child usually welcomed us back.

We found that the descriptive interview design and the life mode interview format was usually an effective way to research the everyday life experiences of children. Using this format allowed us to determine what children meant and felt about different matters of concern and made it easy for us to follow up on significant issues over the course of several interviews. This was a form of communicative validation, which, according to Kvale, means verifying information obtained in the interview situation (Kvale & Brinkmann, 2009). Many children indicated that they were comfortable sharing in-depth information about their everyday life and offered many reflections about matters of concern, particularly in the later interviews. However in reviewing the transcripts, we sometimes realized that we had failed to follow up adequately on important issues and missed out on in-depth information about a child's experiences and reflections. On the other hand, we did adapt our interviewing style to accommodate the children`s many and varied ways of communicating – for example, when a child preferred to answer in short phrases rather than long, more revealing sentences.

Researchers also have to be equipped to deal with a range of themes, some of them uncomfortable, that may emerge during an interview and to be able to decide in the moment how to interpret and follow up on what is said (Nortvedt, 2006). Brinkmann & Kvale point out that the unpredictability of the responses generated in qualitative research means the interviewer has to be prepared to deal with issues such as how to react when the informant finds a theme distressing (Brinkmann & Kvale, 2008). In a few situations, when the issue disability came up it was evident that the child found being called disabled hurtful and difficult to talk about. When this topic or any other that children regarded as sensitive came up, they were usually able to explain their reaction and the interviewer adapted to that response. In some instances we did not pursue the issue and changed the topic.

Brinkmann and Kvale insist that the beneficial sum of knowledge gained from a study should outweigh the risk of harm to participants (2008, p. 267). Our perspective as researchers is that for our informants, the possibility of negative repercussions from participating in the interviews was and is low and that most of the children appeared to enjoy being interviewed; on the whole, they were attentive and talkative. We also had a general impression that most of the children were willing to share their experiences; some of them were eager to tell us about particular interests. We did not get the impression that any of children were responding in a particular way simply to please us. However, some of them did require narrowly formulated questions, which they preferred to answer in short phrases.

The ethics of interviewing children includes a concern about adult status and power asymmetry. Children can be willing to “obey” adult authorities and unable to foresee the long-term consequences of taking part in research (Hill, 2006: 78). A boy in our study who had been quite willing to share his experiences in primary school was reticent and embarrassed at his second and third interviews, although he politely went through with them. Such situations raise the issue of whether or not the researcher should continue an interview when the child is clearly reluctant to participate. In other cases, researchers might suspect that a child is trying to please them and disregard responses that are, in fact, sincere (Hill, 2006). In some of our interviews, a child was willing to tell us “everything,” which meant we were responsible for determining what information the child might not be comfortable sharing with “the public” after the interview session was over. At the same time, children can be agents who have the ability to negotiate around adult power and control in interview situations (Emond, 2006). One boy, for example, responded to some of my questions by saying (sometimes with a smile) that what I was asking about wasn’t any of my business, compelling me to move to a different topic.

4.4 The process of analysis

This section describes the interpretational process and data analysis that consisted of transcribing the material, analyzing the text together with co-researchers and co- authors and publishing the articles attached to this thesis together with co-authors. It will also describe and discuss ethical and methodological concerns identified during the process of interviewing, and collaborating with co- researchers and co- authors.

4.4.1 Transcribing the data material; initial interpretation

Each of the three researchers transcribed the digitally recorded individual interviews they had conducted themselves from digital recorders. Scholars have found that transcribing the material personally strengthens the reliability of a study (Nortvedt, 2006). In my own experience, listening to and transcribing my own interviews produced a better transcript and enhanced my ability to understand and interpret it. For example, being able to recall a particular situation with an informant made it became easier to transcribe what was said. The process of transcribing also affected the analysis by enriching my memories and perceptions of each child and the way we had influenced each other in this situation and/or the conversations. My memory of the conversation incorporated the context of the school or home environment in which the interview with the child, family members or school personnel took place. The process of transcribing also revealed significant information concerning the children`s level of interest and attention, as well as their rebuffs and expressions of discomfort during the interview. Finally, the process of transcribing generated self-reflections on how I had conducted each interview and what I had been able to elicit.

Our process does, however, raise a question of reliability, given that it involved three researchers conducting and transcribing interviews. We tried to adhere to generally accepted standards of reliability by transcribing as accurately as we could (Kvale & Brinkmann, 2009), an effort that required a vast amount of time. Nevertheless, we did not listen to the recordings of interviews conducted by our co-researchers, nor did we check their transcription procedure. We relied on reading and discussion the transcriptions. However, since we were transcribing data while we were conducting interviews, we met regularly to discuss how the individual interviews had come out and the different experiences that they generated. These meetings and discussions were a valuable exercise in inter-subjectivity and in many cases significantly enhanced my interpretations of the interviews that I had conducted myself. I believe the same was true for my co-researchers. This strengthens the validity of how we have used the material as a whole. We also discussed what was unclear in each other's transcripts. Discussing the interviews among the three of us was extremely valuable. It gave us an opportunity to share our differing interviewing experiences and refine our craft. We also used these meetings to discuss the content and form of the transcribed interviews, and consider ethical issues related to interviewing children. Finally, it was the time when we jointly examined our work of understanding and analyzing the empirical material. During these meetings we discussed all of our encounters, including the observations with children. Often, these experiences challenged our prior understanding of "children with disabilities" and of "disability" as a commonly used concept; our discussions helped us clarify our thinking. In all of these ways, this give-and-take had a profound influence on the analysis in our study, which raises significant questions of validity in terms of how the researcher used material that she did not produce herself. I will consider this issue in the next section.

4.4.2 Analyzing text material

The purpose of this thesis is to explore the perspectives of children on their own experiences. These perspectives were given full attention in the process of analysis and in writing the papers. The interviews with parents and school personnel provided a richer context for the children's experiences. In the first round of analyzing text material derived from interviews with children, each of us read our transcripts over and over again to get a better sense of the "whole" that would help us discern meanings we might have missed initially and glean more of what the interviews could tell us (Kvale & Brinkmann, 2009). According to Kvale & Brinkmann, determining validity in qualitative research includes judging the craft applied in analyzing empirical material, the questions addressed to a text and the logic of the interpretation of dialogues (Kvale & Brinkmann, 2009). In my own case, I thoroughly discussed and interpreted my experiences in the interviews, as well as the meaning of text, with my supervisors and co-authors, Sølvi Helseth and Gunn Engelsrud. Communicative validity was enhanced by our common responsibility for analyzing the empirical material, including the application of theory in making these analyses and reporting the results in articles. As discussed in the previous section, the process of reading and interpreting the text material had already begun during the process of transcribing and in discussions with my co-researchers, but in this phase we focused more attention on getting a sense of what the material derived from the interviews with children could tell us and how it could give meaning relevant to this thesis.

The additional reading process and analysis of interviews with children drew our attention to what appeared to be a range of themes in the material. It also provoked reflections on how children had talked about themselves, which was often related to being engaged in their many activities during the day and specific interests in their life world. Their perspectives on relationships with others also had an important influence on the analysis, in particular their perspectives on different friendships and their experiences collaborating with teachers and school aides. How children talked about themselves as active kids also provoked questions about how they viewed themselves and how they experienced being characterized by others in their everyday life environments. All of these observations inspired thoughts and reflections that supported our efforts to interpret and understand how a “child perspective” is embedded in socio-cultural discourse. Out of this process three lines of inquiry emerged that played a crucial role in determining how the analysis was conducted, the results we derived from the analysis and the written papers:

- How do children talk about themselves in relation to their social and cultural context?
- How do children experience being characterized by others?
- How do children engage in everyday life activities and relationships?

4.4.2.1 Exploring themes and coding the text material

Kvale & Brinkmann has noted that a qualitative research design and analysis is inductive and establishes patterns or themes; the work of coding should therefore be understood as a way of elucidating what is already present in the text (Kvale & Brinkmann, 2009, p. 197). In reading the text material, we identified many themes and issues, which we commented on in the margins as an early interpretive approach. This helped us formulate an overview of all the interviews with the children, highlighting themes and issues that became the starting point for a deeper and more extended analysis. Each quotation that we found relevant in the text material was marked with a specific color, determined by the underlying theme, and commented on briefly in the margins of the text material, as well as more fully in a written text. I might, for example, write “talking about normal friends” in the margin. The meaning we derived from different comments was included in our preliminary analysis as a starting point in sorting out units of meanings, which took place in the next phase of our analysis. Some themes, such as friendship, appeared explicitly in the text: The children frequently talked about their different friendships, which they enjoyed in a variety of contexts. Not all “themes” were that obvious and some could be allocated to several themes or issues. “Disability,” for example, became significant as a way of an understanding how children had positioned themselves as active and “normal” kids and how they adapted to norms and expectations in everyday life. Based on this conclusion, we treated disability separately in our further analysis. Another theme we coded was participation at school. Finally, in the process of coding some of the children`s specific interests, such as computer activities and sports, we combined them into a separate theme. In this process of coding, we did not sort some statements related to issues that we considered “irrelevant” from an everyday life perspective, such as some experiences of hospitalization or events related to a specific holiday, and did not incorporate them in our further analysis.

4.4.2.2 Meaning condensation; defining meaning units

Meaning condensation is defined by Kvale & Brinkmann, as what the researcher determines has been expressed by the subjects in a study (Kvale & Brinkmann, 2009). Since the primary purpose of our study was to explore the everyday life experiences of children with disabilities, we subjected each theme related to that purpose separately in our deeper analysis. For each paper we used many different meaning units. When we explored the theme “friendships” in the first paper, one of the meaning units was “friends with disabilities.” When we analyzed the theme “participation at school,” one of our meaning units was children`s collaboration with school professionals.” We also condensed and analyzed many different meaning units in the presentation of sub-topics, such as “mutuality and interdependence” which addresses some of our results pertaining to participation at school. Thus, the condensation of meaning we performed in the process of analyzing each theme is reflected in the titles, headings and sub-headings of each paper. This is consistent with a socio-cultural understanding of our material.

4.4.2.3 Meaning interpretation

Interpretation of meaning became more explicit and specific in our in-depth analysis of each theme or issue examined in the four papers. Kvale & Brinkmann define interpretation of meaning as where analysis of text goes beyond structuring the manifest meaning of what is said to developing a deeper and more critical interpretation of the text, including a theoretical interpretation (Kvale & Brinkmann, 2009, p. 207). We began our in-depth analysis with the coded texts, including the comments and suggested themes and issues in the margins and elaborated text. Our process followed three steps of interpretation suggested by both Fangen (2009) and Kvale & Brinkmann (2009). First, self-understanding, then critical common sense and, finally, theoretical understanding (Kvale & Brinkmann, 2009, p. 214). In our first step, as described earlier, we identified, explored and interpreted a total of four themes or issues; we also identified and assigned separate theme/issue meaning units (e.g. "friends with disabilities") to each of these theme. In our second step of text analysis, we attempted to distance ourselves from what the children had said and examine the quotes and statements more critically. In our third step, which Fangen, as well as Kvale & Brinkman characterize as third-level interpretation, we applied a different set of theoretical approaches to highlight and explore important aspects of each theme (Fangen, 2008; Kvale & Brinkmann, 2009).

In the first paper, on friendships, we based our analysis on the social understanding that friendships are relational and interdependent, an analysis that originated with Aristotle. As noted in the paper, our interpretive perspective was inspired from a hermeneutical theoretical understanding of the human being and lived experiences being in the world with others (Gadamer, 2004 [1989]; Heidegger, 1962). In our analytical process we used and interpreted the text material to reveal meaning (Danaher & Briod, 2006, p. 223) -- in this case, the meaning of children`s friendships. As a theoretical validation we drew on Aristotle in developing our results (Aristoteles & Stigen, 1999).

For the second paper, "ordinary kids," we explored relations of meaning in what and how the children in our study had expressed (or not expressed) their views and feelings about being a child with disabilities and how they adapted to norms and expectations in everyday life. As defined by Kvale & Brinkmann, meaning interpretation goes behind what is explicitly said to discern structures and relationships of meanings that are not immediately apparent in the text

(Kvale & Brinkmann, 2009, p. 207). The analysis for this paper was heavily influenced by the children`s reactions to, and interpretations of, the issue of disability that I encountered in the interviews, as well as by my readings of the text material. My approach here was influenced by descriptive phenomenology, which asserts that researchers should not try to avoid their own intentional acts (Danaher & Briod, 2006, 23). In some interview situations I intentionally used the term "disabled" to see how the children reacted. Their reaction to the term was so strong that being referred to as disabled became a central issue in the critical interpretation for this paper. In an effort to understand children`s positions in the interview situation and how they positioned themselves, our research question concerned how children who are labeled (including by me, the interviewer) with disability experience their situation and adapt to demands and expectations that they encounter in everyday life. Here it should be noted that the critical interpretation in this paper was no doubt influenced by the interviewer's (my) prejudices concerning how disability should be understood.

The theoretical analysis in this paper was informed by post-structuralist theory, which is often used to critique and deconstruct dominant theories. One of its tools is to look at how identity is determined (Creswell, 2007, p. 29). Post-structural ideas might seem contrary to a socio-cultural understanding of experience. However, in trying to relate children`s self- -identity to their everyday context we found theoretical ideas developed by post-structuralist and gender reader Margit Shildrick particularly helpful. As noted earlier, Shildrick is critical of categories like abled/ disabled on the grounds that they tend to stigmatize people who are designated disabled and suggests that disability studies could benefit from research using people`s experiences (Shildrick, 2009). This theoretical argument heavily influenced our exploration of the issue of what it means to be "ordinary kids,"´ which focused on children`s self-identities in an everyday life context.

The interpretation of meaning in Paper III followed an interpretive and descriptive design, in which we remained close to the events of everyday life in everyday terms (Sandelowski, 2000), as described by the children. Relying on the children`s self-understanding, we described some of their interests, along with their enthusiasm and/or concerns about some everyday life interests and/or activities they attended. We organized the information into specific themes and sub-themes that also tracked the evolution of children`s interests and activities in a transitional phase. Applying a critical common sense interpretation (Kvale & Brinkmann, 2009, p. 214) the analysis focused on understanding what appeared as meaningful pursuits to children and their adaptations to what are considered to be socially and culturally significant activities and interests in everyday life for “all” children, and defined as socially meaningful in this context. The analysis in this paper was, to a great extent, influenced not only by the written material, but interpretations based on recollections of the enthusiasm that some of the children shared in the interview situation. This enthusiasm also inspired the focus on some children`s “engagement in what they do” the pursuits that seemed to be significant in a transitional phase. The third-level interpretation drew on socio-cultural ideas derived from the field of occupational science, specifically the concept of meaningful pursuits that people are engaged in during the course of everyday life (Yerxa et al., 1990).

In the third paper, our interpretation of meaning was based on interpreting children`s experiences of everyday school life. The children`s self-understanding was the basis of the research question, What determined the children`s sense of inclusion and participation? Their self-understanding is evident in quotes and patterns in the material that manifest common experiences or experiences that differed among the children. The theoretical interpretation was based on a socio-cultural perspective and theory of participation and inclusion, including children`s agency as manifested in their power to influence and be influenced by others (Lansdown, 2010; Sancar & Severcan, 2010).

4.4.3 Publishing articles-- back and forth process

Interpretation of meaning for the purpose of writing and publishing the four articles attached to the thesis took the form of an extended analysis. This consisted of extensive discussions with the reviewers and co-authors prior to publication, a process that can also be viewed as a form of communication validity undertaken to reach out to a specific “audience” and research community (Kvale & Brinkmann, 2009, p. 214). Specifically, the published versions of the empirical material and final analysis have met the approval of peer reviewers and journal editors, who believe they will be useful to particular audiences of other researchers and/or professionals in a variety of fields (Kvale & Brinkmann, 2009).

This process was motivated and influenced in part by a macro-ethical concern with what happens when the methodologies and knowledge produced on a topic of great sensitivity circulate in the wider culture and might have an effect on a significant segment of the population and the society they live in (Brinkmann & Kvale, 2008, p. 274). This was certainly true in the current situation, where the principal message to readers of all four papers is the importance of recognizing that children with disabilities possess many abilities and want to be viewed as actively engaged in a wide variety of interests and capable of adapting to the many social and cultural settings in which they participate.

Once researchers have established the principal message they wish to communicate, they must shape the article so that the appropriate "audience" will find it persuasive. For example, in writing the first article (friendship) we found it important to present the perspectives of "children with disabilities" within a childhood context, rather than a "disability" context. The next article "Being an ordinary kid" was submitted to a journal of disability studies, with the goal of contributing a perspective based on a theoretical interpretation of children`s self-identity to the debate on ability and disability. Article three, concerned with what children do, was written for a particular journal of occupational science to show how daily activities can engage children and lead to participation in many other activities and interests. The last article focuses on inclusion and participation at school. The authors drew on different theoretical concepts for each article to highlight and analyze its theme.

4.5 Validity; during the research process

This research to gain insight into children's everyday life and their most significant experiences relied primarily on interviews with the children themselves. Thus, questions of validity include the reliability of these interviews and the arguments based on them (Danaher & Briod, 2006). In addition, as Kvale & Brinkmann emphasize, judgment of the skill and credibility of the interviewers is an essential element in determining the validity interview studies (Kvale & Brinkmann, 2009).

The validity of an investigation also rests upon the soundness of its theoretical presuppositions (Kvale & Brinkmann, 2009). In this study, the theme "everyday life of children with disabilities in Norway" was based on the premise that children`s experiences can be explored through their everyday life settings. According to this socio-cultural theoretical perspective, how children relate to the world and talk about it is very largely a function of their cultural context, and their discourses play a key role in their efforts to structure their world and determine their place in it (Greene & Hill, 2006). I believe that both the research questions and the theoretical framework used in analyzing the interviews are consistent with this perspective.

As noted above, our heavy reliance on an interview format, and specifically interviews with children concerning their everyday life, raises questions concerning the trustworthiness of the subject reports and the quality of interviewing (Kvale & Brinkmann, 2009, 249). The interviewees did not know the children prior to conducting the initial interviews with them. I recognize that children will never report their full everyday life experiences and perspectives to an interviewer they barely know. In addition, as I have already problematized, the skills of the interviewers varied; even though all of the interviewers applied the same life-mode approach, their style and form varied significantly – for example, the extent to which a particular interviewer followed up on key themes with open questions. These variations affected the quality of interviews, limiting the possibility for generalizations within the broader context of research on the everyday lives of children with disabilities. At the same time, our process of meeting with each child several times over an extended period strengthens the communicative validity of what was said; it provided an opportunity to explore the children`s experiences further, as well as to ask about what had happened since the previous interview. Interviewing many children on several occasions also enabled us to improve our interviewing skills. In addition, meeting with and interviewing parents and some school personnel helped validate our judgments of key issues in the children`s everyday life.

Our analytic validation of our perspectives on the children`s everyday life began during the course of the interviews and included discussions of our initial individual interpretations with our co- researchers. The entire process, including validation of the theoretical analysis, is presented in detail in the papers. For a variety of reasons, the other researchers and I made a decision not to ask the children, parents and school personnel for feedback on either the transcripts or the analysis. This could be considered detrimental to the communicative validity of the presented results. On the other hand, the results of the study have been reported in different journals, which allowed us to go through a process of peer review and communicate with audiences that share our interest in this field of research.

To sum up, the design used for this thesis is based on descriptive interviews in which the children themselves were encouraged to describe many of their everyday life experiences. Over the course of several interviews separated by a long interval, they had an opportunity to describe their experiences over time, and during a period of transition between primary and secondary school. The three researchers used a life mode format in interviews with 15 children. Their parents, nine teachers and three school aides were also interviewed about the everyday life of these children. The analysis for this thesis took place over an extended period of time, beginning with mutual critiques in collaboration with my two co-researchers during the interview process itself and continuing throughout the processes of transcribing and interpreting the material. I conducted the formal analysis in collaboration with Sølvi Helseth and Gunn Engelsrud, who were my supervisors, as well as the co-authors of the four published articles.

5 Summary of the papers

5.1 Research questions for each paper

The following section gives a summary of the principal findings of this study. They correspond to the research questions posed in each paper, as follows:

Paper I: How do children with a physical disability experience different kinds of friendships? How do they adapt to friendships with “mainstream” children in their local environment and/or friends with a disability? How are these friendships shaped by the children themselves?

Paper II: How do children with disabilities talk about themselves in relation to their experiences and their adaptation to everyday life?

Paper III: What do some Norwegian children with disabilities do and how do they engage in some occupations in a transitional phase?

Paper IV: How do children with physical (dis)abilities experience school life?

5.2 Synopsis for each paper

Paper I

The aim of the first study was to examine how children with a physical disability experience friendship during the transition between primary and secondary school. Two themes were explored: (1) different kinds of friends: friends with a disability, friends without a disability and technology-mediated friendships; and (2) qualities of friendship: understanding, intimacy and trust, mutuality and friendships with other children, both with and without a disability. The conclusion is that children with a physical disability are able to form and adapt to different types of friendships.

Paper II

The aim of the second study was to investigate how children with a disability express their self-identity and personal experiences in their everyday life, including at school. The analysis indicates that being perceived as “ordinary kids” is a major concern. The children talked about themselves from this preferred self-identity, but they also made it clear that being included in the broader community and perceived as “ordinary kids” in their environment often required considerable effort. In their everyday life they were aware of, adapted to, and supported certain social and academic norms in their environment and knew that other people’s expectations of them were affected by these norms. This study provides insights into the everyday life challenges that some children experience.

Paper III

The aim of this study was to explore what some children with disabilities do and how they engage in activities in the transitional phase between primary and secondary school. They show how various occupations can be filled with particular challenges, as well as fun, enjoyment, learning and social participation with others. The children in our study, like their peers, engaged in, adapted to and negotiated activities in accordance with individual and social meaning in their culture. From an activity perspective, knowledge based on children’s experiences of what they do can contribute to a better understanding of how they can participate in and be included in activities they find meaningful, both with their peer group and in their local environment.

Paper IV

The aim of the fourth paper was to explore the ways in which children with a physical (dis)ability experience everyday school life. Our focus was on analyzing their experience in relation to inclusion and participation. Our results show that the children wanted to be with the other children and do things their own way. However, some of them complained that of being given “too much help” by school aides or “too little help” by their teachers. We also address how some of the children experienced a lack of involvement in the planning to provide them with the best possible learning and social situation at school. In this paper we have used the term (dis)abled to emphasize our finding that the children in our study were more concerned with their abilities than they were with addressing the issue of disability. We conclude that these children wanted opportunities to participate on their own terms in learning and being with the other children; they expressed a desire for what they considered to be appropriate help and nothing more. They also wished to have some degree of self-determination and expressed a desire that professionals should understand their situation. Finally, we conclude that developing the best possible school environment requires taking children`s history of (dis)ability and impairment into account.

To sum up, the four papers highlight experiences and knowledge that the children in this study shared concerning their everyday life. The children expressed their engagement in what they were doing by talking about their everyday activities and particular interests, as well as their relationships with others, in particular other children. They also shared their experiences and knowledge about challenges they face in everyday life situations. The children spoke extensively about school experiences; their observations suggest ways in which school practices could be changed to promote greater participation and inclusion.

In their entirety, the findings described in these four papers reveal a variety of ways in which context and relationships with others can influence children`s engagement in everyday activities. I will now sum up the most significant results from the study and discuss their implications for practice in school and rehabilitation services, as well as for future research.

5.3 Summary of results

The results of these papers illustrate many ways in which children engage in different friendships and peer relationships at school and in their leisure time. They show how friendships depend on being able to do things together and stand up for each other. Whom these children called a friend varied, but they distinguished between friends with disabilities and friends without disabilities, whom they sometimes referred to as “normal friends.” The children made it clear that they appreciated it when friends at school and in the community viewed them as “normal” friends. They also valued their friends with disabilities, who took part at the “same level” in activities -- for example, wheelchair-sporting. In these friendships, they felt able to share perspectives on disability and impairment. Some expressed the view that other children with disabilities can be friends who “understand you better,” which may serve as a particularly important quality in, and qualification for, friendships. Friends living in the neighborhood were the most appreciated and important to the children, partly due to how convenient it was to get together with them. The children spoke extensively and in enthusiastic terms about using the Internet, and identified several positive meanings derived from digitally mediated friendships. Facebook and Microsoft Live Messenger (MSN) were cited as particularly helpful for establishing new friendships, making social friendships easier and communicating with a boyfriend or girlfriend. The children based their friendships on qualities of mutual understanding, intimacy and trust. In this context, they sometimes expressed the view that they particularly valued friends with disabilities with whom they could share “secrets,” regarding consequences of their impairments.

The results described in Paper II show that the children did not refer to themselves as disabled/children with disabilities. The term disability evoked “disappointment,” alienation and other negative reactions in some children. The use of this term in children`s lives reinforces the impression that it is defined by others and can be alienating if used in the everyday life context of children. At the same time, the children we studied talked about and were very well aware of their personal limitations and the challenges they experienced in everyday life. These children worked hard to be considered “normal” and be included in the broader community. This sometimes included adapting their performance to the norms and expectations embedded within their environment, including at school and in their “work” -- by, for example, using less conspicuous supports at school rather than a wheelchair.

The results described in Paper III show that what children value most about school are the opportunities to learn and be with friends. (The only exception was a boy who had been given a diagnosis of learning difficulties; for him, the top school priority was getting sufficient academic help.) The children made it very clear that they want to be viewed and treated like the other children at school. They wanted to participate at school “the regular way” and, at the same time, “their personal way.” They did not see these desires as contradictory. To them, it meant being “independent” and receiving help and support only when they needed it. The children both adapted to the demands and expectations of the “mainstream” school system and/or “supported” the activities of the other children. Sometimes, they confronted an attitude in the school system that children who cannot participate in a particular activity on equal terms are left out. This occurred most frequently in physical education.

Most of the children in our study related experiences in which they participated in sports or other activities in secondary school on their own terms, and expressed satisfaction with the grades they received in them. Some of the children found their adaptations and hard work in some everyday life experiences highly demanding, even problematic. These children explained that keeping up with common expectations was sometimes “tiring.” For some of the children, particularly those with learning challenges, never being good enough was experienced as a frustrating struggle.

Several children recognized that they needed extra support to succeed at school academically. They preferred that their teachers provide it, and that the assistance of school aides be limited to practical issues – help which they valued a great deal. They also expected teachers at school to adjust learning programs to meet their needs and provide appropriate support – but no more. Some complained they were "over-protected" and given "too much help" by school aides, and/or "too little help" by teachers. In learning situations, being with other children during the school day was the most significant factor in fostering a sense of participation and inclusion. Many of the children felt they were in control if they got help when they asked for it. Some of them expressed a desire for a degree of influence in school matters, including the right to make some decisions in school matters that concerned them. In general, they were particularly concerned with their influence in the classroom, their learning process, the role of aides and the transition to secondary school. School meetings were, however, considered "parents'" business. Most of the children had not participated in them while in primary school and did not express any interest in participating.

The results from Paper IV address how the children in this study engage in activities and focus on the transitional phase between primary and secondary school, a time when some activities change in both form and content. The results show how some activities such as applying makeup and shopping can symbolize transition. The change in relationships between boys and girls may be characterized by the way the term "childish" is used. Dancing at a birthday party can symbolize a transition towards becoming a teenager. As the children grew older, social networks and social media expanded their opportunities for developing new interests and relationships. Some "mainstream" activities such as football (soccer) and other sports were important to many of the children in our study. Even if they found on-field participation difficult, they sometimes found it easy to participate in other ways. Our findings reveal how the physical structure of a school can contribute to shaping social participation. For example, the layout of a secondary school cafeteria or classroom can either encourage or thwart participation in activities such as social interaction, communication and flirting. Overall, our results showed that the children in our study usually found ways to engage in their particular interests, and were not always deterred by an inability to perform well.

In the next, concluding chapter, I elaborate on the knowledge gained from the children in this study, based on their experiences of everyday life. In their home environment, a majority of these children spent most of their time in "mainstream" activities with "mainstream" children. My discussion will focus on this context, and describe how the children engaged in and adapted to everyday life demands, relationships and activities. I will then propose ways in which the perspectives of children like the ones in this study might contribute to the field of disability research. I will then present some implications that I believe this study has for professional practice in communities, schools and (re)habilitation services, and a number of suggestions for further research. I will also make the argument that when the children meet professionals in a medical, school, or any other institutional context, knowledge from the perspective of children should influence the interactions, as well as the outcomes. In conclusion, I will summarize what I consider to be the most pressing challenges in the field of disability and offer my final thoughts concerning this study**.**

6 Discussion

6.1 Everyday life: the perspectives and experiences of a sample of Norwegian children with disabilities

The research question of this study and the findings presented in the articles that follow raise two important issues: How can everyday life experience inform the knowledge field, and how can professionals take such experiences into consideration in their professional work? One basic question, both theoretical and practical, that the findings pose is whether or not children with a disability can be considered "ordinary," particularly since they reflect that they are. The children in this study typically spent most of their time with "mainstream" children, both at school and in their home environment. They made whatever adaptations they thought necessary to be and appear as ”ordinary kids," participating in an everyday social life replete with opportunities, as well as challenges and demands. In their everyday social life, being "ordinary kids" demanded strong "agency." Their experiences made it abundantly clear that this is how they saw themselves and wished to be perceived. At the same time, these children often needed particular help and experienced a lack of capacity or opportunities in many situations. This condition of "sameness with a difference" poses questions of what constitutes "disability," and who are children with disabilities and who are not? The findings of this study indicate that the children we interviewed were both children with disabilities and at the same time children with considerable abilities that emerged with impressive force in the analysis of their perspectives.

6.1.1 Friends and Peer relations

Consistent with other studies, our analysis of the experiences related by the children in ours indicates that spending time with friends and peers means a great deal to children with disabilities (Morrison & Burgman, 2007; Bourke & Burgman, 2010; Seymour et al., 2009; Shikako-Thomas et al., 2009; Stewart et al., 2012). They readily adapt to join in a wide range of shared experiences, and feel they get to know their peers and friends better as a result. According to Asher et al. (2014), friendships are often based on shared history and this was borne out in our study. Many (though not all) of the children we interviewed described close friendships with other children with disabilities and their “shared understanding,” which other researchers have also found many children in their life situation consider important. More noteworthy, however, is the high value they placed on shared experiences with “mainstream” peers and friends in their local environment. These experiences validated their belief that they were “normal” friends with “normal” interests, rather than “different” children, who could be shunted into segregated activities.

The children in this study corroborated the theory that friendships, often based on shared history, are regarded as essential to social participation (Ytterhus & Tøssebro, 2006; Asher et al., 2014). The experiences they related also support the view that friendships are based on some form of “equality.” One aspect of that was a willingness to “stand up” for each other, which they indicated solidified their friendships. Some of the children indicated that disability presented a challenge to friendships in local community based on “equality.” One example was making friends with children who met (and potentially formed tighter bonds) on the football field. This is consistent with previous studies that found children with disabilities were sometimes hindered in developing and sustaining friendships by obstacles such as lack of physical access (Seymour et al., 2009; Ward, 2010). Asher et al.(2014) point out that friendship can be fragile and hard to achieve. An inability to share in common interests and meet in common venues can exacerbate these difficulties and support the construction of an image of disability in local environments.

At the same time, the children`s perspectives illustrate that children can be “normal friends” and “stand up” for each other in many ways. Given that sharing interests and activities and communicating about common experiences is vital to friendships in local communities, it is significant that the children in this study did feel a sense of agency in their environment. They believed that they had many opportunities to develop and sustain peer relationships and friendships by participating in many different social arenas and group activities such as theater productions or a marching band, as well as on the Internet, and were very aware of the importance of these interactions for developing and strengthening friendships and peer relationships. Whether in person or online, communication and interaction with others over time is essential to developing new and important relationships among children. Their experiences show how the Internet offers children new and wide-ranging opportunities to include themselves or to be included in peer groups that now play a major role in the children’s culture (Corsaro, 2009). Children in our study enthusiastically described their participation in peer groups for particular interests, such as Harry Potter, which they had joined on the Internet. Sharing in these kinds of mainstream, everyday life activities and developing friendships through them had a particular meaning for the children that differed markedly from their feelings about the benefits they derived from participating in disability-specific activities. Some of the children who experienced mobility or capacity challenges considered these "mainstream" relationships extremely important. Other recent studies have similarly found that children with disabilities who use the Internet benefit in many ways, particularly through an increase social participation, including formation of new friendships (Raghavendra et. al., 2013). It has also been suggested, from a theoretical perspective, that for children, having many varied and shared spaces where they can share common experiences and interests is essential to the successful formation of peer relationships (Corsaro, 2009). From the perspective of the children in our study, the Internet was such a shared space, and it had the added benefit of facilitating their efforts to develop and sustain self-identity as an "ordinary kid" or "normal" friend among peers with common interests.

Participating in social arenas over time provides many opportunities for children with a disability to develop a sense of interdependency and mutuality with other children and avoid a designation of difference that children like them often experience and would like to avoid. At the same time, the Internet made it possible for the children in our study to be in contact with other children with disabilities whom they could share specific challenges that they had encountered in "real life" due to an impairment or disability. Such challenges can be difficult for friends without a disability to understand and some of the children felt that long-lasting relationships on the Internet and in their local environments with other children who confronted similar challenges were particularly important to maintain. The desire to keep friendships is likely to be especially acute during a transitional phase, such as the transfer from primary school to middle school, when a sense of interdependency, mutual knowledge and understanding can be particularly valuable and important.

6.1.2 Being an "ordinary kid"; self- identity "normality" and "disability"

As in other studies, the children in ours talked about themselves as "normal" and "independent." (Connors & Stalker, 2007; Mundhenke et al., 2010; Dreyer et al., 2010). These children typically spent most of their everyday social life with children without disabilities and would not want to appear to be "different" in that context.

The validity of self-identity raises an issue of major importance. These children`s subjective view of themselves in everyday social life was that they should be – and were -- regarded as “ordinary” and “normal” children. If their perspective is accepted as a valid representation of reality, it poses the question of how the self-perceptions of children with disabilities should influence professional practice in the children’s social environment and in institutions such as school.

Theoretical arguments supporting the concepts of self-awareness and embodied beings portray them as constantly changing. Pursuing this approach, children like those in our study would have one self-concept while “wheelchair-sporting” and quite another in their everyday social life. Their adaptations to “normal” and “ordinary” included changing their concept of who they were and how they viewed themselves according to each particular context of everyday life. At the same time, as Thomas has observed, when children with disabilities talk about their everyday social life they also express and experience their awareness of the risk of being viewed and treated as “different” from other children. From their perspective, this recognition of their situation is necessary, however it also presents challenges to both their capacity to adapt and their self-identity. In an everyday life context, their experiences of disability and the consequences of impairment are embodied in their self-awareness, which also affects their self-identity (Thomas, 2007). The children in this study did express that form of self-awareness, perhaps because the social situations in their everyday life, the focus here, were not a context in which they would wish to acknowledge restrictions or limitations. Their consciousness was to a great extent shaped by the adaptions they were making to create a meaningful life with “ordinary” children, which included how they talked about themselves and what they talked about, as well as what and how they did things.

Some theorists of disability believe that the opposite dynamic occurs in a comparative life world, which provides a context in which these children become aware that when the term “disability” is invoked in social situations they are positioned outside the normative expectations embedded in everyday life. According to this theory, the concept and term disability symbolizes the opposite of a “normal” way of living and is embedded with a range of negative cultural images, such as “dependency,” “individual problems” and a “marginalized” position (Thomas, 2007; Grue, 2010; Goodley, 2014). Used in a social context, “disability” can represent what Thomas refers to as “disablism,” by which she means a hurtful terminology (Thomas, 2007). Professionals use the term disabled as well, to position certain children as “different.” When children “reject” the disability label they seem to share this understanding. In rejecting the label, they are also rejecting this position for themselves,

Shildrick argues that knowledge about disability needs to include people`s subjectivity and identity (Shildrick, 2009). When children prefer to talk about themselves as “ordinary kids,” it indicates that their self-identity is socially linked to everyday life situations, particularly situations involving other children. Thus, the children`s self- identity is largely shaped by their social and relational engagement with others who share the same life situation (Giddens, 1991; Lindqvist, 2012). Rather than be considered children with “disabilities,” they want to be viewed as individuals who possess a variety of abilities and talents. This ability stance -- use of one’s capacity and talents to strive for a meaningful life (Siebers, 2011) – could be a particularly useful concept for professionals who work directly with these children. At the same time, as Thomas points out, disability and impairment do impose individual restrictions (Thomas, 2007). The concept of children who are both restricted and at the same time filled with capabilities and talents presents complex issues for theory of ability and disability because they are naturally embedded with each other. Shildrick’s response is that sameness and difference and all that is human are unstable and labile; we should abandon complex and sometimes exclusive binaries and recognize differences without resorting to an ability/disability dichotomy (Shildrick, 2009). This would be more in keeping with the perspective of children like the ones in our study, who wish to be regarded as complex individuals with (dis)abilities that may reduce their opportunities in a variety of situations, but do not prevent them from enjoying fulfilling lives enriched by their engagement, interests and many talents.

6.1.3 Everyday school life; adapting to norms and expectations

School is an institution in which learning and other joint activities with peers and friends are organized around particular norms and expectations of “normal” behavior. How children as agents are influenced by and influence these norms and expectations are topics that merit further exploration. When the children in this study spoke of doing things the “regular” or “normal” way or being “treated” and “viewed” like the other pupils, they were adopting a “normalizing” discourse. Like any other children, they wanted to belong to their social group. However, in their case, efforts to adapt to the normative expectations of their institution had both positive and challenging aspects. Other researchers have also found that children with disabilities dislike being treated “differently” (De Schauwer et al., 2009; Curtin & Clarke, 2005; MacArthur, 2013). This suggests the need for further exploration of the ways in which the self-identities of children with disabilities influence their situation at school. Research on how children with disabilities are affected by the “normal” discourse at school would be particularly welcome in Norway, where several researchers have reported that many children in their studies believe they are being treated “differently” at school. This may indicate that marginalization is increasing in Norwegian schools (De Schauwer et al., 2009; McArthur, 2012; Svendby & Dowling, 2014; Wendelborg & Tøssebro, 2010 a, b, 2011). Some descriptions of marginalization are presented in this study, including children`s experiences of being “over-protected” or not receiving homework that is given to their classmates. From the children’s perspective, this type of behavior represented unnecessarily discriminatory professional practice. As noted earlier, from a theoretical perspective, it can be seen as an aspect of a repressive social order that society imposes in schools and other arenas by establishing standards of “normality” (Solvang 2000, 2006). Such practices restrict the agency of children with disabilities, when they should be allowed or encouraged to be “independent” in schoolwork and have influence on their own school situation. It should be problematized, as it was in a recent study focusing on Physical Education (Svendby & Dowling, 2014).

A different theoretical perspective, cited earlier, posits that “normality” is a necessary component of social order (Solvang, 2000, 2006). From this perspective, when children in this study worked very hard to get “good enough” grades in secondary school it wasn’t necessarily problematic for them. In fact, it encouraged some of these children to use their abilities and take part “on their own terms.” These children often found fulfilling the requirements of common school work fun, engaging and meaningful. At the same time, other children may find the same work overly challenging and difficult, even if they ultimately complete it successfully. This can be a particular problem for children with learning difficulties, who sometimes require specific help at school. In situations like this, the children are willing to acknowledge their “differences” from other children, including not having the same capabilities (Egilson & Traustadottir, 2009; Shihako-Thomas et al., 2009).

To be “ordinary kids,” children with disabilities need to collaborate with their teachers and school aides on a regular basis, primarily in the classroom. Many studies have found that their interactions and inter-relationships with other children and teachers promote social inclusion and acceptance (Koster, 2009; Almqvist & Granlund, 2005). In a learning context, this usually occurs when they can interact and take control of their situation by asking for help. When the children in this study were given an opportunity to express how they wanted to do their schoolwork, they felt a “sense of control” in the classroom. However this could only occur when their teachers and school aides had sufficient opportunity and capacity, as well as the space and time, to be available to all of the children in a “mainstream” classrooms on “equal terms” and provide adapted learning and individually adapted practical help where needed. Within these constraints, respect for the children’s agency requires recognizing their perspectives and giving them the power to act and have influence on their school situation while also being influenced by others (Oswell, 2013).

When children in our study suggested that they should have something to say about their learning process and social process they also made it clear that they were feeling extremely vulnerable during the transitional phase between primary and secondary school. Other researchers have also noted that this is a sensitive time, particularly for children with special educational needs (Hughes et al., 2013; Ytterhus, 2012). Consequently, this is a period when professional attention to understanding the perspectives of children with disabilities on their learning and social situation is vitally important. Even though many children in our study seemed reluctant to participate in formal school meetings at such a young age, ways should be found to solicit their opinions and primary school experiences. This could suggest new practices that would greatly enhance their future educational and life situations in terms of social inclusion, participation and disability.

6.1.4 Being engaged; making use of their abilities

The material in this study illustrates how the everyday life experiences of children with disabilities are full of meanings related to their engagement, as well as their abilities to follow their interests and to interact. These experiences also support Mariane Hedegaard’s assertion that the social environment and culture have considerable influence on what these children find meaningful and important (Hedegaard, 2012). In this study, we found a good deal of evidence that supports this perspective. The possibilities which the children mentioned were numerous and varied. At the same time, I am aware that many studies indicate that children with disabilities are at risk of participating in social and recreational activities less frequently than other children, in particular when they are becoming teenagers (King et al., 2010). From the perspective of children with disabilities, inclusive communities are those that offer a broad spectrum of activities that welcome participants with various (dis)abilities.

When children are given opportunities to participate they find ways to develop new relationships in the transitional phase, and develop the ability to advance with other children from childish activities and relationships to more “grown-up” behavior and attitudes. Even when they encountered barriers to engaging in an activity they considered meaningful and important, children in this study found ways of collaborating with specific adults and children in their communities to overcome them – to be more involved in a sport or some aspect of their schoolwork, for example. This can be viewed as instances in which these children constructed their own “ability,” assuming the particular form of engagement was freely chosen and negotiated based on their particular situation. At the same time, and most important from the perspective of being children with many abilities, the children in this study seized opportunities to follow their individual and social interests. In their everyday life at school and in their leisure time they were actively and enthusiastically engaged in various forms of social participation (Kousholt, 2012). This achievement is consistent with the perceptions of children in other studies exploring successful participation and quality of life issues (Heah et al., 2009; Shikako-Thomas et al., 2009). Thus, influence can be understood as children`s ability to assert individual and social agency based on mutual interdependency and collaboration with others (Oswell, 2013). The finding that the children in our study exhibited agency when circumstances allowed it is consistent with the results of other studies that focused on children`s strengths, rather than their limitations (De Schauwer et al., 2009). Greater insight into the perceptions that children with disabilities have of their abilities could be obtained through further investigation of how they pursue their interests and activities in everyday life (Gullestad, 1998), including at school. The next section will discuss the results of this study regarding the rights of children with disabilities to participation in society.

6.2 Implications for professional practice

Norwegian legislation on discrimination and accessibility in society prohibits discrimination and is intended to promote equal opportunities and equality for people with impairments and eliminate social discrimination against people with impairments (Diskriminerings- og tilgjengelighetsloven, 2011, NOU 2001: 22). This law contributes to dismantling existing disability barriers and preventing the creation of new ones. It declares that people with impairments should be treated the same as any other members of society (Diskriminerings- og tilgjengelighetsloven, 2011). As Shildrick has proposed, “we” -- a category that includes all professionals and researchers that are involved in the lives of children -- are all responsible for disability issues. This responsibility includes being willing to listen and act upon the perspectives of children in formulating professional practices affecting the everyday lives of children with disabilities. To do so, all of us, including professionals in the community as well as in schools and (re)habilitation services, need to be aware of and help influence what constitutes disability (Shildrick, 2009). As suggested by Michael Gallagher, our responsibility includes supporting all “ordinary kids” in asserting their social agency to be full participants in all of the social structures they encounter, which include relationships between people, as well as shared social spaces such as the football field, the school cafeteria and community venues where children live (Gallagher, 2006). To fulfill this commitment, professional practices need to look into and problematize how well physical and social environments ensure that children with disabilities have the time and space to pursue their interests, whether in public arenas or and their home environment.

To exercise their agency to be “ordinary kids” on their own terms, children with disabilities need support and understanding from others, including friends and professionals at school, in (re)habilitation services and in the many other social environments they are part of. This support and understanding includes a recognition that these children sometimes choose not to participate actively because they determine that in a particular situation it is “best for all” if they adapt by accepting a position on the sidelines, even if that means acquiescing to a repressive structure in society (Solvang, 2000, 2006). As noted earlier, children like the ones in our study do not feel discriminated against if professionals or others support them in engaging in their interests and taking part in activities with other children “on their own terms.” In, some situations, such as participating in football, this might mean cheering on their team from the sidelines.

On a social level, disability can be defined as limitations or loss of opportunities that affect participation in common social life (DPI, 1981). Understanding and discussing what disability means as a phenomenon and how it affects children can provide professionals, researchers and others with an opportunity to contribute their reflections on disability issues in their practice and help them develop practical guidelines to promote inclusion. This would include reflection on how and why a variety of social structures may support and even justify treating some children as different or placing them outside “normal” contexts – by, for example, assigning them to special education classes. It would also include reflection on how to modify practices that reify disability as a social phenomenon, such as Physical Education programs. Particular awareness should be paid to the traditional tendency to view disability as an individual concern, or as a defect associated with concepts such as special education, normative schooling and exclusion (Siebers, 2008; Goodley, 2014). One common practice that subtly reinforces this negative stereotype is the tendency of many school aides to be "overly helpful," effectively supporting what Solvang has characterized as a disabling and repressive structure (Solvang, 2006).

All children have a specific right to be included in school as equals and inclusion is a main principle in Norwegian school policy (Oppll, 1998; St. Melding 30, 2003/ 2004). Recognizing that all children are different, the Salamanca Statement (UNESCO, 1994) requires that every child are given the right to be included based on his or her potential,. Many studies document that signatories do not always fulfill their commitments under this statement. In Norway, for example, a recent study found that some children do not believe they get the support they need to take part in Physical Education (Svendby, 2012). Inclusion means participation on equal terms (Davis & Hill, 2006). From the perspective of children like the ones in our study, this means that all children should be treated as "ordinary kids" and be perceived as "normal." In this regard, it should be noted that when prompted to elaborate on what being "normal" meant to them, the children in our study typically responded with their views and suggestions on specific issues, such as aides' roles, what kind of help they needed, and how they could participate in various activities such as Physical Education or other learning situations at school if they were asked what they required and treated as collaborators.

Recent theoretical work and research have contributed to an increased consciousness that how children view themselves sometimes differs from how they are viewed by others, including professionals. Greater attention to how children view themselves, including what they see as their talents and potential, could improve their participation and satisfaction in areas such as education and (re)habilitation. In general, professionals ought to follow the principle that children with disabilities should be treated "the same" as other children and given opportunities to do things "their own way." From the children's perspective, supporting their agency to be "ordinary kids" and providing the support and professional help they need to be as close to "normal" as possible is a major priority. In our study, many of the children recounted experiences when they were treated "differently" from other children or not given adequate help to be able to take part in activities that were part of their everyday life. At the same time, disability cannot be separated from impairment. If they are going to provide appropriate and effective support in learning situations and social participation, professionals need specific knowledge about consequences of the impairments of children they are responsible for. These children depend on professionals to a greater extent than other children. Both at school and in their home environment, they need extra help and adaptive strategies to activate their power of agency and maximize their participation in mainstream activities..

Ensuring the individual rights of children with disabilities to be heard is a shared responsibility. Professionals have an obligation to listen to and heed the perspectives of these children on their potentials and limitations, and respect their right to influence choices and decisions in schools and other areas of professional practice, as well as in research (Ulvik, 2009; UNICEF, 1989). The mandate to respect these rights places a special responsibility on professionals in schools, community services and (re)habilitation services. Researchers in Norway have recommended ways in which (re)habilitation services could be more attentive to the voices and perspectives of children with disabilities and incorporate their views on their everyday life in evaluations (Bekken, 2014). In this study, it was similar apparent that professionals in community services and school have the potential to do a better job of listening to children`s “voices,” trying to understand their perspectives on a particular institution’s practices and developing suggestions for improvements in dialog with the children. As individual agents, children with disabilities have first-hand information, experiences and knowledge concerning their own situation. From the perspective of the children in this study, taking their suggestions into account was most important in ordinary situations, such as the classroom. They placed a high value on having an opportunity to collaborate with their teachers and school aides during the day. Some of the children also suggested that they can and should take part in discussing significant issues like learning progress or the roles of school aides, even in primary school, although most thought that collaborative meetings in primary school were “parents’ business.”

Children with disabilities can be particularly vulnerable. Soliciting their knowledge and understanding of the consequences of their conditions can be crucial to their successful participation in activities of everyday life. Professionals in schools need to be particularly sensitive to their experiences and the inherent complexities of disability and impairment. As noted earlier, some of the children in our study were particularly concerned about sustaining relationships when they made the transition to a new school environment. In situations like this, listening carefully to what the children are saying and modifying practices in response can make a major difference in their participation level.

From a disability perspective, limitations on opportunities are a social problem. The onus is on professionals in the classroom and elsewhere to adopt a broader conception of "normal" ways of doing things. To do so, they will have to challenge the traditional concept of what disability means and revise the "helping attitude" that has accompanied it. They will have to recognize that children with disabilities are individual agents whose competence and capacity for self-determination should be considered when decisions are made about the learning process, the role of aides and other practices that affect their participation and well-being.

6.4 Implications for further research

This study is a response to the critique that research on children is rarely based on their individual voices, agency and experiences (Corsaro, 2011; Greene & Hogan, 2006). It solicited the voices of children with disabilities, allowing them an opportunity to draw attention to their abilities and adaptions to everyday life. The focus was on researching children's perceptions of their own experiences. Further research using different designs and methods, such as institutional ethnography and observations, could provide other valuable insights into how children are abled and use their abilities in everyday life. Future research could also move away from focusing on the restrictions that accompany impairment and explore how children use their abilities to meet challenges and make adaptations that enable them to participate more fully in "mainstream" activities. It could also elicit the perspectives of children with disabilities on how individual and social barriers hinder or prevent their participation, and what should be done to eliminate them. In future research, children's agency could be a part of the process, as well as a subject. Some studies would benefit from allowing children with disabilities to assist in designing them, together with other children.

Without question, future histories of disability will assign a major role to technology, including medical technology and digital media (Depoy & Gilson, 2011). These modalities will also have a significant influence on any new "history of friendship and other social relationships." Using digital media creates new possibilities for everyone, but it is likely to be particularly beneficial to children who are challenged by limited physical capacity and mobility. Exploring the possibilities and challenges presented by online communities should be a significant aspect of future research.

More research from the perspective of children with disabilities on how they experience different practices could draw greater attention to attitudes and practices that limit their participation, involvement and self- determination in environments such as (re)habilitation and school. More research on how these children think they should participate in different contexts and practices would be valuable. The ways in which they experience having a say in choices and decisions at school and in (re)habilitation services also need further exploration. Finally, our study sample included two children with specific learning difficulties. More research is urgently needed on the kinds of challenges that children like them encounter at school, including current ambiguities in the assignment and intent of special education.

We need greater knowledge not only on how individual children with disabilities view themselves, but how these children view, understand and adapt to the behavior of other children in a common social world -- in school, for example. Another fruitful area of research would be explorations of how these children perceive their situation in the broader community, and how they adapt to each other from an “ability” standpoint. I also believe that it would be interesting and valuable to explore how other children experience participating in activities with children who have disabilities, as well as their relationships with them. This is an important question from an agency perspective; participation and inclusion are both based on interdependency among children.

Taking a broader view, the field of disability offers a vast range of topics meriting further study. Virtually all of current disability theory is based on the perspectives of adults, whether individuals with disabilities or professionals. The potential for new theoretical insights based on children`s experiences of disability and impairment is huge. Finally, we ought to know why professionals retain certain practices even though interviews with them indicate that many believe that some of these practices are based on dichotomies of disability/ability that should be questioned.

6.4 Conclusion

This qualitative interview study extends previous knowledge on children with disabilities and everyday life. By interpreting children`s experiences, the results from this study have contributed with a deepened understanding of their participation in everyday life and their perceptions of themselves as active kids, living full and active lives from using their abilities in different settings. This study also provides insight into the dilemmas and challenges these children encounter in their everyday life, and provides compelling evidence that spending time with "mainstream" friends and peers is vitally important to them. This study have also presented findings that challenge the concept of disability from the perspective of children`s self-representation and self-identity of being "ordinary kids". The results indicate that when given the opportunities and support they require, these children are talented at identifying and adopting strategies that enable them to establish relationships and engage in collaborative activities at school and elsewhere.

The results suggest that being attentive to children`s experiences and "voices" and observing their agency and collaborating with them in practice situations and in research can contribute to creating a more positive future of the "history of disability." The results reveal that the children in this study are quite able to share and represent their own experiences. Finally, the study concludes that using material based on children`s perspectives in research is a fruitful method for producing valuable knowledge that could enhance professional practices and the participation of children with disabilities in institutions such as schools, as well as in communities and (re)habilitation services.

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Scandinavian Journal of Disability Research, 2013
http://dx.doi.org/10.1080/15017419.2013.787368

'Being an ordinary kid' – demands of everyday life when labelled with disability

Mona Asbjørnslett[a]*, Sølvi Helseth[b] and Gunn H. Engelsrud[c]

[a]*Faculty of Health Sciences, Occupational Therapy, Oslo and Akershus University College, Pb. 4, St. Olavs plass, 0130 Oslo, Norway;* [b]*Faculty of Nursing, Oslo and Akershus University College, Oslo, Norway;* [c]*Department of Physical Education, Norwegian School of Sports Sciences, Oslo, Norway*

(*Received 23 November 2011; accepted 15 March 2013*)

Children who are labelled with disability resist being considered 'different'. This study was initiated to investigate how some children experience being positioned as disabled and how they adapt to demands of everyday life, including at school. Based on an analysis of interviews completed with 15 Norwegian children aged 12–14 and their parents, this study concluded that the children talked about themselves from their preferred self-identity as 'ordinary kids'. At the same time, they knew that being included in the broader community and being perceived as 'ordinary' required hard work. They were aware of, adapted to and supported certain social and academic norms in their environment and knew that other people's expectations of them were influenced by these norms. This study provides new insights into how children who are labelled with disability experience their situation and adapt to demands and expectations that they encounter in everyday life.

Keywords: children; disability; demands of everyday life; school; self-identity

Introduction

Medical and more general social perspectives and terms indicate that people labelled as disabled are considered 'different' or 'others' in relation to those considered to be 'normal' (Moser 2000; Grue and Heiberg 2006; Grue 2009). Researchers in disability studies state that the label is typically applied as an unproblematic concept that 'only' denotes functional limitations – for example, with movement and in fulfilling tasks in everyday life (Kuppers 2001; Tøssebro 2004). However, disability as a word or concept is ambiguous and contested, both in its usage and how it is understood, and has been critically examined within the social sciences, as well as in disability studies (Wendell 1996; Overboe 1999; Kuppers 2001; Grue 2011). In discussing the phenomenon of psycho-emotional disablism, Carol Thomas also problematizes hurtful words and social actions, intended or unintended, endured by people with impairments (Thomas 2007, 72). Research based on subjective experience and children's perspectives shows that children who are viewed as disabled tend to resist being labelled as different or 'other' (Jahoda et al. 2010). They usually position themselves with and like any other child, and describe themselves in terms of their

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*Corresponding author. Email: mona.asbjornslett@.hioa.no appearance and personality, rather than as disabled or impaired (MacArthur et al. 2007; Bjorbækmo 2010; Dreyer, Steffensen, and Pedersen 2010). They categorize their diagnosis or disability as something they happen to possess and manage; some of them assert that it is not a 'big deal' in their life (Connors and Stalker 2007; Shihako-Thomas et al. 2009). Despite their diagnosis and/or physical limitations, children can adapt to activities and friendships at school and in their neighbourhood, as well as while spending time with friends who have the same or a similar diagnosis (Bjorbækmo and Engelsrud 2008; Asbjørnslett, Engelsrud, and Helseth 2012). These children want to be where things actually happen. Rather than focus on their limitations; they prefer to adapt in any way necessary to overcome obstacles in their environment (Asbjørnslett and Hemmingsson 2008; Harding et al. 2009). Nevertheless, they inevitably encounter structural elements in their daily lives, as well as in cultural practices of both adults and children, based on discriminatory conceptions of 'normality' and 'difference' (Davis and Watson 2001). School is an institution where children are expected to fit into pre-existing educational and social processes and practices based on 'normality' that allow little room for investigating or understanding differences (Davis and Watson 2001). In particular, children who are classified/labelled with learning difficulties/intellectual 'impairments' suffer from being marginalized from regular classroom activities (Wendelborg and Tøssebro 2010). Some teachers appear to take little responsibility for ensuring that all of the children in their classes have equal opportunities to learn (MacArthur et al. 2007). One explanation for this identified by Egilson and Traustadottir is that some teachers find it difficult to stray from the standard curriculum (Egilson and Traustadottir 2009). Despite these obstacles, children who are viewed as disabled speak positively about school (MacArthur et al. 2007).

Like other researchers, we believe that the views of children and their parents often differ, and that many studies omit significant elements of a child's own story, in which he/she is are represented as an active social agent (Garth and Aroni 2003; Uprichard 2008). Despite this argument, parents/caregivers remain the primary source for insights into the experiences of children; child informants remain notably rare in published studies. This article seeks to partially redress this paucity of research by exploring how some children who have been labelled as 'disabled' experience their efforts to demands of their everyday life.

Theoretical approach

As previously stated, a growing number of social scientists have challenged the view of disabled people as 'different'. Margrit Shildrick, for example, a professor and reader in gender studies, challenges the concept of disability that treats it as a 'universalizing discourse' (Shildrick 2009). These discourses, she argues, view disability as a single classification and treat people with disabilities as 'others', a perspective that distorts normative expectations and destabilizes the self-identities of disabled persons. She believes that disability should be viewed as an existential phenomenon, which requires people to be understood through their own experiences (Shildrick 2009).

Shildrick acknowledges that if 'we abandon the conventions of fixed identities of disabled and non-disabled people, we enter into "risky territory"' occupied by people who manage to evade the grasp of normalization and, to a certain extent, by researchers/theorists willing to move beyond the perceived demands of 'emancipatory' research (Shildrick 2009, 144, 177). She argues that academics and the general public, including those who live with disabilities, need to be willing to take that risk. If we breakthrough the impasse of existing forms of discourse on disability, Shildrick asserts, we can achieve new and more productive thinking about people's own embodiment that is not dependent on labelling bodies as able or disabled. She recognizes that deploying this post-conventional discourse involves uncertainty and fluidity, as well as risk, but believes that this type of 'dangerous discourse' yields a more accurate description of the experience of disability than researchers can obtain using conventional medical models and definitions. Phenomenologist and dance researcher Tone Pernille Østern takes a similar approach. The word 'disability', she points out, is burdened by a set of associations that make it difficult to relate to experiences outside its predefined parameters. She suggests substituting the term 'differently bodied', which would include everybody and offer an alternative to normative embodiment (Shildrick 2009; Østern 2009).

The discourse on disability is an ongoing process, continually changing and being renewed (Kuppers 2001; Shildrick 2009). This study is meant as a contribution to this process. It is informed by the arguments of Østern and Shildrick that disability studies could benefit by developing a phenomenological perspective, which holds that everybody, regardless of how they are defined by society, has valuable experiences that can contribute to the field of research.

Methods and sample

Design

To elicit everyday life experiences, we arranged qualitative interviews with both children and their parents, though we regarded the children as our primary informants. The interviews took place during the transitional period between primary and secondary school. This provided an opportunity to explore and analyse the children's expectations and the changes in their life situation as they entered adolescence. Three researchers conducted the initial interviews, which took place as the children completed primary school. We also interviewed their parents at this time, to get their take on the situation of the children, particularly the transition to secondary school. Thus, our data on the everyday life concerns of the children, as well as their life changes and expectations for their future, was comprised of material from both children and their parents (Christensen and James 2008). In this article, we have relied primarily on data from the children, though we have sometimes complemented or contrasted their perspectives with data from the parent interviews.

Life mode interviews

The present study was based on 39 tape-recorded interviews with the children and 22 tape-recorded interviews with parents. To investigate how children and their parents experienced everyday life events, we asked questions about a specific day, i.e., the day before the interview occurred (Haavind 1987; Andenæs 1991; Gulbrandsen 2010). This ensured that real events and experiences formed the basis for reflection and a joint exploration of meaning by the child and the adult (Gulbrandsen 2010). The life mode interviews consisted of open questions such as 'What happened then?' and follow-up questions like ‘Is that usual?’ Within these parameters, the form and content of the interviews varied according to the predilections of the interviewee. Some took place in the child’s home, others at school. The duration ranged from 20 to 75 minutes. Most of the children readily offered rich descriptions of their everyday interests and activities, but some tended to answer questions with a ‘yes’ or ‘no’ or some other short phrase. We interviewed each child between one and four times, usually three times. We also interviewed the mother, the father or both parents of each child, either at home or at their workplace, some once and some twice. These interviews lasted between 35 and 70 minutes.

Sample

Fifteen children (nine boys and six girls) between 12 and 14 years old participated in this study. All of them were living in or near the city of Oslo, Norway and had been diagnosed as having a physical impairment, including one who had a visual impairment. Two had learning impairments as well. At the time of the interviews, all of the children were attending mainstream schools.

The sample was recruited by health professionals such as occupational therapists and school nurses in the communities where the children lived. We contacted them directly, and asked them to identify potential informants and contact the parents for us. The parents were informed about the project verbally, in an information letter and through a brochure. Parents who gave their consent were asked to see if their children were willing to participate in the project. If a child agreed, the health professionals notified us and we made direct contact with the parents to arrange our first interview with her or him.

Ethical considerations

This study was approved by the Regional Committees for Medical and Health Research Ethics (REC) and the Norwegian Social Science Data Services (NSD). It adhered to all of the legal requirements for the protection of personal information and prevention of recognition based on diagnoses. In addition to requiring informed parental consent (Brinkmann and Kvale 2008; Kvale and Brinkmann 2009), we ensured that each child was given a consent letter to read and discuss with his or her parents and sign it before we made direct contact (Helseth and Slettebø 2004; Hill 2006).

Partly out of respect for ethical considerations in an interview situation, we made every effort to listen attentively to the children, as well as to remain aware and conscious of the overall situation and the informant’s own perspectives (Brinkmann and Kvale 2008; Neumann and Neumann, forthcoming). The responses and reactions of the children encouraged the researchers to reflect upon their own normative preconceptions. These reflections played a crucial role in shaping the central theme and theoretical approach of this study (Greene and Hill 2006; Neumann and Neumann, forthcoming). Our use of the dichotomous terminology of ability/disability before we had heard and understood the perspectives of the children could have biased our research and may have hindered the development of new and productive ways of thinking about the phenomenology of embodiment (Shildrick 2009). However, we believe that by placing our own experience ‘at risk’ and acknowledging our own prejudices, we were able to achieve insights into the significance of the label ‘ordinary kids’ (Graham and Fitzgerald 2010; Neumann and Neumann, forthcoming). The children’s modes of participation in the interviews varied from simple politeness to serious interest, depending on the information provided by the parents and on the personality of the individual child. The level of participation may also have at least partially reflected the parents’ degree of engagement in the project; some felt that it was in their child’s interests to participate and encouraged her or him on that basis (Hill 2006).

Analysis

The initial analysis was performed by the first author, who conducted most of the interviews; it continued throughout the transcription of the texts (Kvale and Brinkmann 2009). Some interviews and transcriptions were completed by two research fellows. As a result, the analysis of these interviews did not benefit from enrichment based on the context of the interview and direct contact with the interviewee. The quality of the interviews varied; some of them suffered from a lack of in-depth information. As a result, some of the children’s interview transcripts were used more extensively than others. In all cases, the researchers and the authors of the article discussed the assumed meaning of the text material.

Following the initial analysis, the authors read the material several times to discern core meanings in the text and get a sense of the whole (Danaher and Briod 2006; Kvale and Brinkmann 2009). Based on the impression that the children did not talk about themselves as disabled, the authors proceeded to a more advanced analysis, posing two questions: (1) How did the children express their self-identity in the interviews? and (2) How did the children talk about their everyday life experiences? The authors determined that the most salient aspect of the material was the children‘s self-identity as ‘ordinary kids’. Since this concept was used to capture the way in which the children talked about themselves and their lives as ‘ordinary’, but expressed this in different ways, we also reflected on how they applied the concept. Their reflexive usage indicated awareness that they had embodied the feeling that being thought of as ‘different’ and treated as ‘other’ was a risk in everyday life situations. We therefore determined that being viewed as ‘ordinary’ was an important issue for our children and used it as a prior focus in our analysis. We also decided to look at how the children adapted to demands of everyday life from this perspective, and the hard work they sometimes undertook in an effort to see themselves and be seen as ‘ordinary’.

In our analysis, we frequently used quotations from children and parents to remain as faithful to their own voices and expressions as possible. We used theoretical perspectives about disability discourse in terms of subjectivity, embodiment and self-identity to highlight some of the cultural ideas embedded in the expressions that subjects used in their interviews (Kuppers 2001; Østern 2009; Shildrick 2009). The authors concluded the process of examining and rewriting the text by conducting a final collaborative verbal and written analysis (Van Manen 1990). The importance of ‘being an ordinary kid’ is the overriding message in our analysis and our presentation of results. Based on this perspective, we present three subthemes: rejecting the disability label, adapting to norms and expectations, and working hard to be ‘an ordinary kid’.

Being ‘an ordinary kid’

‘Being an ordinary kid’ always seemed to be the prior and preferred self-identity when children talked about themselves and what they did in everyday life. The children talked about ‘community and inclusion’ from a self-identity of being active kids engaged in a variety of activities, such as a theatre group, singing in a choir or scouting, which demonstrated their capacity to participate with their peers. The children talked about the importance of being with other children on a regular basis, and described experiences they had shared with their classmates and friends. They described some of these experiences positively, reflecting their feeling of inclusion in a community. For example, playing in a marching music band created a positive feeling of mutual dependence and of ‘a rhythm inside you’. These feelings were not constrained by the child’s use of a wheelchair or other functional challenges. In describing their participation, the children consistently expressed an ‘ordinary kid’ self-identity.

Rejecting the ‘disability’ label

The children in our study did not present themselves as being disabled, nor did they talk about themselves as disabled. Some of them observed that being positioned as disabled by others was problematic. They expressed their discomfort by explaining that they did not want to be viewed as ‘different’ among their friends, pointing to the disability label’s association with difference. One teenage girl said that the term ‘disabled’ referred directly to her lack of ability and dysfunction. These associations were incompatible with her self-identity. She went on to note that she appreciated having friends who ‘don’t consider me different from anyone else’; their attitude supported her perception of herself. Through these statements she demonstrated her resistance to being called disabled, a term that she felt was encumbered with negative associations and put her at risk of being positioned as ‘different’ within her local community of friends.

The disability label sometimes aroused a sense of alienation and discomfort in the children. The clearest expression of this came from a 13-year-old boy in response to an interviewer’s initial query: ‘What does it mean to be disabled?’ Clearly surprised, he asked quietly, ‘Am I disabled?’ He had not considered himself to be disabled and expressed discomfort at being placed in this category by the researcher. In his view ‘others’, slightly worse off than he could be classified as disabled, but this was not a term that he considered relevant to himself. His answer reminded the researcher of her own prejudice. Despite her intention to contribute to new understandings of disability, she had employed the term in accordance with the very tradition that she sought to problematize.

Some children stated that instead of labelling themselves as ‘disabled’, they used their diagnosis to talk about problems related to their condition. ‘I say that I have back damage’, a 13-year-old girl stated, ‘not that I am disabled’. By using the word ‘damage’, she and other children pinpointed their limitations or the lack of capacity and function that they had to cope with as part of their daily bodily experiences; something they needed to ‘overcome’ when working with or negotiating with others. Children also referred to their diagnosis when they wished to make certain conditions understandable to others. ‘When you have [this diagnosis] many things could be the matter, not only physical’, one boy explained, ‘and these things with my legs are pretty stupid'. He considered his legs the main obstacle to his desire to play football. Not only were such specific descriptions of damage and diagnosis convenient for explaining problems to friends, the children found they also provided guidelines for professionals who already had knowledge of the situation based on a diagnostic clue, e.g., 'When the doctor knows my diagnosis, he knows what to do'. The children's thinking was that the personal inconvenience resulting from a diagnosed issue or damage could be treated as part of their individuality, so they could still view themselves as similar to others.

Adapting to norms and expectations

Children in our study would often push boundaries and adapt their appearance and behaviour to what they considered to be 'normal' among the children they were with. This view was exemplified by the comments of a 12-year-old boy and a 13-year-old girl. 'I usually walk [with orthopaedic aids] at school, because it seems more normal', explained the boy, who was still in primary school, 'but when I'm with friends who are in a wheelchair I use my wheelchair more'. The girl, who had entered secondary school, declared that she would not use an electric wheelchair or the bike with supporting wheels that she had used in primary school.

These children adapted their strategies of locomotion to what was considered 'normal' in a particular context. What was important to them was to a get around in a similar manner to the children around them, whether that meant walking or using a wheelchair. For the teenage girl, using a wheelchair embodied a subjective sense of embarrassment. To avoid this feeling at secondary school, she preferred to walk. The choices of this boy and girl reveal that children are at least sometimes willing to exert great effort to get around as their peers do rather than risk the stigma they may already endure in other areas.

In learning situations at school these 'ordinary kids' expected to be included in their classmates' 'mutual struggles' to complete activities such as homework, even if they knew that this meant surmounting extra challenges. One boy classified with learning difficulties questioned why he had not received any homework, which he believed should be expected of him, as well as his classmates. Such expectations required sufficient support if he were to succeed. The same boy commented that the individual help provided by his secondary schoolteachers was not always what he felt was required. Other children in this study, however, pointed out that teachers had to be accessible to the whole group. 'I cannot expect that he will only take care of me' one put it. 'In this group, everybody must be allowed to join in'. These experiences show that individual needs sometimes exceeded a teacher‘s availability, however the children also acknowledged that in a learning environment they had to adapt to the common interests of the entire group.

The children were concerned about their own situation, but they did not want the constraints on their own abilities to affect other children. Sometimes, not being able to fulfil normative requirements put children on 'the side-lines', in various learning situations. For example, a girl who participated in physical training commented: 'In the gym I'm always sitting . . . sitting on the side-lines, but I think that's okay, because there are some things I can't do, or I don't have anything to do, so I can sit and watch the others'. Her adaptation to not being able to perform in the same way as the other children was to support what the others did. This attitude of behaving and adapting in a manner that was best for all was also evident in leisure-time activities. One boy, for example, told the interviewer, 'I like football, but I can't play myself, even though I have friends playing, because it would ruin the flow'. Sports were considered culturally rewarding, and the most popular children were said to participate in handball or football. The children in our study were functionally excluded from these activities. In addition to the intrinsic attractiveness of sports, the children in our study cited the interdependence and long-lasting friendships that they fostered as important reasons for participating. One 12-year-old boy who had been on his local football team for a long time told us how he was able to continue playing:

> Often, when we have games, I'm allowed to play.... If I just attack, I can switch with someone else on my team between attacking and defending, so I don't have to run across the whole field; I just run half.... If we rush, I ask if I can stay back on defence.... Now, I also play table tennis twice a week.

As this example shows, innovative strategies coupled with mutual understanding and support from teammates and trainers could help some children participate in a variety of sporting activities. In this case, the boy's lack of strength, balance and physical capacity ultimately compelled him to give up playing the sport he loved. However, his interest in football and his local long-lasting friendships he developed while participating continued to be meaningful to him, and he remained a supporter of the team.

Working hard to be 'an ordinary kid'

As a rule, the children did not problematize their situation and were motivated to meet the challenges they encountered in everyday life. At the same time, meeting these challenges demanded hard work and raised concerns about their use of time and energy to function on a daily basis. Keeping up with schoolwork and getting good grades were a particular concern in the transition to secondary school. The pressure anticipated was depicted in various ways. 'I can't always manage everything', one 12-year-old girl admitted when discussing her schoolwork, 'but I'm almost there'. A 13-year-old girl was less confident while expressing this fear when she had just started secondary school: 'I have difficulty dealing with a lot of pressure, and I thought it would be really exhausting...with just loads...loads...loads of homework that I wouldn't be able to get through'. Another girl added that twice a week she was spending four hours on homework. Her mother agreed: 'The time she spends on homework is insane; three to four hours if she finishes it properly'. The mother of a 12-year-old girl with a visual impairment said that her daughter spent more time on homework than her schoolmates and still lagged behind. She admired her daughter's determination to succeed in secondary school, but thought that wouldn't be enough: 'She is trying...She's got a brave mind-set...She is prepared...[but] it is going to be too much'.

When organizing and completing schoolwork was a problem, the difficulties were often related to a child's learning and/or physical difficulties. The considerable stress that could result from a lack of physical capacity meant that learning difficulties could sometimes be exhausting. This often raised questions for the children, such as 'I wonder if they [the teachers] know about my diagnosis; I feel like I have to do so much'. The child who said this suggested that his diagnosis might have served as a guideline to help teachers understand his situation. It also illustrates his concern that the teachers be qualified and support his efforts to be an 'ordinary kid' by accommodating his personal challenges in the school environment.

Despite their worries about performing well enough, the majority of the children in this study did well in secondary school. Most of them achieved average or better grades, and did not consider the workload more onerous than it had been in primary school. They established good friendships with classmates. Most said they liked the greater freedom in secondary school and thought the teachers there were 'more fun'. Being able to choose among different subjects helped some of them feel 'more relaxed'. A few children, however, experienced feelings of loneliness and academic failure; they found the school requirements too challenging.

Some of the children also reported that their leisure-time activities, including jobs, required hard work and placed them in mentally demanding situations. 'I would like to sell all [the papers], but it takes such a long time', said a boy who had been diagnosed as having physical and learning impairments. 'Still, I don't know of any other job I would like better'. Selling newspapers was a common activity among boys his age, and he did it voluntarily during his leisure time. Four months later, he continued to talk about his work and the challenges it presented: 'I have some regular customers, but I don't always remember which ones I've been to. I don't remember who wants to buy and who doesn't, because the apartment buildings have so many doors'. This boy exemplified the great efforts that the children in this study expended in their daily life, based on their expectations of the normal behaviour of their peers. The demands of his job were considerable: time management, planning, organizing and remembering what to do. From the experience of failure this boy, as well as other children frequently demonstrated his capacity to identify new ways of doing things and new things to do, partly by soliciting the assistance of others by asking; 'what can I do instead?'

Discussion and conclusion

In this study, we have examined everyday life demands from the experiences of children who are labelled with disability and thereby positioned as disabled by others. In this section, we will discuss three elements of our analysis. First, our main finding: The children in our study present a preferred self-identity as 'ordinary kids'. Second: These children adapt to norms and expectations in everyday life. Third: These children expend great efforts to be perceived as 'ordinary' by others and be included in the broader community.

Like children in other studies on similar issues, our young informants did not want to be viewed as 'different'. When comparing themselves to other children, they focused on similarities rather than differences (Connors and Stalker 2007). In their role as active kids, they told us that they were embodied with feelings of 'rhythm', mutual dependence and inclusion with other children. They stressed the importance they gave to sharing and participating in different social arenas with others, corroborating previous research (Grue and Heiberg 2000). This conclusion supports the value of Østern's argument for viewing all children as 'differently bodied', which creates a space that includes a wide range of different and individual abilities and avoids the conceptual exclusion of some children based on a perceived deficit in abilities. Her perspective might be beneficial in modifying professional understanding and attitudes (Østern 2009).

The term disabled can be problematic when introduced in everyday situations and language. Some children associate a label of 'disabled' with alienation and discomfort. Furthermore, as other researchers have observed, the word disability is ambiguous and contested (Thomas 2007; Grue 2011). The children in our study preferred to explain certain challenges they encountered by characterizing them as diagnoses and damages, which could be integrated into their self-identity and used to specify particular difficulties and provide guidelines for professional practice. Our results reinforce the view that labelling children without considering their self-identity risks destabilizing it (Shildrick 2009; Jahoda et al. 2010). This supports the argument of researchers who have called for a discussion of how the concept of disability is embedded and used in professional practice and everyday language (Wendell 1996; Watson 2002; Tøssebro 2004; Edwards 2007; Shildrick 2009; Jahoda et al. 2010).

Our study illuminates how children often extend categorical boundaries to include what they consider 'normal' and their commitment to what they consider to be the common interests of all children. School is an example of an institution in which exclusive normativity is embodied (Shildrick 2009). The children in our study demonstrate that they can adapt to this institutional normativity; for example, by choosing not to use technical aids in certain situations. Such adaptations are consistent with the findings of prior studies concluding that children find strategies that allow them to position themselves as competent, normal subjects relative to the people around them (Bjorbækmo and Engelsrud 2008). However, the sometimes strenuous efforts of these children to adapt to norms and expectations in their environment also indicate that they do not want their reduced capacity to impede other children. They sometimes support what other children do by viewing activities such as physical training exercises or football games from 'the side-lines'. These children sometimes have the experience of being on 'the side-lines' in learning situations. Some of them express a desire for more help than they actually get. As other researchers have pointed out, children with learning difficulties run a higher risk of being marginalized from learning activities than other children (Wendelborg and Tøssebro 2010). At school, the children in our study expected to be included in 'mutual struggling', for example, with homework, which enabled them to try to make sense of the school world in the same manner as other children (Jahoda et al. 2010). Our results problematize whether schools can truly promise equality for all children and on what basis this might be possible. They indicate that the adaptations of some children to normalizing processes create a danger that they will not be 'heard and seen' appropriately for their particular needs. Schools and other institutions should be alert to this danger, as well as to the contrary risk that being 'heard and seen' as 'disabled' could lead to exclusion from social and scholastic situations.

Some environments include all 'differently bodied' (Østern 2009) children. The support and understanding of teachers, trainers and other children is vital to ensure that all children are included, both at school and in meaningful leisure-time activities. Being an 'ordinary kid' often requires hard work and judicious use of time and energy. The children who need to meet these challenges are motivated to do so. As the study of Harding et al. shows, they adapt to and overcome obstacles, rather than focus on how their impairment might limit their participation (Harding et al. 2009). The transition from primary to secondary school is particularly challenging for some children. Based on normative expectations, both children in our study and their parents expected pressure, including heightened demands in homework and organizing schoolwork. Some of these children spent a lot of time keeping up with other children and overcoming myriad everyday challenges. They had to maintain a 'brave attitude' while 'preparing themselves' to succeed in their life goals. Occasionally, this entailed experiencing failure. Teachers need to be aware of the amount of stress and exhaustion that some children experience due to deficits in capacity. As one of our informants observed, the challenge for the teacher is to provide sufficient attention to children who do not require special accommodations while meeting the diagnostic requirements of children who do. Our study revealed the great efforts children with disabilities are willing to make based on their own conceptions of the school and leisure-time behaviour of their peer group. Our results are consistent with those of other studies, which found that these children usually develop strategies for overcoming limitations and constantly adapt to their life situation as active social agents (Uprichard 2008).

Children who live with a 'disability' label and are treated as disabled see themselves as 'ordinary kids', even though they are aware of being 'different' in some respects. They adapt to everyday life and 'work' to 'normalize' themselves at school and in their leisure time. Most significantly, our results indicate importance of eliciting the perspectives of the children themselves when investigating their daily lives and experiences. What they reveal may challenge the ways in which researchers, as well as health and school authorities, currently perceive and label some children, and suggest new strategies to create more inclusive environments that enrich the lives of all participants.

Acknowledgements

Special thanks to the children and parents who participated in this study, sharing their unique experiences. The authors would like to acknowledge Kari Opsahl and Bennedichte R. Olsen for collaborating and conducting interviews to this study. We would like to thank the peer reviewers for qualified and valuable support. This article is part of an interdisciplinary research project Professional Practices and Children‘s Participation, at Oslo and Akershus University College (OAUC), which has contributed to an overall inspiration and support. This study received financial support from The Research Council of Norway (RCN) and Oslo and Akershus University College (OAUC).

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How Children with Disabilities Engage in Occupations during a Transitional Phase

Mona Asbjørnslett, Gunn Helene Engelsrud & Sølvi Helseth

This study explored the engagement in occupations of Norwegian children with physical disabilities during a transitional phase between primary and secondary school. Fifteen children described their ordinary day, and we applied a life mode interview method. Three themes were identified: 1) occupations that symbolized the transition to becoming a teenager, 2) expanding possibilities by occupational engagement in social networks and media, and 3) particular challenges when adapting to participation in culturally valued occupations. The children in our study engaged in typical occupations associated with this transitional phase. Some occupations, such as shopping and putting on makeup, symbolized a transitional phase. Engagement in occupations such as using social media, the Internet, and gaming represented expanding possibilities, where children with disabilities could participate without limitations. However, adapting to culturally valued occupations such as sports, which can be particularly challenging, might require a change in how they engaged, for instance by becoming the leader of a cheer group rather than playing soccer. Knowledge of children with disabilities and their engagement in everyday occupations is essential for discussing how they can participate in occupations they find meaningful together with their peer group in their community.

Keywords: Children, Disability, Everyday life, Occupation, Participation, Transition

■ Mona Asbjørnslett, PhD candidate, Faculty of Health Sciences, Oslo and Akershus University College of Applied Sciences, Oslo, Norway

■ Gunn Helene Engelsrud, Professor, Department of Physical Education, Norwegian School of Sports Sciences, Oslo, Norway

■ Sølvi Helseth, Professor, Oslo and Akershus University College of Applied Sciences, Faculty of Nursing, Oslo, Norway

■ Correspondence to: mona.asbjornslett@hioa.no

Journal of Occupational Science, 2014
http://dx.doi.org/10.1080/14427591.2014.952365

Children's development is inevitably allied to their engagement in everyday life occupations, their social environment and culture, and most significantly their relations with other people (Humphry, 2002). In the transitional phase of becoming teenagers, they increasingly focus on their physical appearance. While they struggle to gain acceptance, they are engaged in continuous subjective negotiations with respect to their bodily practices and behavior (Hauge, 2009). During this phase, teenage clothing may become tighter and more revealing for some girls, and a change that represents a "disappearance" of childhood may also become more important (Rysst, 2010). Although many early adolescents are overwhelmed by feelings of self-doubt and insecurity, this is also a period filled with optimism, when 12- and 13-year-olds welcome the removal of childhood constraints. As they become less dependent on others they transform themselves, such that this period represents a phase when young people indeed "find themselves" (Bakken, 2013; Frønes, 2011). Thus, the early adolescent and transitional period between primary and secondary school can also be a particularly vulnerable and stressful period, when the risk of identity crisis and being bullied may increase (Hallberg, Stavropoulos, Mohlin, & Hagberg, 2012; Pellegrini & Long, 2002; Zeedyk et al., 2003). For children, this phase involves adapting to new environments and routines, and some children worry about becoming lost in their new school situation, as well as their increased workload and new status among their friends (Rice, Frederickson, & Seymore, 2011).

The occupations of children are also affected by their gender, as well as being shaped by the dialectic between individual and social meaning in their environment, where the two might not always be the same (Beagan & D'Sylvia, 2011; Gulbrandsen, 2003; Hauge, 2009). Children's identities are also shaped by what they do and the people they spend time with (Phelan & Kinsella, 2009, 2013a). In general, young teenagers in Norway spend time with family and friends; they often meet at home or in organized occupations such as sports (Bakken, 2013). Children in Norwegian culture also spend a considerable amount of time watching television and using their computers (Vaage, 2012).They also meet on the streets, and teenagers generally want to be involved in city life, such as socializing in cafés (Bakken, 2013; Kroksmark, 2005). During the transitional phase of becoming a teenager, they also engage in new types of relationships that involve talking and flirting between boys and girls (Gulbrandsen, 2003).

Children with disabilities are at risk of limited participation in daily occupations, alone or with others, while experiencing fun, enjoyment, and the exhilaration of success (Heah, Case, McGuire, & Law, 2007; Nyquist, 2012). In a transitional phase, children with disabilities can also be particularly vulnerable, and a change of school can be especially challenging (Rumsey & Harcourt, 2004). Visible differences from the 'norm' can be a 'social disability,' sometimes leading to negative self- perceptions and difficulties in social interaction (Rumsey & Harcourt, 2004). To be viewed as different in their early teenage years can be particularly challenging and some children find that the years between the ages of 10 and 14 are the most difficult period for negotiating self-image, peer interactions, and social position (Gulbrandsen, 2010; Ytterhus, 2012). For example, it is suggested that children with specific learning difficulties are at risk of lower levels of social support and more peer victimization after the transition to becoming a teenager (Hughes, Banks, & Terrass, 2013). For children with disabilities, participation in everyday life can require hard work, but like any other children in the transitional phase, they are concerned with peer relations, schoolwork, and meaningful occupations (Asbjørnslett, Engelsrud, & Helseth, 2012; Asbjørnslett, Helseth, & Engelsrud, 2013). If their main motivation is to be with other children, they use whatever accommodating strategies their life situation requires to participate in their social and cultural environment, thereby adapting to 'common' occupations and building friendships (Asbjørnslett & Hemmingsson, 2008; Asbjørnslett et al., 2012; Bjorbækmo & Engelsrud, 2008).

Research into the experiences of children is limited in this context. The voices of young people with disabilities, in particular, have been marginalized and ignored by researchers (Carpenter, 2012; Corsaro, 2011; Scott, 2008). A consequence of marginalizing children in research is that they are viewed as the objects of research, rather than subjects (Greene & Hill, 2006). The design of this present study is in response to this deficiency by exploring the experiences of children with physical disabilities and their engagement in everyday life occupations, including their relationships with others. We focused on the period when children become teenagers during the transition from primary to secondary school in Norway. We selected this period because it is filled with new expectations and changes, including engagement, as well as concerns about school and new relationships. We applied an occupational science perspective and a sociocultural approach to study the everyday lives of children with disabilities and their engagement in apparently meaningful occupations during this transitional phase, where we elicited their own perspectives on these experiences (Davis & Watson, 2001; Scott, 2008; Watson, 2012).

Scientific and Theoretical Perspectives

An occupational perspective, which is a way of looking at human doing and everyday occupations (Njelesani, Tang, Jonsson, & Polatajko, 2012), informed the study. To outline and understand the occupations of the children in this study, we employed three premises from occupational science. First, since its inception, occupational science has been associated with exploration of the culturally and personally meaningful occupations in which people engage on a daily basis (Yerxa et al., 1990). Thus, the first premise assumes that what people do shapes who they are; that is, that occupation expresses both individual and social identities (Hasselkus, 2002; Wilcock, 2006). Second, everyday occupations are situated and interrelated. Individuals continually interact with their environment, including conversations and feedback in specific contexts, which connect people within local cultures via ongoing actions (Alsaker, Josephsson, & Dickie, 2013; Cutchin & Dickie, 2013; Rudman, 2013). Third, explorations of the meaning of occupations in everyday life have the potential to be emancipating because they can support the right to engage in meaningful occupations, thereby facilitating inclusion and participation in society (Hocking & Whiteford, 2012; Rudman, 2013).

From a sociocultural perspective, people's engagement is embedded with meanings that can be personal and individual, as well as social, which in some ways are always intertwined (Leontiev, 1978). Children's development and what they do occur through active engagement with their environment, including engagement with other people (Corsaro, 2011; Hedegaard, 2008; Hedegaard, Ulvik, Aronsson, & Højholt, 2012). Children use their engagement within their cultural and social environments to construct their own childhood through their simultaneous understanding of what it means to "be a child" and to "become an adult" (Uprichard, 2008). From a sociocultural perspective, children are active participants in their own lives and agents who represent and are capable of articulating their own childhood experiences (Hedegaard et al., 2012; Percy-Smith & Thomas, 2010).

The perspective adopted in the present study is that the meaning of being a child and becoming a teenager embraces a particular transitional situation. Thus, children who are engaged in specific situations, including occupations and relationships, take their opportunities and adapt continuously based on their perspectives. We applied this concept to the exploration of the everyday life experiences of some children with disabilities. Based on the premises stated earlier, we asked the question: "What do Norwegian children with disabilities do, and how do they engage in various occupations during the transitional phase between primary and secondary school?"

Methodology

This study employed an interpretive and descriptive design, where the individual and social meanings given by the informants to their own occupational experiences were of particular interest (Sandelowski, 2000). We obtained and explored the children's experiences by using a life mode interview method, which is an open interview approach that is suitable for interviewing children (Ulvik, 2007). We elicited the actual everyday life experiences of each child by asking her or him to talk about what happened on the previous day and what usually happens during a normal day (Andenæs, 1991; Gulbrandsen, 2010; Haavind, 1987). The open interviews gave children the opportunity to describe what they did when they were alone or with other children, and their interactions with other children during an ordinary day. Each interview began with introductory questions such as "Tell me about what happened yesterday" or "When did you get up?" Next, we asked follow-up questions, such as "Is that what usually happens?" or "What happened next?" After interviewing each of the children on several occasions, we learned how the things they talked about evolved over time and how their engagement in what they considered meaningful occupations did or did not change over the same period. To encourage them to provide this information, the follow-up interviews included prompts such as "The last time I was here you told me what you had … what has happened since then?"

Sample

This project involved 39 interviews with 15 children (nine boys and six girls) who lived in rural and urban communities in and around Oslo, Norway. They used a variety of equipment to assist independent mobility, and were interviewed between one and four times when aged 12–14 years. See Table 1.

Table 1: Demographic Details of the Children's Physical Status and Age When Interviewed

Children	Physical Status	Age at Interview (Years)	Number of Interviews
Boy 1	Walks with aids or wheelchair	12, 13	4
Boy 2	Wheelchair	12, 14	2
Girl 3	Visual impairment	12, 13	3
Girl 4	Wheelchair	12, 13	3
Boy 5	Walks with aids or wheelchair	13	3
Girl 6	Wheelchair	12, 13, 14	4
Girl 7	Walks with aids	12	1
Boy 8	Wheelchair	13, 14	3
Boy 9	Wheelchair	13	2
Boy 10	Walks with aids	13	1
Boy 11	Walks with aids	12, 13	3
Boy 12	Walks with aids	13	3
Boy 13	Walks with aids	12, 13	3
Girl 14	Walks with aids	12, 13	2
Girl 15	Walks with aids or wheelchair	12, 13	2

Inclusion criteria

This study included children who had some form of physical impairment; in one case, this was a visual impairment. Two of the children also had learning challenges. All of the children attended mainstream schools and classes. We only recruited children from the final year of primary school because the aim was to follow them in the transitional phase to secondary school. Data were collected between the spring of 2009 and the spring of 2011. We recruited the children first by direct telephone contact with professionals, such as occupational therapists located in the communities where the children lived. These professionals made contact with the children's parents to discuss their potential participation in the project. After the children had agreed to participate, the researchers made direct contact with the families to obtain written consent from the parents and children.

Three researchers conducted the interviews, with the first author interviewing nine of the children. We conducted the interviews at the child's home or school, and they lasted 30–90 minutes. The goal was to interview each child three times: once during the last year of primary school and twice during the first year of secondary school. Ultimately, we interviewed two children on only one occasion, four on two occasions, seven on three occasions, and two on four occasions. That variation occurred because one child moved to another part of the country, one informant was reluctant to participate in more than one interview, and one boy was interviewed four times because a particular interest was followed up relating to some concerns about his school situation. We initiated some of the early interviews simply to give the interviewer and some of the children a chance to become acquainted, but these data were also included in the study material.

Ethical processes and permissions

The Regional Committees for Medical and Health Research Ethics and the Norwegian Social Science Data Services approved the study. The study conformed to all legal requirements to protect personal information and to prevent any of the children from being recognizable based on a diagnosis. All of the parents gave informed consent to their child's participation (Brinkmann & Kvale, 2008). In addition, each child was provided with a written age appropriate assent letter, which they were asked to read and discuss with their parents before signing (Helseth & Slettebø, 2004; Hill, 2006). All of the children gave their permission for the interviews to be recorded, analyzed, and included in the study. The one child who withdrew from the study after one interview was asked for, and gave us, a new assent letter to confirm that we could include that interview in the study.

Interviewing children requires ethical reflection and sensitivity during the process of inquiry (Etherington, 2007; Phelan & Kinsella, 2013b; Warin, 2011). It is important to consider balancing the power relationship between the researcher and the child to ensure the child's safety and dignity, as well as to give a voice to the children who participate (Etherington, 2007; Phelan & Kinsella, 2013b). During the research process, we tried to empower children to share their experiences and to express their opinions by using safe environments such as their home or at school. We considered the nature of consent as well as the relational awareness and sensitivity between the child and the interviewer during each interview (Warin, 2011). We also asked the parents to be sensitive about their child's participation, and they were told that they could withdraw at any time.

With the exception of the one child who withdrew, we found that most children were interested and positive about participating in the interviews. They welcomed us back and treated the interviewers with politeness, while they were willing to share their experiences in different ways. We also found that our method of interviewing about everyday life occurrences provided an opportunity for the children to talk about what they found most interesting and important in their life situation, as well as a chance to choose what they wanted to talk about (Phelan & Kinsella, 2013a,b). Also from our experience, this approach can be a good method for eliminating the power imbalance between the child and the researcher (Etherington, 2007).

Analysis

The analysis followed a qualitative approach based on the interpretation of meanings (Fangen, 2008; Kvale & Brinkmann, 2009). The first step aimed to capture the child's "voice" and experiences in interview situations (Kvale & Brinkmann, 2009). Because the first author conducted most of the interviews and met the children several times, she influenced this part of the analysis by encouraging them to talk about how they were engaged in occupations in their everyday life and followed up significant themes on occasions. She also recognized when children talked enthusiastically about specific occupations. All of the interviews were recorded. The analysis involved spending hours listening to the tapes, recalling the interview sessions, and transcribing them verbatim. The entire body of text material was read several times, including a back-and-forth reading (Kvale & Brinkmann, 2009).

How the children engaged in specific occupations while they were becoming teenagers was a specific focus of the analysis; that is, how the children engaged in occupations and how they utilized their potential in everyday life. The inherent meanings of some occupations were discussed thoroughly with the coauthors, and three themes were identified: 1) occupations that symbolized transition, 2) expanding possibilities by occupational engagement in social networks and media, and 3) particular challenges when adapting to participation in culturally valued occupations. During this phase of the analysis, we determined and "rephrased" the language used by some of the children when discussing these occupations to a deeper extent. The second step was a critical commonsense understanding (Kvale & Brinkmann, 2009), which involved considering the "rephrased" language identified in our study from a critical distance. In the third step, theoretical understanding (Kvale & Brinkmann, 2009), we used occupational and sociocultural perspectives to enrich our understanding of the material.

The findings and discussion draw on the children's own experiences, including their personal meanings and engagement. The findings relate to the period when the children became teenagers and describe the occupational changes that they experienced, based on the second and third interpretations. In our presentation of the findings, we reiterated our belief that cultural and/or gendered constructions influenced the differences in occupational engagement by the children and the meanings of specific occupations, as well as their inherent potential. Translation of illustrative quotes from Norwegian to English was completed by the first author and checked by a language reviewer after the analysis was completed.

Findings

Occupations that symbolized transition

The girls in our study talked about their looks and appearance, and how that related to "*becoming*" a teenager. As they grew older, they talked about what to wear in terms of their "*new style*" and about using makeup. Two of the 13-year-old girls (one who used a wheelchair and one with a visual impairment) were happy to discuss their new style of dressing.

> *I realized that I had many sweaters I could give away. I had not outgrown them, but I had grown away from them.… I needed a good shopping trip with my helper.*

> *My style has changed since the first [interview]. My clothes are more extreme, with a lower neckline and trousers with holes in them—an edgier style.*

Both girls demonstrated their engagement in their transition toward a more "*teenage look*" or "*edgier style.*" This change or transition also included the need to "*purchase new clothing.*" The first girl preferred to shop with her helper, but the second girl told us that she used to purchase clothing with her father, who had not approved of her desire to wear trousers with holes in them. She also admitted that her father still paid for the clothes she bought. At this point, she revealed that her "*new style*" had to be negotiated with her father.

Around the age of 13, some girls also declared that they had begun using lip-gloss, and they advanced to wearing powder, foundation, mascara, and eyeliner. To compensate for her poor vision, one girl had negotiated extended time in the bathroom each morning. Putting on makeup could also have a playful element. "*We love to put on makeup and fool around*," said one girl who described a situation in her helper's apartment, "*so we put on a lot of red lipstick and showed ourselves off. It was fun.*" Her engagement in "*fooling around*" and "*showing off*" with makeup demonstrated that she was "*still being a child.*" At the same time, experimenting with new cosmetics and using different types of face makeup became a statement of a more "*adult look*," which they showed off at school, for example.

As they grew older, boys and girls tended to exhibit a "*change*" in their relationships. The comments of one of the boys when he was in primary school illustrated the earlier stage. He frequently used the term "*boy's stuff*" when reflecting on the interactions among boys at that age. During class breaks, he related; "*I talk with a lot of my friends. There are a lot of boys who are my friends.*" It was clear that he did not know what the girls were doing, nor was he interested at this stage in his life. When recalling the behavior of the boys in primary school, the girl with a visual impairment stated that they were doing "*childish stuff*," behaving in a noisy, disturbing, and annoying manner that disrupted the classroom situation. However, when discussing her experiences with the boys in her new secondary school class, she remarked; "*It's impossible not to laugh at what they do, and it's a lot of fun talking to them.*" Thus, the girl's experience of the behavior of boys in secondary school had become fun rather than irritating, which also contributed to the experience of acceptance in a new school setting. At the same time, this transition from being "*childish*" was infused by her growing interest in boys, and her attitude may have been influenced by the policy of allowing secondary school students to remain in the classroom during breaks. This gave the girl, who did not see well, an opportunity to be physically closer to both boys and girls. Thus, she was also able to "*laugh with the boys*" when they said or did something funny, which is a good way of building relationships in secondary schools.

One occupation that symbolized a transitional change in relationships was the birthday party described by one girl. Her story also reflected her disability due to a visual impairment. She had recently moved to a new school where she did not know anyone and making new friends was a social challenge. She talked about attending the party with some of her new classmates, which occurred in a rented public place and lasted from 7 pm to 11 pm. Equal numbers of boys and girls attended, and they came from a variety of places, environments, and schools. Parental support was still present because her father brought her to the party and came back at 11 pm to take her home. Here is what she said about dancing at the party.

> *We did slow dancing. I danced with three different boys. The first one was very tall. The second one was just right, only a little taller than me. The third one was about the same height as me.*

She demonstrated her positive engagement in dancing with the boys by her description. Her experience aligns with her need to adapt to a new occupation, where she engaged in more "*adult-like*" dancing in a rented "*environment that was adapted for a teenage birthday.*" In the context of this transitional phase, dancing represented an opportunity for interaction and getting to know boys in new ways. It gave the girl an opportunity to approach boys in a more physical manner and to learn a new way of dancing, possibly for the first time. Dancing allowed the girls and boys to learn new ways of performing an occupation and exploring new types of social relationships and ways of being together, which appeared to be both meaningful and fun for young teenagers.

Expanding possibilities through occupational engagement in social networks and media

The children engaged in using the Internet and reported its potential for increasing participation in meaningful occupations and communities with other children. For example, they used Facebook to keep in contact with others, and one 13-year-old girl stated: "*Everybody is on Facebook*," adding that her "*friends*" went on Facebook every day to keep up with each other. One boy also commented that he made new friends with older pupils in secondary school, where Facebook provided an opportunity to start conversations and to get to know others better: "*You get more connected because you know who everybody is.*" Keeping in contact on Facebook also related to keeping in contact with other children who shared the same interests, such as one boy who kept in contact with about 100 Facebook friends in a Harry Potter fan club.

Boys often discussed playing television and/or internet games, which included opportunities for fun and social play. For example, when the boys were in primary school, they often went to each other's houses to play with a Wii, a television-based game, and they competed using different sets of controls. One boy, who was a wheelchair user, had advanced equipment, and he explained how other boys frequently came to his house while he attended primary school. Thus, the boys played video games, which encouraged them to be both social and playful. To some extent, computer games have a different form and content, and thus they did not require the boys to participate together physically as they grew older. This was true of the computer war game Counter Strike, which they could play after school with their friends in their own individual homes. For children who had an increasingly debilitating condition or who tired easily, this could be a welcome change that facilitated their participation in a social and interdependent occupation with other boys.

One occupation that facilitated both individual and social meanings for one boy in our study was Harry Potter World. During the first interview, while attending primary school, he said that he had no time for anything else because: "*My leisure time is devoted to Harry Potter*" and "*when I have free time, that's all I think about*." He demonstrated how this occupation filled his mind and influenced many of the things he did on a daily basis, such as how he organized his school day and work: "*At school, I name things with words from Harry Potter World. I've also written about it a lot, and I was told recently that I can't do that anymore*." He then explained that the teacher who had imposed this ban was still allowing him to write about an actress from the Harry Potter movie for his individual project (a developmental adaptation that supplemented his school work) and to choose books about Harry Potter for his English language reading.

This fascination with Harry Potter exemplifies how an occupation can advance from an internet interaction to planning to attend camp for the first time. The camp would include acting and dressing as characters from the movies, as well as meeting and socializing with other children who share the same interest. As part of becoming a teenager, these opportunities allowed him to extend the individual engagement and social meaning that Harry Potter had for him. It included meeting and sharing his passion with other children in real life in an environment where they spent an entire week without their parents, and where they played their roles so fully that he had to order a special costume. During his last interview, he talked about how much he was looking forward to attending a Harry Potter Christmas ball, and said that he would be writing about Harry Potter in an exam.

This example illustrates how engagement in computer-based occupations can influence a child's life by developing meanings and potentials. This also exemplifies how a passionate occupation can add meaning and influence how schoolwork and other occupations are performed. To some extent, it shows how total engagement in computer occupations can generate continuity and expand various individual and social possibilities. In this case, an internet occupation developed interdependency with communities that involved other children. As part of becoming a teenager, this boy's interest developed from being "*only*" an internet occupation to spending time with children in real life away from his parents.

Particular challenges in adapting to participation in culturally valued occupations

The children in our study strongly emphasized the significant cultural value of sports-related occupations, which a girl with reduced muscle strength and mobility expressed clearly: "*Those who play a lot of handball and football are the most popular ones in a way.*" At the same time, performing sports such as football, skiing, or jogging was challenging for the children in our study. The influence of performance and context on their participation was exemplified by a girl who used a wheelchair, who shared her experiences of a week-long rehabilitation retreat: "*We were working out, working out, working out*," she related enthusiastically, where she used a term that is filled with significant cultural value in her society. Her experience and success in working out related to performing well, because she expressed pride in the great progress that she had made in activities such as adapted cross-country and downhill skiing. In addition to social interaction with other children who had the same or a similar diagnosis, participating in sports in an adapted environment had given her a sense of equality and the satisfaction of being able to "*work out*." However, her sports performance was not automatically transferable to her home environment. Undoubtedly, some children found it difficult to perform at the same level as "*others*" in their local environment.

Similar to the example of working out, one boy who used a wheelchair explained the cultural significance of football: "*Playing and talking about football and stuff is normal*." From his perspective, football could appear easy to engage in as a game and to talk about, but playing demands a certain level of ability. Another boy, who was also a wheelchair user, discussed his situation at school and commented: "*I think it's a little dumb that so many pupils are so interested in football. They want to play it a lot, and I find it difficult*." His comments illustrated how some boys with a limited capacity to master the physical demands of football were discouraged by its high social status. At the same time, children developed adaptive strategies for participation, such as a girl with reduced visual ability who problematized jogging at school, but still participated and was accompanied by her friends. A boy who could walk (and run) short distances but used an electric wheelchair for long distances said that he liked to jog and did his best by "*jogging*" shorter distances, although he admitted that he tired easily.

Participating with others required engagement in what was "*common*" and "*normal*" for children in the present study. For example, one boy had a disease that progressively weakened him physically over time. However, he demonstrated his long-term engagement because he continued to be a member of the local handball team. At the age of 12, he was following "*different rules*" (e.g., not running across the entire court), and the team accepted this. "*It's fun*," he commented in an interview, "*but tiring*." At a later stage, he transformed his engagement into cheering on his teammates from the sidelines. Similar to other children, his engagement in sports such as handball remained as strong as ever because participation in sport often has a strong and enduring history, as well as interdependency and relationships with other children.

Discussion

Based on occupational science and sociocultural perspectives, the present study explored how Norwegian children with disabilities experience and engage in occupations. We also took a transitional perspective because the children were in the transition between primary and secondary school.

The first theme in our study addressed transitional changes in looks and relational occupations. The expression to "*grow away from clothes*" symbolizes a transitional change from being a child to a becoming teenager, and it indicates how individual and social identities are characterized by looks and appearances (Hasselkus, 2002; Wilcock, 2006). Similar to other reports, the girls in our study highlighted how physical appearance, body image, and behavior have cultural significance (Hauge, 2009; Rumsey & Harcourt, 2004; Rysst, 2010). When girls are engaged in changing their style of dressing and show increased attention to wearing makeup, they are influenced by their environment. Their engagement in what to wear is shaped from the dialectic of individual and social meaning (Leontiev, 1978). From an occupational perspective, their attention to their appearance is influenced by feedback and interaction with others in the environment, as well as their specific culture (Alsaker et al., 2013; Cutchin & Dickie, 2013; Phelan & Kinsella, 2009, 2013a,b). The social meaning of a teenage style, for example, was exhibited when girls in our study made a transition toward an "*edgier style*," such as a lower neckline or "*trousers with holes in them*". The girls also showed how the individual meaning of an appropriate teenage look might not always conform to that of their parents (Beagan & D'Sylvia, 2011). At the same time, they engaged in negotiations with their parents by seeking approval about what to wear or about paying for their clothes.

During the transitional phase between being a child and becoming adult (Uprichard, 2008), the girls' engagement in how to "*do*" their makeup involved a dialectic between both playful and more serious adult elements. The girls' comments that they were "*fooling around*" and "*showing off*" indicated experiences of fun and play, but the girls in our study were also engaged in showing off as a growing teenager, which was more apparent in secondary school.

Similar to our examples related to the style of dress and makeup, other studies have shown how children adapt to the expectations of acceptable cultural behavior in their age group and how they negotiate new social practices and relationships (Gulbrandsen, 2003; Hauge, 2009; Rysst, 2010). During their time in primary school, the boys in our study indicated that they engaged in "*mostly boy's stuff*" and they indicated that they were not particularly interested in what the girls were doing. The girls highlighted the social practice of boy's doing "*childish stuff*." Our study showed how girls in primary school perceived that behavior as sometimes both annoying and disturbing. From an occupational perspective, the inherent meaning of "doing childish stuff" appears to change as children develop (Humphry, 2002). It also symbolizes the children's continuous doings, including dialogue and feedback between the boys and girls (Alsaker et al., 2013; Cutchin & Dickie, 2013; Hocking & Wright-St Clair, 2011). For example, a girl who was becoming a teenager showed increased acceptance and a change in attitude toward the practice of "*boys who are doing childish stuff*." When girls in secondary school are "*laughing with the boys*," it shows acceptance and support. This support and acceptance connects with their growing interest in getting to know each other in new ways. The classroom represents a specific context for growing relationships. Further, allowing children attending secondary school to remain in the classroom during breaks can help shape these new relationships, which can benefit some children with disabilities.

In the presentation of our findings, we also used the example of a birthday party to symbolize transitional occupations. A birthday party includes conversations and feedback in a particular context, and in accordance with certain ideas from occupational science, it is situated and interrelated (Alsaker et al., 2013; Cutchin & Dickie, 2013; Rudman, 2013). Thus, an occupation such as dancing may provide an opportunity to learn more about age-appropriate 'birthday' occupations, as well as interacting with each other and simply having fun, which was the case for the girl with limited vision.

The children in our study reported their engagement in social networks, media, and gaming, and indicated that these activities expanded the occupational possibilities for children with disabilities. In accordance with an occupational perspective, the children in our study appeared to engage in computer-related activities on a daily basis (Yerxa et al., 1990). Similar to other studies, they demonstrated that computers are a general, time-consuming occupation for children in Norway and offer the potential for enjoyment, engagement, and fun (Gulbrandsen, 2003; Heah et al., 2007; Vaage, 2012). Children with disabilities can benefit from using social networks to engage in social interactions with other children, which has the potential to be emancipating and support inclusion and participation (Rudman, 2013). For many children it is an everyday occupation, embedded in engagement and includes interactions and feedback from different environments (Alsaker et al., 2013; Corsaro, 2011; Hedegaard, 2008; Hedegaard et al., 2012; Hocking & Whiteford, 2012). For example, using Facebook can help children to keep up with their friends and to acquire new connections based on common interests, including friendship (Asbjørnslett et al., 2012). Internet games are an occupation that children may engage in and develop over time (Wiseman, Davis, & Polatajko, 2005). They can also provide children with limited physical strength and/or energy with many opportunities to participate in the culturally significant occupations of their age group.

During this transitional phase, the children in this study were essentially engaged in getting to know other children who shared the same interests. They explained how they communicated and engaged in computer occupations as part of a "*teenage community group,*" for example from a sense of belonging to a "*Harry Potter World*". Such networks provide many occupational opportunities that have the potential to be transformed and extended, depending on the child's engagement and development. In some senses, this world appears to be an ideal occupation where children can experience fun, inter- relational contacts, and shared interests. Social networks can represent a community of common interests, which are influenced by personal and social meanings, including a child's individual and social identity (Hasselkus, 2002; Phelan & Kinsella, 2009, 2013a; Wilcock, 2006). The children in our study exploited these possibilities to learn from their internet worlds, such as identifying with actors from a Harry Potter movie or dressing like one at a camp. This occupation also expanded to possibilities for reading English books or writing about their interests.

The last theme in our analysis considered the significance of the performance, context, and cultural importance of sports for children, which reflected common cultural values. On rare occasions, the children in our study engaged in sports occupations outside their home environment, such as skiing in a rehabilitation environment, which promoted a greater sense of mastery and fun (Heah et al., 2007; Nyquist, 2012). However, most of the interactions between children occurred in their home environments, where children could take advantage of many opportunities (Asbjørnslett & Hemmingsson, 2008; Asbjørnslett et al., 2012; Bjorbækmo & Engelsrud, 2008). If children are limited from physical restrictions, engagement in sports also holds opportunities to support peers by cheering from the sidelines, or participating in conversations about sports at school. As found in previous studies, the teenage years and particular transitional phases can be particularly challenging for children with disabilities or in other ways are 'different' and divide from the norm (Hallberg et al., 2012; Heah et al., 2007; Hughes et al., 2013; Rumsey & Harcourt, 2004; Ytterhus, 2012). In general, the children in our study adapted well to their everyday occupations using various strategies and our findings show that the children participated in culturally rewarding occupations and relationships in different ways.

Contributions and limitations

In this study, 15 Norwegian children with disabilities described their everyday life experiences, which are relevant to the field of occupational science. The children highlighted their engagement in culturally significant occupations within their age group and within Norwegian culture. These experiences were representative of a particular age group and a particular transitional phase, and they indicated the possibilities and challenges for children with disabilities during this period. The main limitations of this study were the small number of children and the narrow age group (12–14 years).

Conclusion

Children with disabilities in this study actively engaged in occupations during the transitional phase between primary and secondary school. The findings demonstrate how various occupations are accompanied by particular challenges, but many occupations also provide fun, enjoyment, learning, and social participation with others. Like their peers, the children in our study engaged in, adapted to, and negotiated in occupations that had individual and social meaning in their culture. From an occupational perspective, this study of children's experiences may contribute to a better understanding of how children with disabilities can participate and be included in occupations that they find meaningful together with their peer group or in their local environment.

Acknowledgements

Special thanks to the children who participated in the study. The authors would like to acknowledge Kari Opsahl and Bennedichte R. Olsen for collaborating and conducting interviews for the study. This article is part of an interdisciplinary research project Professional Practices and Children's Participation, at Oslo and Akershus University College (OAUC), which has contributed to an overall inspiration and support. The study received financial support from The Research Council of Norway (RCN) and Oslo and Akershus University College (OAUC).

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International Journal of Inclusive Education, 2015
Vol. 19, No. 2, 199–212, http://dx.doi.org/10.1080/13603116.2014.916353

Inclusion and participation in everyday school life: experiences of children with physical (dis)abilities

Mona Asbjørnslett[a*], Gunn Helene Engelsrud[b] and Sølvi Helseth[c]

[a]*Faculty of Health Sciences, Occupational Therapy, Oslo and Akershus University College, Postbox 4, St. Olavs plass, Oslo 0130, Norway;* [b]*Department of Physical Education, Norwegian School of Sports Sciences, Oslo, Norway;* [c]*Faculty of Nursing, Oslo and Akershus University College, Oslo, Norway*

(*Received 29 August 2013; accepted 10 April 2014*)

This study explores the school experiences of children with physical (dis)abilities. Based on 39 interviews with 15 Norwegian children, participation in everyday school life is introduced as a central theme and divided into three sub-themes: community and independence; adequate help and influence in the classroom; and influence in planning and decision-making. The findings presented that the children want to participate in school activities the 'regular way', but on their own terms. Achieving this goal depended on their ability to make the necessary adjustments, as well as adequate support from teachers and school aides. Children reported that they were sometimes given 'too much help' by school aides and 'too little' by teachers. They felt that they had some influence over their classroom situation; however, they rarely had occasion to take part in formal school meetings dealing with academic issues and individual assistance, which might have enhanced their inclusion and participation at school. Our findings reflect the significance of incorporating children's own experiences and personal history of (dis)ability into the planning process. We conclude that children with (dis)abilities are willing to make great efforts to participate and be included, primarily so they can be engaged with the other children.

Keywords: children's experiences; physical disability; everyday school life; inclusion; participation

Introduction

Inclusive education has been a primary goal in Norwegian schools for many years. This is to be achieved by providing adapted individual learning, including special education, in the standard classroom (Tøssebro, Engan, and Ytterhus 2006). The official government position is that all children have a right to adapted education in an inclusive school environment (KD 1998, 2003, 2010–2011). Schools are obligated to accommodate all children, and teachers must attend to and include all children (KD 2006/2007). Together with teachers, school aides play an important role in creating an inclusive educational environment.[1]

The form that inclusion takes may vary; however, it is always understood to be based on the protection of rights of citizenship. This implies acceptance of all children

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*Corresponding author. Email: mona.asbjornslett@hioa.no and mandates the establishment of interactive diversity to accommodate them and encourage acceptance and positive attitudes towards universal participation (Slee 2001). True inclusion is not primarily about special education or children with (dis)abilities;[2] it means placing a high priority on ensuring that the school system can educate all children in the same setting (Tøssebro, Engan, and Ytterhus 2006). An inclusive pedagogical approach focuses on creating a classroom community in which everyone participates and children with (dis)abilities take their rightful place within the population of *all* children (Florian and Black-Hawkins 2011; Read, Blackburn, and Spencer 2012). It is also requires a concern for the educational experiences and outcomes of all children (Slee 2001).

Despite Norway's proclaimed political goal and vision on establishing a school system based on inclusive education marginalisation has actually increased, which reflects a medical understanding of (dis)ability in the school system (Wendelborg and Tøssebro 2010b). These children also risk to be positioned as dependent and reliant on others in the school system (Davis and Watson 2001).

As already indicated, joining peers in shared learning and social activities is considered crucial to the participation of children with (dis)abilities at school and to the creation of an 'inclusive society' as the younger generation grows up and people with (dis)abilities socialise in the broader community (Grue and Heiberg 2000; Hemmingsson, Gustavsson, and Townsend 2007; Dolva et al. 2010; Lowe and Chapparo 2010). Researchers have found that being excluded from educational activities with peers is a hindrance to social participation in the school environment, which is generally considered to be a key element of inclusive education (Pijl 2007; Wendelborg and Tøssebro 2010a). Using school aides rather than qualified teachers to provide learning experiences for children with (dis)abilities may slow their academic progress (Nordahl and Hausstätter 2009). Relying on special education and teacher's aides may also hinder social participation, particularly when the child has an intellectual (dis)ability (Wendelborg and Kvello 2010; Wendelborg and Tøssebro 2010a).

The ideal of inclusive education is embraced by children with physical (dis)-abilities, who consistently state that even if they cannot always perform at the same level as theirs peers and schoolmates, they very much want to share learning and social situations with them. (Asbjørnslett and Hemmingsson 2008; Svendby 2013). Children with physical (dis)abilities or special diagnosis express frustration when they are excluded from physical education even when they want to participate and believed they could, on their own terms (Bredal 2012; Svendby and Dowling 2012; Svendby 2013). It takes extra effort and energy for them to be 'ordinary kids' and appear as similar/equal to their peers as possible, but they are usually willing to do whatever they can to meet school norms and expectations, rather than run the (real) risk of being excluded from school activities (Asbjørnslett, Helseth, and Engelsrud 2013). The participation of children with (dis)abilities is also imperative from a rights perspective, which recognises the potential of children's 'voice' or 'agency', as well as its limitations. These rights should be viewed from the perspective of children's everyday lives in diverse social and cultural contexts (Alanen 2010). The aim of this article is to explore the ways in which children with physical (dis)abilities experience everyday school life. Our interest is to analyse their experience in relation to inclusion and participation.

A socio-cultural perspective

Our approach to understanding children's experiences in everyday school life is to rely on the perspectives of the children themselves (Hedegaard, Aronsson et al. 2012). A central premise of this approach is that experiences are created through participation in everyday events and are influenced by the conditions in which they take place (Greene and Hill 2006). Our premise is that the ways in which the children in this study experience their school situation is strongly influenced by their social and cultural environment, as well as their relationships with other people in this environment. Their individual values are influenced by societal cultural values, which also model and structure participation and socialise children in particular ways (Percy-Smith and Thomas 2010).

The terms participation and inclusion are intimately linked. Inclusion is concerned with being allowed or enabled to take part, while participation means actually taking part (Davis and Hill 2006). Participation has become an important term in the socio-cultural paradigm and is widely used to describe forms of social engagement and belonging. Participation is also used in relation to rights. Another term commonly applied in discussing children's rights to express their views is 'agency', defined as having the power to make decisions that affect one's self and others and to act on them (Lansdown 2010; Sancar and Severcan 2010).

Like other institutions, schools are a socio-cultural environment; in them, children meet and absorb social and cultural concepts expressed through the attitudes and practices of social authorities such as school personnel. These attitudes and practices are influenced by social and cultural concepts of (dis)ability, which for the last century have been dominated by a medical, diagnostic and individual perspective (Depoy and Gilson 2011; Grue and Rua 2013). In this environment, children are exposed to concepts such as inclusion and (dis)ability in their historically and socially determined meaning (Baltzer 2003). Social meanings, however, are relational and influenced by each child's individual way of perceiving the world and engaging in his or her own circumstances. Personal motives are related to what matters to someone, what he or she finds personally meaningful and important, and what he or she expresses in intentional activities and wishes (Hedegaard 2012).

Considering the concepts of inclusion and participation together provides an opportunity to explore ways in which students with (dis)abilities experience their interactions and diverse possibilities in a school environment. To get a more nuanced understanding of the student perspective, we have viewed their experiences from a relational perspective, eliciting their personal responses as well as the social perceptions that reflect their socio-cultural understanding of their situation.

Data and methodology

This study is based on interviews with 15 Norwegian children (nine boys and six girls) who live in or around Oslo. Our informants were born with and diagnosed with a variety of physical impairments, including one with a visual impairment. Two of the boys had a second diagnosis of a learning disorder. Demographic details about their physical status and age when interviewed are presented in Table 1.

When we first interviewed them, all of the children were in their last year of primary school. Our final interviews took place when they were at the end of their first year in secondary school. The empirical material is based on a total of 39 tape-recorded interviews, transcribed into approximately 456 pages of text.

Table 1. Demographic data, children.

Children	Physical status	Age at interview	Number of interviews
Boy 1	Walks with aids/or wheelchair	12, 13	4
Boy 2	Wheelchair	12, 14	2
Girl 3	Visual impairment	12, 13	3
Girl 4	Wheelchair	12, 13	3
Boy 5	Walks/aids	13	3
Girl 6	Wheelchair	12, 13, 14	4
Girl 7	Walks	12	1
Boy 8	Wheelchair	13, 14	3
Boy 9	Wheelchair	13	2
Boy 10	Walks/aids	13	1
Boy 11	Walks/aids	12, 13	3
Boy 12	Walks/aids	13	3
Boy 13	Walks/aids	12, 13	3
Girl 14	Walks/aids	12, 13	2
Girl 15	Walks/and wheelchair	12, 13	2

We contacted professionals such as teachers and occupational therapists from a variety of communities to ask for their help in recruiting children for the study. Most of them considered the study worthwhile. They identified potential participants and then contacted the parents. These parents were informed about the project verbally, and also provided with an information letter and a brochure. If they agreed that the study would be valuable, they talked to their children and asked them if they wanted to participate. If a child's response was positive, the parents made direct contact with us and we could arrange the first interview with the child.

This study was approved by the Regional Committee for Medical and Health Research Ethics and the Norwegian Social Science Data Services agency. It satisfies all legal requirements for the protection of personal information and measures to prevent children from being recognisable through a diagnosis. All of the parents gave informed consent for their children to participate (Kvale and Brinkmann 2009); each child was provided with a consent letter to read and discuss with his or her parents. The parents signed it before we made direct contact (Helseth and Slettebø 2004; Hill 2006). All of the children consented to having their interviews recorded, analysed and included in the study. The one child who withdrew after the first interview was subsequently contacted and provided a letter of consent allowing the interview to be used in the study.

Researchers who seek to explore children's experiences through interviews must have considerable skill in listening to and encouraging children to express their views while minimising their own authority (Hill 2006; Kvale and Brinkmann 2009). We recognised the responsibilities that researchers have as authorities. Their relationship with informants is inherently unequal: their role as researchers is to delve into informants' private lives and place these accounts into a public arena. This role comes with an ethical imperative to consider the purpose and value of the study carefully from the time it is conceived (Kvale and Brinkmann 2009). Our interviews varied in form, contents and duration. Some of the interviews in this study were more skillfully conducted than others, and more successfully encouraged the children to express their views; the consequences of uneven craft in interviewing can be problematised (Kvale and Brinkmann 2009). The children's interest and willingness to share their views also varied. Along with the different levels of interviewing skill, this resulted in some interviews being more informative than others, and consequently more heavily used in the study.

Analysis

In our effort to explore aspects of everyday experiences from school as fully as possible, we read through and back and forth the transcribed material several times to obtain an overall impression of the research topic (Kvale and Brinkmann 2009). Based on these back and forth readings, we asked ourselves: what mattered to the children's sense of inclusion and participation? We identified three themes that were crucial to their experience of inclusion and participation: community and independence; adequate help and influence in the classroom; influence in planning and decision-making. Despite these common themes, the experiences related by the children were individual and diverse. We have cited specific remarks to illustrate the themes as exemplified in children's individual experiences; sometimes they can be generalised, other times not. We quoted children's experiences as a first step in our analysis and presented findings. In this first level of analysis, we looked at how informants expressed their self-understanding, and then identified and interpreted what was occurring using terms close to or identical to those of the informants (Fangen 2008). In two of our examples, we have supplemented what the informants told us with information provided by a school aide and a mother that supported or elaborated on the children's experiences.

In a second level of analysis, called critical commons sense understanding (Kvale and Brinkmann 2009), we analysed the information based on our understanding of their meaning or elaborated on the children's experiences. In our second level of analysis, we attempted to go beyond the informants' own understanding of their situation, asking what does the statement express about the phenomenon (Brinkmann and Kvale 2008; Fangen 2008). Here, we drew on the researcher's own understanding and experiences in interpreting what the informants felt and thought about a topic (Kvale and Brinkmann 2009). Employing theoretical concepts, explanations and context (Fangen 2008), this analysis began with the children's identification of school as a place for getting together with other children and forming a community. They expressed a desire 'to be a part of the broader community' and to do things 'the regular way' but on their own terms, noting that this required getting 'adequate help'. In this analysis, we found that having influence over their situation in the classroom was extremely important to the children; some of them described experiences in which they took part in school meetings.

Following Fangen (2008) our third level of interpretation involved a certain 'suspicion', in which we questioned the underlying processes such as ideologies and other expressions of domination that might lead us to neglect significant themes (Fangen 2008). In this analysis, we also applied a theoretical understanding (Kvale and Brinkmann 2009). A socio-cultural approach, involved trying to understand the informants' experiences from their perspective by identifying their motives, understanding and engagement in school life. We critically examined and discussed our personal and general experiences and interests which had influenced the dialectic of practice and research that shaped this study. In the final discussion, we integrated the informants' experiences and concepts of participation and inclusion with research on children's participation at school and relevant socio-cultural meanings and history.

Findings

Our findings concern how children with (dis)abilities advocate for participation and inclusion in everyday school life. By foremost demonstrating their abilities, they suggest how their views can be included in learning processes and planning, and most significantly, how they can participate with other children. 'It's important to be a part of the broader community', one of the boys, who used a wheelchair, declared explicitly. By 'broader community', this child and others meant a community for learning as well as the experience of sharing a community with their peers. All of our informants considered participation in both types of community at school a top priority. They described school as a place where 'everybody gets together' and as quoted 'you talk to more people than you spend leisure time with'.

The children told us that their major concerns at school were learning, being with the other children, paying attention and getting enough help with learning. Other priorities they cited were being or feeling independent and not being 'treated differently' from their peers. They told us that teachers should be 'fair' and treat all children 'the same'. From their perspective, social togetherness was a significant aspect of participation in everyday school life and influenced the kinds of experiences they found meaningful and engaged in with enthusiasm. Their concern with social togetherness also influenced how they described the ways that they wanted to participate at school.

Community and independence

The children in our study considered being together with the other children the most significant aspect of participating in the school community. For many of them, physical education was a valued and meaningful activity. They described it as a 'social activity' that involved fun, groups and 'teamwork'. Most of our informants told us that they liked and were happy with physical education, but some said that they did not participate to the extent they wanted to. This anecdote related by a 12-year-old boy who used a wheelchair but also walked with the help of orthopedic devices exemplifies the efforts of our informants to increase their participation in physical education at school:

> [. . . . ..] A report was written about these [sports classes], about some exercises and things. There were things [in that report] that I didn't agree with . . . . I talked to the school nurse about the report, including that it said I was sitting in the wheelchair all the time, but I really only sit in it when I'm doing sports that I can't do without the wheelchair. So we arranged a meeting with the physiotherapist, the aide and the teacher and we all agreed to change what had been written . . . ..

Like other children in the study, this boy found that his participation in physical education was threatened based on an understanding of '(dis)ability' that, had he not protested, would have relegated him to the 'sidelines', for example, by having him do exercises in another room. He insisted on his status of being 'mostly a walker' rather than 'mostly a wheelchair user' so that he would be treated as 'less (dis)abled' in physical education activities. This boy was able to assert his position successfully; since the meeting, he reported, 'I'm included in all the physical training, which is something that I should participate in the most'. Like the other children, he wanted to be more closely involved with the other children in physical education. This is consistent with a social motive of maximising participation. His situation also illustrates the ways in which a child's perspective on (dis)ability may differ significantly from that of school personnel.

The children made it clear that feeling independent in their everyday school life was very important to them. Children who said that they wanted to do things on their own terms and in their own way with just the right kind and amount of help associated those goals with participating and pursuing their own interests. In addition to coping with physical challenges, some of those who struggled with academic subjects such as math told us that they sometimes found it 'tiring' to feel that their work was not good enough. Quite a few of the children indicated that they were expending considerable effort trying to keep up with what was 'ordinarily' expected in the school environment. Our informants also talked about the kind of assistance they wanted and needed from both school aides and teachers to be a part of the community of their peers and at the same time 'independent' in doing schoolwork.

Adequate help and influence in the classroom

When the children talked about the kind of help they needed they often associated it with what they considered to be 'common arrangements' and 'normal' for all children at school. The role of school aides was a consistent theme in the interviews, indicating their importance in providing help the students needed to participate fully. For example, and as indicated in particular by a boy and a girl with reduced physical strength and a girl with reduced visual sight they assisted the students in copying information from the blackboard, taking notes on what a teacher was saying and carrying heavy books and other material for them between classrooms. The type of help school aides should offer was a sensitive and significant issue for the students. One of the girls referred to her aide as 'kind' and easy to ask for help, indicating her satisfaction at having this kind of influence in the classroom. In fact, most of the children were pleased to have an aide whom they could rely on for help. As a 13-year-old girl, who walked, but with reduced physical strength in primary school described it:

> She helps me with my backpack, and with dressing [… …]. She's very good to have when I need help with books and heavy stuff, but right now we don't have any books, so there isn't so much for her to do.

In this situation, where the issue was insufficient strength, the girl felt that help from the aide was extremely valuable. She also believed that the assistance was provided on her terms in specific situations of her choosing. The student's power in this relationship was confirmed by an aide, who, in describing her role, declared, 'We cannot overrule …. We are there all the time to see what kind of help she needs'. The girl and her aides shared an understanding that in the classroom the girl should appear to be mostly independent. The relationship was significant and valuable to the girl precisely because she recognised that she needed specific help at school and that was the only assistance that the aide were providing.

One 'regular' classroom activity cited by the children was 'reading or working in books'. During these activities, the children wanted their aides to limit their assistance to what was essential. A 12-year-old boy, who used a wheelchair and did not struggle so much with his schoolwork, referred to this as 'being allowed to be independent'. He described several situations in which his school aides were 'overly helpful'. as he put it. One was during a learning activity:

> For example, in math, the aide was looking at my book. This went on for five minutes, and then it happened again . . . so sometimes I covered the book. He told me that my work was incorrect and I didn't think he should have, because that could have been explained on the blackboard or I might have discovered that I had counted wrong on my own.

In general, he thought this aide was providing 'too much care' in the classroom, limiting his opportunities for 'figuring things out for himself' and learning the 'regular way'. He complained that the aide was taking over in practical situations as well:

> I have some fine motor problems with my fingers, which make it a bit difficult for me to use a saw. He might have helped me get started, but I don't like the kind of help that's doing it for you.

This boy perceived the level of assistance provided by his school aide as interfering with his ability to perform this activity in 'his own way'. His sense of being viewed as (dis)abled was most pronounced when the aide took over his individual tasks. From his perspective, his level of competence was greater and higher than the aide was allowing him to demonstrate. This experience illustrates the way in which a wish for more self-determination in the classroom can coexist with a need for accommodated help and signals requesting it. Conversely, the student's sense of independence and community in the classroom can be diminished by an aide who offers 'too much help'. This boy's primary school experience led him to declare that he wanted the teacher to help him with his school work and not the school aide.

Even though only two of our informants were identified as having specific learning problems, several other children stated that they were struggling with subjects such as math. These students stressed the importance of getting help from teachers. As one girl with a visual impairment put it in describing a math lesson, she wanted her teacher to 'help me to find an easier way, a way that isn't so difficult'. This girl also said that the best way for her to learn was to go through the assignments alone with the teacher. However, teachers are not always available to provide the degree of individual help that some of the children felt they needed. A boy with learning difficulties said during his primary school interview that he was not receiving sufficient assistance from teachers in the classroom. He added that he often had to 'wait for the help I need'. His discomfort increased in secondary school, where he felt more alone than in primary school. Other children talked about the opportunities in secondary school to go over math problems in small groups, which made it seem like a place where it was *easier to* get help and work alongside other children who had similar learning difficulties. Other students described learning groups as a 'common way' of working on math problems, even in primary school. As one boy in primary school put it, 'I'm in a math group with other students who need extra help; it's common in a way ...'

Influence in planning and decision-making

As noted earlier, the children exercised the greatest influence on their school situation through classroom collaboration with school aides and teachers. When we asked our informants if they had participated in more formal school meetings they usually replied that this was ‘parents’ business’; only a few of them had participated. Even among that minority, some said that they did not remember why they had been at such meetings, or what they were about. Some of the children characterised school meetings as ‘boring’. Others, however, described positive experiences at primary school meetings. One boy, using a wheelchair and with some extra need for learning assistance asserted that children should take part in most meetings where academic issues and ‘assistance’, were discussed, even in primary school. This opinion reflected negative experiences of not being listened to; he made it clear that he wanted to be involved in decisions regarding his own education, even in primary school.

School officials frequently invited the children to meetings in the transition period between primary and secondary schools at which they could outline their needs and plan their learning and physical adaptations to the new school environment. Their involvement in planning was solicited to ensure that their wishes might be accommodated in both their current and their future school. Some children chose to participate, others did not. Those who did described a range of experiences.

The children felt good about meetings which someone whom they considered to be an important staff member attended, asked about their situation and listened to what they had to say about their past experiences, as well as their suggestions of ways their school experience could be improved. Other descriptions of meetings provided by our informants indicate that accommodating children’s individual needs and opinions is a complex issue, and solutions suggested by children with (dis)abilities can be denied when school officials believe they conflict with what is best for the school as a whole.

When children were invited to discuss significant topics at a transitional meeting their social motives and needs often reflected their previous school experiences, including their personal history of ‘(dis)ability’ and illness. One boy, for example, suffered from a progressive disease, which slowly reduced his muscle strength over time. He mainly used an electric wheelchair. His history illustrates the significance of peer-group stability when he indicated that he wanted to continue to share classes with his closest friends, who had been familiar with his condition for many years. However, on his first day at secondary school, he discovered that he had been placed in a different class. His request for a transfer was not accommodated, and he found the social transition to secondary school difficult. In this case and others, the school officials stated that the demands of ‘caring and organising’ classes for the benefit of all the children had taken precedence over his wishes and needs.

Discussion

The children in our study are motivated to participate in school primarily by a wish ‘to be part of the broader community’. This is consistent with the view that the key element in inclusion is being allowed or enabled to take part (Davis and Hill 2006) and the belief premise that personal motives are shaped by what matters to the child, what he or she believes to be personally meaningful and important (Hedegaard, Ulvik et al. 2012). What mattered most to the children in our study was being socially grouped and involved in the school community. They had a particularly strong desire to be included in learning activities with their peers, which they saw as a form of participation (Davis and Hill 2006). To achieve the highest possible degree of inclusion and participation, they worked hard to be ‘ordinary kids’ (Bjorbækmo 2011; Asbjørnslett, Helseth, and Engelsrud 2013).

Like previous studies, ours found that children were frustrated when they are excluded from participation in physical education or common classroom activities, as this limited their social participation (Pijl 2007; Wendelborg and Tøssebro 2010a, 2010b; Bredal 2012; Svendby and Dowling 2012; Svendby 2013). They cited physical education as a particularly social and fun activity, noting that it involved groups and teamwork and was viewed as one of the most important aspects of school life. At the same time, it was an activity from which they might easily be excluded based on the prevailing conception of '(dis)ability' (Depoy and Gilson 2011). To participate on their own terms, the children in our study sometimes involved challenging the concept of '(dis)ability' held by school professionals. Our study shows that (dis)ability, as well as participation, are not predetermined, but malleable and negotiable based on the motivations and experiences that children bring to the table (Greene and Hill 2006; Asbjørnslett, Helseth, and Engelsrud 2013). This is consistent with a socio-cultural perspective on (dis)ability.

The children in this study made it clear that they valued their independence as well as their participation in everyday school life. They wanted to be active and learn subjects in the 'usual' and 'regular' way, and at the same time 'on their own'. They did not want to be treated 'differently'; they wanted to 'fit in' with their peers, as well as in the school environment in general. They believed that teachers should be 'fair' and treat everybody the same way, but found that struggling with physical challenges and, sometimes, learning problems can make school life exhausting.

The way in which assistance was provided had a significant influence on whether these children felt included. Classroom experiences they related show the importance of practical help from aides – when needed. However, the aides' role can be problematised in terms of the children's desire to be 'equal' and participate in the 'regular way', but on their 'own terms'. Ideally, the aide's role supports a concept of inclusion that includes the need for interactive diversity to accommodate all children and allow them to take part (Slee 2001; Davis and Hill 2006). In actuality, the aide's assistance did not always 'fit in' with children's desires for 'independence' in school work and to be treated as 'equal' to other children. Our study, like prior studies, found that educational help provided by aides can retard the academic progress of children with (dis)-abilities (Nordahl and Hausstätter 2009). Our informants sometimes complained that their school aides were 'overly helpful' or provided 'too much care'. The aides who provided more care than the children wanted may have adopted a social concept of (dis)ability that sees it as an individual problem, rather than a societal issue, and views a child with a (dis)ability as dependent and reliant on others (Davis and Watson 2001; Depoy and Gilson 2011; Grue and Rua 2013).

On the other hand, most children were pleased with the aides help. Having someone they could ask for help seemed to strengthen the children's sense of participation: they knew help would be available when they asked for it. This suggests that school aides must play a complex, sensitive and significant classroom role, maintaining a respectful distance while being present and attentive. The school system may profit from carefully considering what 'educational help' should entail and make this determination in collaboration with each student. To recognise that children may see themselves as less (dis)abled than school personnel do, in part based on their social motivation to participate fully in school life is significant. At the same time, it must be recognised that teachers have limited time for individual instruction, and may not always be able to provide the attention a student needs to discover 'an easier way, a way that is not so difficult'.

Children's conditions and experiences are created through participation in everyday events (Greene and Hill 2006). In addition to their physical condition, children's participation in social and learning situations is determined by their experiences and societal perceptions of (dis)ability. Our study indicates that children want some influence over their school situation. They promote their 'agency' primarily out of a desire for 'equality' with their peers in a social sense as well as in learning situations. Their experiences make it clear that opportunities for children to influence and plan their school situation vary considerably, despite their mandated right to be heard and heeded on issues that affect them (UNICEF 1989; Lansdown 2010). The most significant opportunity for children to be heard or have the power to make decisions concerning their school participation (Lansdown 2010; Sancar and Severcan 2010) is through classroom collaboration with teachers and aides. Even though most of our informants considered school meetings to be 'parents business', some shared positive experiences they had enjoyed in these meetings. These experiences invariably occurred when they felt that their individual solutions and opinions were listened to and taken seriously. In contrast, the children felt frustrated if they concluded that their suggestions had not changed school practice.

As Alanen (2010) argues, children's 'agency' or 'voice' from a rights perspective should be viewed from diverse social and cultural context. Although school meetings that include children are one way of promoting their 'voice' or 'agency', they should be viewed and conducted with attention to the social and cultural contexts in children's everyday lives. The children's participation in these meetings can profit from taking their rights into account, but also their views on what the meeting might accomplish and its consequences for them. If the children will have no practical influence over what happens and no power to make decisions through their 'agency' (Sancar and Severcan 2010), their participation should be problematised.

Based on this study, we conclude that in their everyday school life, children with physical (dis)abilities make considerable efforts to achieve inclusion, participation and acceptance of their own view of their (dis)ability. Their top priorities are being part of a learning community with their peers and establishing their own independence. They want to do things the 'regular way', as well as in their 'own way'. Adequate help from teachers and school aides enables them to achieve both goals, especially if the children's own solutions are taken into account when their school situation is planned. The greatest challenge for these children that we identified is the need to be part of a broader community and feel included and at the same time obtain adequate help for their special needs and respect for their individual concerns and solutions.

Acknowledgements

Special thanks to the children who participated in the study. The authors would like to acknowledge Kari Opsahl and Bennedichte R. Olsen for collaborating and conducting interviews to the study. This article is part of an interdisciplinary research project Professional Practices and Children's Participation, at Oslo and Akershus University College (OAUC), which has contributed to an overall inspiration and support.

Funding

This work was supported by the Research Council of Norway (RCN) and Oslo and Akershus University College (OAUC).

Notes

1. They can assist teachers and provide care, support and training to the child, but may not assume a primary role in education and/or special education (KD 2010–2011).
2. In this article, we have decided to use the terms (dis)ability, child with a (dis)ability/children with (dis)abilities. They signify that the person(s) described may possess many abilities, as well as the will and capacity to compensate for any they might lack.

Notes on contributors

Mona Asbjørnslett is an assistant professor at the Department of Occupational Therapy, Faculty of Health at Oslo and Akershus University College. She is also a PhD candidate at Norwegian School of Sport Science. Her research interests are children with disabilities and their experiences of participation in everyday life; her research involves qualitative methods.

Gunn Helene Engelsrud is Head of Department of Physical Education, Norwegian School of Sport Science and Professor II at Oslo College. Her research interest revolves investigation into health and illness in contemporary times therefore represents interesting, critical and vital channels to basic cultural preconceptions, institutional schemes and discourses, as well as subjective experiences and living conditions.

Sølvi Helseth, RN, PhD, FEANS, is a professor of Nursing Science, Faculty of Health at Oslo and Akershus University College (OAUC). She also holds a part time professorship at the University of Agder. Her research interests are quality of life in children and adolescents; pain in children and adolescents; use of over-the-counter medicine in children and adolescents; postoperative pain management; overweight and obesity during childhood; children with persistent health challenges; children as relatives/next of kin; infant research (infant colic and infants in NICU) and Web interventions. Her research involves qualitative and quantitative methods, and a broad variety of research designs, lately with a main focus on complex interventions. She is the leader of the research group; Quality of life and pain research at OAUC. Further, she is one of the founders of the Norwegian network for quality of life research; and she is a fellow and a board member of the European Academy for Nursing Science.

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Appendix

1. Notification from Regional Committees for Medical and Health Research Ethics (Regional komité for medisinsk og helsefaglig forskningsetikk Sør- Øst D/ REK Sør- Øst D)

2. Notification from the Norwegian Social Science Data Services

3. Information and assent - letter, children

4. Information and consent- letter, parents

5. Information and consent- letter, professionals

UNIVERSITETET I OSLO
DET MEDISINSKE FAKULTET

Professor Sølvi Helseth
Avd. for sykepleie
Høgskolen i Oslo
Stensbergaten 27
0130 Oslo

Regional komité for medisinsk og helsefaglig
forskningsetikk Sør-Øst D (REK Sør-Øst D)
Postboks 1130 Blindern
NO-0318 Oslo

Telefon: 22 85 05 93
Telefaks: 22 85 05 90
E-post: i.m.middelthon@medisin.uio.no
Nettadresse: www.etikkom.no

Dato: 19/12/2008
Deres ref.:
Vår ref.: S-08820d, 2008/21141

"Om å være der det skjer " - profesjonsutøvelse og barns deltakelse i skole og habilitering.

Komiteen behandlet søknaden 09.12.08. Prosjektet er vurdert etter lov om behandling av etikk og redelighet i forskning av 30. juni 2006, jfr. Kunnskapsdepartementets forskrift av 8. juni 2007 og retningslinjer av 27. juni 2007 for de regionale komiteer for medisinsk og helsefaglig forskningsetikk.

Prosjekttema:
Studien representerer en av tre delprosjekter innenfor paraplyprosjektet "Snakk med oss." - Profesjonsutøvelse og barns deltakelse. I dette delprosjektet skal man undersøke barn med fysiske funksjonshemmingers overgang fra barne- til ungdomsskole. Fokus vil være rettet mot samhandlingsmåter mellom barn og profesjonelle i skole og kommunehelsetjenesten som kan fremme barnas deltakelse det daglige. Studien er kvalitativ og man vil benytte individuelle samtaler og fokusgruppesamtaler med barn og foreldre og profesjonelle.

Forskningsetisk vurdering:
Komiteen ber om en redegjørelse for om det skal gjøres registreringer om barnas funksjonshemninger. I tilfellet ja, ber komiteen om en begrunnelse for hvorfor og hvordan det skal gjøres, og hvilke opplysninger som skal registreres.

I studien inngår det en blogg som skal benyttes av barna. De gjøres imidlertid ikke oppmerksomme på at denne overvåkes av prosjektleder. Komiteen finner det ikke akseptabelt at prosjektleder skal overvåke denne på disse vilkårene.

Samhandlingen mellom barn og lærere kontra barn og fysioterapeuter vil sannsynligvis være veldig forskjellig. Komiteen ber om en utredning av hvilke sider ved de ulike profesjonene man ønsker å undersøke i forhold til dette.

Komiteen har følgende merknader til informasjonsskrivet:
Språklig overselges prosjektet i informasjonsskrivet. Komiteen ber om at ordlyden nedtones og at informasjonsskrivet utformes i en mer nøytral form.

Komiteen ber om at REKs mal for informasjonsskriv benyttes. Malen finnes på http://www.etikkom.no/REK/skjemaer/forskerportal/infoskriv

Samtykkeerklæringen skal kun inneholde samtykket. Alt det samtykkes til skal stå i selve informasjonsskrivet.

Vedtak:
Vedtak utsettes. Det bes om tilbakemelding på de merknader som er anført, før endelig vedtak kan fattes.

Vedtaket var enstemmig

Vi ber om at svar på merknader gis i brevs form og påføres vår referanse.

Med vennlig hilsen

Stein A. Evensen (sign.)
Professor dr.med.
leder

Ingrid Middelthon
Ingrid Middelthon
Komitésekretær

Kopi: Nina Nordvik, Norges Forskningsråd, Postboks 2700 St Hanshaugen, 0130 Oslo

UNIVERSITETET I OSLO
DET MEDISINSKE FAKULTET

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NO-0318 Oslo

Telefon: 22 85 05 93
Telefaks: 22 85 05 90
E-post: i.m.middelthon@medisin.uio.no
Nettadresse: www.etikkom.no

Dato: 06/02/09
Deres ref.:
Vår ref.: S-08820d, 2008/21141

Vedr. svar på merknader for studien ”Om å være der det skjer - Profesjonsutøvelse og barns deltakelse i skole og habilitering”

Komiteen behandlet svar på merknader 27.01.09. Prosjektet er vurdert etter lov om behandling av etikk og redelighet i forskning av 30. juni 2006, jfr. Kunnskapsdepartementets forskrift av 8. juni 2007 og retningslinjer av 27. juni 2007 for de regionale komiteer for medisinsk og helsefaglig forskningsetikk.

Forskningsetisk vurdering:
Det skal inkluderes 15 barn i studien. Flere diagnoser vil være representert i utvalget. Dette er et lite utvalg og identifisering av deltakere gjennom diagnose vil kunne være mulig. Komiteen forutsetter at studien legges opp og presenteres i en slik form at identifisering av deltakere gjennom diagnose ikke kan skje.

Komiteen har følgende merknader til informasjonsskrivet:
Komiteen ber om at det utformes et eget, alderstilpasset informasjonsskriv til barna. Informasjonsskrivet sendes komiteen til orientering.

Vedtak:
Prosjektet godkjennes under forutsetning av at merknadene som er anført ovenfor blir innarbeidet før prosjektet settes i gang.

Vedtaket var enstemmig

Komiteenes vedtak etter Forskningsetikklovens § 4 kan påklages (jfr. forvaltningsloven § 28) til Den nasjonale forskningsetiske komité for medisin og helsefag. Klagen skal sendes REK Sør-Øst D(jfr. forvaltningsloven § 32). Klagefristen er tre uker fra den dagen du mottar dette brevet (jfr. forvaltningsloven § 29).

Med vennlig hilsen

Stein A. Evensen (sign.)
Professor dr.med.
leder

Ingrid Middelthon
komitésekretær

Kopi:

- Norges Forskningsråd, Nina Nordvik, Postboks 2700 St. Hanshaugen, 0130 Oslo

Norsk samfunnsvitenskapelig datatjeneste AS
NORWEGIAN SOCIAL SCIENCE DATA SERVICES

NSD

Harald Hårfagres gate 29
N-5007 Bergen
Norway
Tel: +47-55 58 21 17
Fax: +47-55 58 96 50
nsd@nsd.uib.no
www.nsd.uib.no
Org.nr. 985 321 884

Sølvi Helseth
Avdeling for sykepleierutdanning
Høgskolen i Oslo
Postboks 4 St. Olavs plass
0130 OSLO

Vår dato: 02.02.2009 Vår ref: 20562 / 2 / GRH Deres dato: Deres ref:

TILRÅDING AV BEHANDLING AV PERSONOPPLYSNINGER

Vi viser til melding om behandling av personopplysninger, mottatt 27.11.2008. Meldingen gjelder prosjektet:

20562	*Om å være der det skjer. Profesjonsutøvelse og barns deltakelse i skole og habilitering*
Behandlingsansvarlig	*Høgskolen i Oslo, ved institusjonens øverste leder*
Daglig ansvarlig	*Sølvi Helseth*

Personvernombudet har vurdert prosjektet, og finner at behandlingen av personopplysninger vil være regulert av § 7-27 i personopplysningsforskriften. Personvernombudet tilrår at prosjektet gjennomføres.

Personvernombudets tilråding forutsetter at prosjektet gjennomføres i tråd med opplysningene gitt i meldeskjemaet, korrespondanse med ombudet, eventuelle kommentarer samt personopplysningsloven/-helseregisterloven med forskrifter. Behandlingen av personopplysninger kan settes i gang.

Det gjøres oppmerksom på at det skal gis ny melding dersom behandlingen endres i forhold til de opplysninger som ligger til grunn for personvernombudets vurdering. Endringsmeldinger gis via et eget skjema, http://www.nsd.uib.no/personvern/forsk_stud/skjema.html. Det skal også gis melding etter tre år dersom prosjektet fortsatt pågår. Meldinger skal skje skriftlig til ombudet.

Personvernombudet har lagt ut opplysninger om prosjektet i en offentlig database, http://www.nsd.uib.no/personvern/prosjektoversikt.jsp.

Personvernombudet vil ved prosjektets avslutning, 31.12.2012, rette en henvendelse angående status for behandlingen av personopplysninger.

Vennlig hilsen

Bjørn Henrichsen

Grethe Halvorsen

Kontaktperson: Grethe Halvorsen tlf: 55 58 25 83
Vedlegg: Prosjektvurdering

Prosjektvurdering - Kommentar

20562

Det registreres sensitive personopplysninger i form av helseopplysninger (jf. pol § 2).

Utvalget av barna og deres foreldre rekrutteres ved at kontaktpersoner i behandlingsapparatet og i interesseorganisasjoner formidler skriftlig forespørsel fra prosjektleder. Foreldre returnerer samtykke direkte tilbake til prosjektleder.

Foreldre, barn og profesjonsutøverne informeres skriftlig om studien og samtykker skriftlig til deltakelse.

Vi har registrert at profesjonsutøverne ikke intervjues om enkeltbarn, men om erfaringer med samhandling generelt. Vi minner om at dersom det i intervjuene med profesjonsutøverne vil fremkomme direkte eller indirekte personidentifiserbare opplysninger om enkeltbarn, må aktivt samtykke til intervjuene med utøverne innhentes fra barnas foreldre.

Vi har fått opplyst at bruk av blogger utgår fra prosjektet.

Lydbånd slettes og øvrige personidentifiserbare opplysninger anonymiseres ved prosjektslutt, 31. desember 2012.

Dersom det skal gjennomføres en oppfølgingsstudie, meldes denne til personvernombudet for behandling før den settes i gang.

Informasjonsbrev til barnet med samtykke

Vil du samarbeide med oss i prosjektet

”Om å være der det skjer”?

Vi har startet et prosjekt hvor vi ønsker å høre barns meninger om hva som er viktig å delta på i hverdagen og spesielt i skolen. Vi ønsker også å høre hva barn mener voksne kan gjøre for at barn skal kunne delta mest mulig i det de ønsker. Vi vil intervjue barn som har en fysisk funksjonshemming og som skal starte på ungdomsskolen enten høsten 2009 eller høsten 2010.

Hva innebærer dette prosjektet?
Vi skal snakke med ca 15 barn om deres skolehverdag, hva skjer og med hvem? Vi ønsker å snakke med deg både når du avslutter barneskolen og etter at du har begynt på ungdomsskolen På slutten av første år på ungdomsskolen kan det hende vi spør om å få prate med deg igjen. I tillegg skal vi foreta observasjoner i skolen. Det er fordi vi vil se på de fysiske omgivelser og hvordan skolen organiserer undervisningen, friminutt og andre aktiviteter. Alle samtaler med deg skal tas opp på bånd. Vi skriver notater fra observasjonene på skolene. Det er ingen som skal gjenkjenne deg fra det som vi skal skrive om.

Dine foreldre/ foresatte har fått eget brev om dette prosjektet der de godkjenner at du kan delta på dette. Hvis det er i orden ringer vi deg for nærmere avtale.

Frivillig deltakelse
Det er frivillig å delta i dette prosjektet. Du kan trekke deg når som helst og du trenger ikke å si hvorfor. Ønsker du å delta, kan du undertegne på siste side. Har du spørsmål kan du ringe, sende sms eller e-post til:

Mona Asbjørnslett
Pilestredet 48, 0167 Oslo

Tlf: 22 45 24 62/ 97 76 27 07

Mail: mona.asbjornslett@hf.hio.no

”Om å være der det skjer”

Samtykke til deltakelse i prosjektet

Ja, jeg vil delta:

(Barnets underskrift, dato)

Informasjonsbrev til foreldre/ foresatte med samtykke

Forespørsel om deltakelse i forskningsprosjektet;

”Om å være der det skjer- profesjonsutøvelse og barns deltakelse i skolen”

Bakgrunn og hensikt
Dette er en forespørsel til deg/dere og ditt barn om å delta i en forskningsstudie for å se på barns sosiale deltakelse i skolen. Hensikten er å løfte frem gode samhandlingsmåter mellom barn og ulike profesjonsutøvere i skolen som kan bidra til sosial deltakelse for barn med fysiske funksjonshemminger. Vi har spesielt fokus på overgangen mellom barne- og ungdomsskolen.

Hva innebærer studien?
I studien skal vi hovedsakelig snakke med barn om deres skolehverdag, hva skjer og med hvem? Vi gjør individuelle intervjuer mens barnet er på barneskolen og på ungdomsskolen. Noen barn vil vi også intervjue i grupper med andre barn i samme alder. I tillegg skal vi foreta observasjoner i noen skolesituasjoner, der vi kartlegger fysiske omgivelser og skolens organisering. Vi vil intervjue foreldre/ foresatte om deres erfaringer med sosial deltakelse for sitt barn og samhandling med profesjonsutøvere. I tillegg vil vi intervjue enkelte profesjonsutøvere der vi vil løfte frem erfaringer fra god samhandling med barn. Profesjonsutøvere kan være lærere, assistenter, helsesøster, ergoterapeuter, fysioterapeuter eller andre som er tilknyttet skolen. Resultatene skal formidles i artikler evt. fagbøker, og seminarer for profesjonsutøvere i skolene.

Mulige fordeler og ulemper
Fordelen med studien er at det er barns egne meninger og erfaringer fra sosial deltakelse i skolen som er hovedfokus. Vi ønsker i størst mulig grad å løfte frem de positive erfaringene som barna har med å samhandle med profesjonsutøvere.

Hva skjer med informasjonen om deg/ dere og deres barn?
Intervjuer tas opp på bånd. Informasjonen som registreres om deg/dere skal kun brukes slik som beskrevet i hensikten med studien. Alle opplysningene vil bli behandlet uten navn og fødselsnummer eller andre direkte gjenkjennende opplysninger. En kode knytter til opplysninger om deg/dere gjennom en navneliste. Alle lydbånd slettes og personopplysninger anonymiseres senes ved prosjektets slutt, desember 2012. Innen prosjektet avsluttes, kan foreldre og barn bli kontaktet igjen med spørsmål om oppfølgingsstudie. Det vil ikke være mulig å identifisere deg og deres barn i resultatene av studien når resultatene publiseres.

Dette prosjektet er meldt til personvernombudet for forskning og Norsk samfunnsvitenskapelig datatjeneste AS.

Frivillig deltakelse
Det er frivillig å delta i studien. Du/dere kan når som helst og uten å oppgi noen grunn trekke ditt samtykke til å delta i studien. Dersom du/dere ønsker å delta, undertegner du samtykkeerklæringen på siste side. Samtykke kan sendes tilbake i vedlagt frankert konvolutt eller leveres direkte til forskeren ved det første møte. Om du/dere nå sier ja til å delta, kan du/dere senere trekke tilbake ditt samtykke.

Dersom du senere ønsker å trekke deg eller har spørsmål til studien, kan du kontakte:

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Pilestredet 48, 0167 Oslo

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Mail: mona.asbjornslett@hf.hio.no

Kapittel A- utdypende forklaring av hva studien innebærer

- Kriterier for deltakelse

Barn som deltar er i avsluttende år på barneskolen ved prosjektets start. Barna har en fysisk funksjonshemming. Foreldre og/eller foresatte til barn med fysiske funksjonshemminger. Foreldre og/ eller foresatte som har anledning og er interesserte i å la seg intervjue underveis i prosjektet kan bli forespurt om å delta. Det samme gjelder enkelte profesjonsutøvere i skolen.

- Tidsskjema – hva skjer og når skjer det?

Våren 2009 - Individuelle intervjuer med barn, enten på skolen, hjemme eller et annet sted som barnet er fortrolig med. Dette er livsformsintervjuer der vi kartlegger hvordan barnets dagligliv er organisert, hva skjer, hvem deltar, på hvilke måter og hvordan opplever barnet det som skjer? Individuelle intervjuer med foreldre/ foresatte om barns deltakelse i barneskolen og samarbeid med sentrale profesjonsutøvere. Enkeltobservasjoner i noen skoler.
Høsten 2009- Oppfølgende intervjuer av barn som har begynt på ungdomsskolen. Enkelte observasjoner.
Vår 2010- Oppfølgende intervjuer med barn og foreldre/foresatte individuelt/ og eller i gruppe. Individuelle og/ eller fokusgruppeintervjuer med aktuelle profesjonsutøvere tilknyttet skoler.

Mulige fordeler
Vi mener at fordelen med denne studien er at vi kan lære noe om hvordan gode samhandlingsmåter med barn kan bidra til sosial deltakelse for barn med fysiske funksjonshemminger. Det er få studier som fokuserer på barns erfaringer om egen sosiale deltakelse i skolen og hvordan profesjonsutøvere kan fremme dette.

Kapittel B - Personvern

Personvern
I tillegg til opplysninger som innhentes gjennom intervjuer og observasjoner vil opplysninger om deg/dere og barnet vil bli registrert i form av navn, alder, adresse og telefonnummer. Barnets diagnose vil også stå som en opplysning. Opplysningene oppbevares i låsbart arkiv og adskilt fra datamateriale som utvikles underveis i prosjektet. Det er kun forskerne i prosjektet som har tilgang til opplysninger om dere. Det er Høgskolen i Oslo som er databehandlingsansvarlig.

Rett til innsyn og sletting av opplysninger om deg
Hvis du/dere deltar i studien, har du/dere rett til å få innsyn i hvilke opplysninger som er registrert om deg/dere. Du/dere har videre rett til å få korrigert eventuelle feil i de opplysningene vi har registrert. Dersom du/dere trekker deg/dere fra studien, kan du kreve å få slettet innsamlet datamateriell, med mindre opplysningene allerede er inngått i analyser eller brukt i vitenskapelige publikasjoner.

Informasjon om utfallet av studien
Resultater fra denne studien vil bli publisert i form av ulike artikler, mulige bokkapitler og i form av kurs, konferanser og seminarer som vi kan tilby til profesjonsutøvere i skolen og andre.

Samtykke til deltakelse i studien

Jeg samtykker til å la mitt barn delta i studien

(Signert av foreldre/foresatte, dato)

Jeg samtykker til selv å kunne delta i denne studien

(Signert av foreldre/ foresatte, dato)

Jeg bekrefter å ha gitt informasjon om studien

(Signert, rolle i studien, dato)

Mona Asbjørnslett

Forespørsel om deltakelse i forskningsprosjektet;

”Om å være der det skjer- profesjonsutøvelse og barns deltakelse i skolen”

Bakgrunn og hensikt
Dette er en forespørsel til deg om å delta i en forskningsstudie for å se på barns sosiale deltakelse i skolen. Hensikten er å løfte frem gode samhandlingsmåter mellom barn og ulike profesjonsutøvere i skolen som kan bidra til sosial deltakelse for barn med fysiske funksjonshemminger. Vi har spesielt fokus på overgangen mellom barne- og ungdomsskolen.

Hva innebærer studien?
I studien skal vi hovedsakelig snakke med barn om deres skolehverdag, hva skjer og med hvem? Vi gjør individuelle intervjuer mens barnet er på barneskolen og på ungdomsskolen. Noen barn vil vi også intervjue i grupper med andre barn i samme alder. I tillegg skal vi foreta observasjoner i noen skolesituasjoner, der vi kartlegger fysiske omgivelser og skolens organisering. Vi vil intervjue foreldre/ foresatte om deres erfaringer med sosial deltakelse for sitt barn og samhandling med profesjonsutøvere. I tillegg vil vi intervjue enkelte profesjonsutøvere der vi vil løfte frem erfaringer fra god samhandling med barn. Profesjonsutøvere kan være lærere, assistenter, helsesøster, ergoterapeuter, fysioterapeuter eller andre som er tilknyttet skolen. Resultatene skal formidles i artikler evt. fagbøker, og seminarer for profesjonsutøvere i skolene.

Mulige fordeler og ulemper
Fordelen med studien er at det er barns egne meninger og erfaringer fra sosial deltakelse i skolen som er i hovedfokus. Vi ønsker i størst mulig grad å løfte frem de positive erfaringene som barn, foreldre og profesjonsutøvere har med samhandling og i overgangen fra barne- ungdomsskolen.

Hva skjer med informasjonen om deg?
Intervjuer tas opp på bånd. Informasjonen som registreres om deg skal kun brukes slik som beskrevet i hensikten med studien. Alle opplysningene vil bli behandlet uten navn og fødselsnummer eller andre direkte gjenkjennende opplysninger. En kode knytter til opplysninger om deg/dere gjennom en navneliste. Alle lydbånd slettes og personopplysninger anonymiseres senes ved prosjektets slutt, desember 2012. Innen prosjektet avsluttes kan dere bli kontaktet igjen med spørsmål om oppfølgingsstudie. Det vil ikke være mulig å identifisere deg i studien når resultatene publiseres.

Dette prosjektet er meldt til personvernombudet for forskning og Norsk samfunnsvitenskapelig datatjeneste AS.

Frivillig deltakelse
Det er frivillig å delta i studien. Du kan når som helst og uten å oppgi noen grunn trekke ditt samtykke til å delta i studien. Dersom du ønsker å delta, undertegner du samtykkeerklæringen på siste side. Samtykke kan sendes direkte tilbake til forskeren i vedlagt, frankert konvolutt eller overleveres direkte ved første møte. Om du sier ja til å delta, kan du senere trekke tilbake ditt samtykke.

Dersom du senere ønsker å trekke deg eller har spørsmål til studien, kan du kontakte:

Mona Asbjørnslett
Pilestredet 48, 0167 Oslo

Tlf: 22 45 24 62/ 97 76 27 07
Mail: mona.asbjornslett@hf.hio.no

Kapittel A- utdypende forklaring av hva studien innebærer

- Kriterier for deltakelse

Barn som deltar er i avsluttende år på barneskolen ved prosjektets start. Barna har en fysisk funksjonshemming. Foreldre og/eller foresatte til barn med fysiske funksjonshemminger. Foreldre og/ eller foresatte som har anledning og er interesserte i å la seg intervjue underveis i prosjektet kan bli forespurt om å delta. Det samme gjelder enkelte profesjonsutøvere som representerer god praksis i å samhandle/samarbeide med barn og foreldre/foresatte.

- Tidsskjema – hva skjer og når skjer det?

Våren 2009 - Individuelle intervjuer med barn, enten på skolen, hjemme eller et annet sted som barnet er fortrolig med. Dette er livsformsintervjuer der vi kartlegger hvordan barnets dagligliv er organisert, hva skjer, hvem deltar, på hvilke måter og hvordan opplever barnet det som skjer? Individuelle intervjuer med foreldre/ foresatte om barns deltakelse i barneskolen og samarbeid med sentrale profesjonsutøvere. Enkeltobservasjoner i noen skoler.
Høsten 2009- Oppfølgende intervjuer av barn som har begynt på ungdomsskolen. Enkelte observasjoner.
Vår 2010- Oppfølgende intervjuer med barn og foreldre/foresatte individuelt/ og eller i gruppe. Individuelle og/ eller fokusgruppeintervjuer med aktuelle profesjonsutøvere tilknyttet skoler.

Mulige fordeler
Vi mener at fordelen med denne studien er at vi kan lære noe om hvordan gode samhandlingsmåter med barn kan bidra til sosial deltakelse for barn med fysiske funksjonshemminger. Det er få studier som fokuserer på barns erfaringer om egen sosiale deltakelse i skolen og hvordan profesjonsutøvere kan fremme dette.

Kapittel B - Personvern

Personvern
I tillegg til opplysninger vi innhenter gjennom intervjuene med deg vil det bli registrert navn, alder, tittel, adresse og telefonnummer. Opplysningene oppbevares i låsbart arkiv og adskilt fra datamateriale som utvikles underveis i prosjektet. Det er kun forskerne i prosjektet som har tilgang til opplysninger om deg. Det er Høgskolen i Oslo som er databehandlingsansvarlig.

Rett til innsyn og sletting av opplysninger om deg
Hvis du deltar i studien, har du rett til å få innsyn i hvilke opplysninger som er registrert om deg. Du har videre rett til å få korrigert eventuelle feil i de opplysningene vi har registrert. Dersom du trekker deg fra studien, kan du kreve å få slettet innsamlet datamateriell, med mindre opplysningene allerede er inngått i analyser eller brukt i vitenskapelige publikasjoner.

Informasjon om utfallet av studien
Resultater fra denne studien vil bli publisert i form av ulike artikler, mulige bokkapitler og i form av kurs, konferanser og seminarer som vi kan tilby til profesjonsutøvere i skolen og andre.

Samtykke til deltakelse i studien

Jeg samtykker til å delta i studien

(Signert av informant, dato)

Jeg bekrefter å ha gitt informasjon om studien

(Signert, rolle i studien, dato)

Mona Asbjørnslett