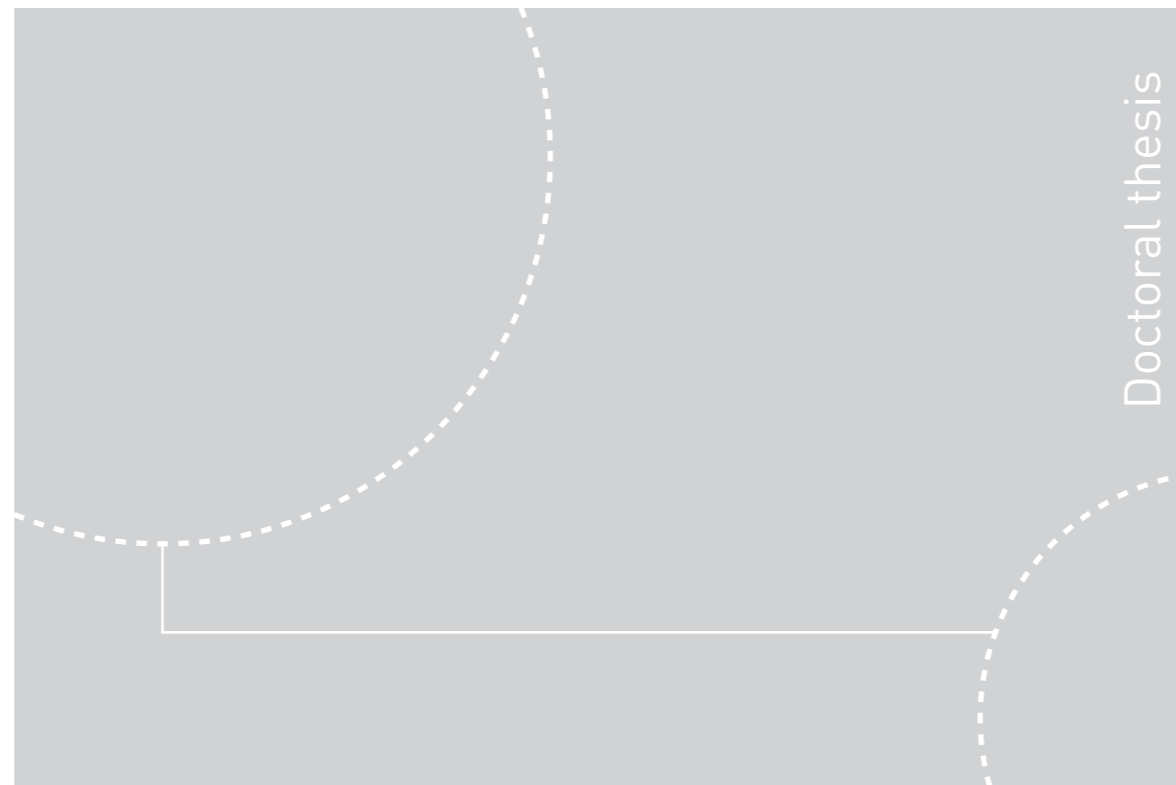


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The paradoxes of the participation dimension in the International Classification of Functioning, Disability and Health (ICF)

NTNU
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PREFACE

I spent two decades in clinical work before finally enrolling in a PhD program. I wrote my MA thesis on the International Classification of Functioning, Disability and Health (ICF) in 2004-2005. As a consequence of my interest in the ICF and my long clinical experience as an occupational therapist at a rehabilitation unit for persons with spinal cord injuries (SCIs), I contacted researchers who specialized in SCI research and the development of the ICF in 2008. Jan Reinhardt, his research associates at Swiss Paraplegic Research and I decided to try “tango dancing” together during an early phase of the European research project, “It takes two to tango-revisited”. Thanks to the extraordinarily supportive head of the clinic in Trondheim, Gisle Meyer, and to Jan Reinhardt and a network of highly supportive SCI researchers and experts, including Marcel Post, Fin Biering-Sørensen and Alarcos Cieza, I reluctantly applied for a three-year research project. To my surprise, I received a generous research grant to conduct the project.

The collaboration with Nottwil and partners initially included a qualitative-based SCI study of the meaning of participation and integration from an “insider perspective” (the Tango Project) and a European survey (ILIAS-SCI) on labour market participation and living conditions that targeted members of national SCI organizations.

The thesis includes four papers. I wrote two of the papers, 1 and 4, alone. I am the first author and did most of the writing of paper 2. I am also the first author of paper 3, but that paper is based on a more active collaboration between the co-authors. In addition to my role as an active writer and contributor to a first draft, I rewrote and finalised paper 3. Three of the papers have been accepted for publication; paper 2 is still under consideration by the journal *Alter*.

Because I prioritized the papers included in this thesis at the expense of ILIAS-SCI, the latter has been reduced to relevant background information on labour market participation and living conditions in the thesis summary. My collaboration with Erling Solheim in the ILIAS-SCI portion of the project was an important gateway to understanding the labour market for and living conditions of persons with SCI in Norway. The results of ILIAS-SCI have been presented at the Norwegian SCI association - LARS annual meetings, Nordic and international SCI conferences and in several meetings in Norway with patients, dependents, and SCI staff. I owe Erling special thanks for his generosity and patience while working with

this qualitative researcher. I am also grateful for the collaboration and support of Leif Arild Fjellheim and Eilin Reinaas (Norwegian Spinal Cord Injury Association, LARS) and Jane Horsewell (European Spinal Cord Injury Federation).

I owe a number of persons special thanks. Jan Reinhardt and Marcel Post played a vital role in the first two years of the project as co-supervisor and mentor respectively. In addition to Jan and Marcel, it has been a pleasure to work with Kaisa Ruoronen, Sibylle Juvalta and Anne Ostermann to code, analyse and write about the Tango interviews. Although the coding process was more time consuming and demanding than anticipated, we all learnt a great deal from this collaboration.

Jan Tøssebro, who has been my main supervisor at NTNU, earns special thanks. He followed this thesis project from beginning to end and was especially important in the second half of the project. In retrospect, I realize that it must have been quite challenging to supervise a student from an SCI milieu with many stakeholders. His comments and support were crucial for transforming the papers from rough drafts to texts and for the preparation of the thesis summary. His confidence in me as a researcher and his ability to convince me that the project would “soon” reach an end helped me to finalise the thesis.

I am grateful to Trond Petersen at the University of California-Berkeley for his hospitality and friendship during my two semesters as a guest researcher in Berkeley and to Aaron Cicourel at the University of California-San Francisco for valuable inputs. I received financial support from the Liaison Committee of the Central Norway Regional Health Authority and the Norwegian University of Science and Technology (Samarbeidsorganet HMN-NTNU). Swiss Paraplegic Research sponsored the ILIAS-SCI Survey in Norway. NTNU Social Research, Ltd. hosted the project and was my employer for a four-year period. It has been a pleasure to work at the Department of Diversity and Inclusion at NTNU Social Research with their hospitable staff and researchers specializing in disability and migration studies. I am grateful to Berit Berg for facilitating my stay at NTNU Social Research and to the members of a lively research community.

I am grateful for valuable comments on chapter 2 from my friend and former colleague, Aileen Bergström, and for valuable comments from Arne Eide on paper 4. Marita Løkås earn special mentioning for her excellent skills helping me to edit and format the text. I am also

grateful for language assistance with the Norwegian summary from my mother in law, Siri Mollestad.

Although I feared that my return to clinical work in 2015 could delay the finalization of this thesis, I have received valuable support from my supervisors at St. Olav University Hospital, Ellen Marie Hatlen and Børn Skogstad, and from my colleagues Elna Wågø and Randi Fjellheim. I am fully aware that my time spent in two different worlds of SCI activities had a price. I hope that it will prove to be a worthy investment for more than just myself in the years to come and that our SCI ward will prioritize research and development both nationally and internationally.

My husband, Håkon Leiulfsrud, has been my primary coach in periods of joy and productivity and in periods when I doubted that I would ever complete the project. Håkon has always been an interesting partner for discussing topics relevant to the thesis project, but equally important are his roles as motivator, friend and loved husband. I hope now I will be a more present and less stressed version of myself with Håkon and our two daughters, Hanna and Frida.

I dedicate this thesis to my 31 generous informants in the Norwegian Tango Project and to LARS members. It is my sincere hope that the everyday life and participation in society of persons with SCI will receive the attention they need and deserve in research, clinical practice and the Norwegian Labour and Welfare Administration (NAV).

LIST OF PAPERS

1. Schedin-Leiulfstrud A: "Social participation in theory and practice: The perspectives of persons with spinal cord injuries". Paper sent to *ALTER* – under review.
2. Schedin-Leiulfstrud A, Reinhardt JD, Ostermann A, Ruoranen K, and Post MWM. "The value of employment for people living with spinal cord injury. *Disability and Society* 2014, 29 (8): 1177-1191.
3. Schedin-Leiulfstrud A. Ruoranen K, Ostermann A, and Reinhardt JD: "The meaning of employment from the perspective of persons with spinal cord injuries in six European countries". *Work - a journal of prevention, assessment and rehabilitation* 2016, 55 (1): 133-144.
4. Schedin-Leiulfstrud A: "International Classification of Functioning, Disability and Health (ICF) in the context of participation". Book chapter accepted for publication 11. September 2015, in *Participation as professional concept and everyday lived experience - The role of health and welfare services* Eds. Eide A H, Josephsson S, Vik K, and Ness N-E. Routledge Publishers.

SUMMARY IN ENGLISH

This thesis has two main goals: to study the meaning of participation in society among persons living with spinal cord injuries, with a special interest in the role of employment, and to explore the participation dimension of the International Classification of Functioning, Disability and Health (ICF). The first main goal is operationalized in two empirical research questions:

1. What does “participation in society” mean to persons with spinal cord injuries (SCIs)?
2. What role does employment play in the participation narratives of persons living with SCIs?

The second main goal is operationalized as a more general theoretical research question:

3. What are the possibilities and limitations inherent in the participation dimension of the ICF framework?

Despite of its universal claims, the ICF is a model with several paradoxes with respect to how participation is presented as a concept.

The thesis is based on 31 in-depth interviews conducted in Norway in 2008-2010 among persons with SCIs. The inclusion criteria in Norway were persons of working age who had been injured a minimum of two years before the interview took place. The Norwegian sample comprised 20 men and 11 women, including 28 with a traumatic/non-traumatic injury and 3 who were born with the injury (spina bifida). Similar investigations were conducted as part of a European project in Switzerland in 2008-09, Finland in 2009, and in Germany, Ireland, and Northern Ireland in 2011. More persons were interviewed in Norway than in the other countries, and the Norwegian informants were recruited from a SCI unit at a hospital. The Finnish informants were also recruited from a SCI unit at a hospital but differed with respect to age (the mean age of the Finnish informants was 37 years compared with 49-51 years for the informants from the other nations) and an overrepresentation of persons with tetraplegia.

The Norwegian interviews have been fully transcribed. The interviews were analysed by reading each case in-depth and performing computer-aided content analysis (the MaxQDA program). The informants in this project were viewed as both insiders and experts because of their own everyday participation in society and their experiences living with SCIs. In addition

to gaining their insights into the meaning of participation, this approach helped us explore ideologies embedded in everyday life and participation.

In this dissertation project, participation is understood as inherently social and geared towards others, namely persons or norms that regulate and affect our actions. Integration refers to the conventional understanding of the relationships between the system and its parts in discussions of the social inclusion and exclusion of persons with disabilities. Given the research questions and an interest in individuals' understanding of participation in society, integration in society is primarily viewed as an outcome of more or less "successful" participation in society. In line with occupational therapy and the theory of social recognition, it is assumed that human beings are capable of reflecting upon their own life privately and publicly and that their voices must be included in a discussion of participation. Because this is a project about participation in society, it was necessary to broaden the perspective from the community and everyday domains to a broader notion of society that also includes workplaces, volunteer organizations and persons' roles as citizens and consumers.

Several theoretical perspectives that focus on how to study participation in society inform this thesis. It is framed in a discussion of both medical and medical rehabilitation models of disability and disability studies. It is also a dissertation wherein the relevance of the ICF and its rival, the Disability Creation Process (DCP model), is revealed and problematized. On paper, both of these models have a number of commonalities with occupational therapy, especially the DCP model. A focus on actors' capacities to conduct activities and roles under different types of constraints arising from each person's way of life (personal factors) and from factors that prevent or enhance participation in the environment is found in both health models and in occupational therapy. The main difference is that occupational therapy has a more developed language and an interest in what the actors need to do, want to do and are expected to do. This is also the theoretical rationale for bringing social recognition and capability perspectives into the analysis of concrete participation processes.

The informants' accounts of participation in society illustrate the importance of social recognition in everyday life and in interaction with others. They also reveal narratives of the informants' social identities; their perceptions of themselves in interactions with co-workers, health care providers and family and friends; and primary references to participation in parity with other citizens. The results lend support to a Nordic relational model of disability that

views disabilities as an outcome of social barriers and a disabling environment but recognizes that disabilities are highly situational and relative to the participation context.

One of the most interesting results from this study is the importance attached to employment as the primary means of participation in Norwegian society. This is a view expressed by both currently employed and unemployed informants. The findings regarding employment are particularly important from a rehabilitation and social policy perspective because the positive long-term effects of employment tend to be under-evaluated in post-SCI medical rehabilitation. Ensuring the utilization of a high share of SCI people who are capable of remaining in long-term employment will require more and better coordination among the Norwegian Labour and Welfare Administration, the medical system and employers. Notwithstanding that more than two-thirds of persons with SCIs have been employed at some stage post-SCI, Norway has a lower share of post-SCI long-term employment than other European countries included in this study.

There is no agreement in the ICF literature regarding how to approach the activity and participation dimensions. A number of instruments have been proposed to tap activity and participation. These conceptualisations continue to be problematic unless it is accompanied with a more critical discussion of whether to use participation as a technical term or as a theoretically informed concept. All encompassing models, such as the ICF, originally based on ideals on the environment found in medicine and natural sciences, becomes especially challenging once they are adopted into real societies and real life situations. As a consequence the ICF contain a number of paradoxes if it should live up to its many claims and fill the gap between concepts in theory and concepts in human everyday practice. In a situation where not even researchers and health care professionals have reached any consensus how to understand participation, ordinary citizens may also have problems. Against this background, it is interesting to observe that the descriptions by the informants are richer than in the ICF model, and what we generally find in the ICF literature.

The main contribution of this PhD project is that it brings the discussion of social recognition into the context of participation in society among persons with SCIs. It also reveals the importance of problematizing the functions of employment from a participation perspective. Finally, this thesis presents a critical discussion of the ICF, which is rare but necessary for research and policies focused on participation in society.

SUMMARY IN NORWEGIAN

Avhandlingen har to hovedformål, nemlig å studere hva personer med ryggmargsskade forstår med deltakelse i samfunnet, samt å drøfte deltakelsesdimensjonen i Internasjonal klassifikasjon av funksjon, funksjonshemming og helse (ICF). Det første formålet forankres i to empiriske forskningsspørsmål:

1. Hva innebærer "deltakelse i samfunnet for personer med ryggmargsskade (SCI)?"
2. Hvilken rolle spiller lønnet arbeid i fortellingene (narrativene) om deltakelse for personene som har ryggmargsskade?

Det andre formålet er formulert som et mer teoretisk forskningsspørsmål:

3. Hvilke muligheter og begrensninger ligger i deltakelsesdimensjonen i ICFs teoretiske rammeverk?

På tross av at ICF har blitt lansert som et universalt rammeverk, så inneholder den et flertall paradokser med et svært fleksibelt deltakelsesbegrep.

Avhandlingen baseres på 31 dybdeintervjuer av personer med ryggmargsskade i Norge i årene 2008-2010. Kriterierene for å inngå i den norske studien var at de var i arbeidsfør alder og hadde vært skadd minst fem år før de ble intervjuet. Det norske utvalget besto av 20 menn og 11 kvinner. Av disse var 3 personer født med ryggmargsskade (ryggmargsbrokk). Den norske studien er en del av et europeisk prosjekt med base i Nottwil, Sveits. Tilsvarende intervjuer ble gjennomført i Sveits i perioden 2008-2009, i Finland i 2009, i Tyskland, Irland og Nord-Irland i år 2011. Flere personer ble intervjuet i Norge sammenlignet med øvrige land i tillegg til at de norske informantene ble rekruttert fra en ryggmargsskadeavdeling på et sykehus. De finske informantene ble i likhet med de norske rekruttert fra en ryggmargsskadeavdeling. De var også yngre enn i Norge og øvrige land, i tillegg til at de var overrepresentert av personer med tetraplegi (cervikal ryggmargsskade med lammelser i armer og ben).

De norske intervjuene ble transkribert i sin helhet. Intervjuene ble analysert ved å gå i dybden av hvert enkelt intervju i kombinasjon med en dataassistert innholdsanalyse (MaxQDA). Informantene i prosjektet ble sett på som særlig "innvidde", og eksperter gjennom sine erfaringer med å leve med ryggmargsskade. I tillegg til å fange deres forståelse av deltakelse i

samfunnet, har denne tilnærmingen hjulpet oss med å utforske ideologiens utleiring i hverdagsdeltakelse.

I avhandlingen er deltakelse forstått som noe iboende sosialt og rettet mot andre. Dette kan være i form av personer eller normer som regulerer og påvirker våre handlinger. Begrepet integrasjon viser til den konvensjonelle forståelsen av forholdet mellom systemet og dets deler. Dette er også et syn som går igjen i avhandlingens drøfting av sosial inkludering og ekskludering av personer med nedsatt funksjonsevne. Ut i fra avhandlingens forskningsspørsmål, ble det antatt at integrering er et resultat av mer eller mindre ”vellykket” deltakelse i samfunnet. I tråd med ergoterapi og teorier om sosial anerkjennelse, antas det at mennesker er i stand til å reflektere over sitt eget liv både privat og offentlig. På lik linje med dette må deres stemmer bli inkludert i meningsfull diskusjon om deres deltakelse. Siden dette er et prosjekt om deltakelse i samfunnet, var det nødvendig å utvide perspektivet fra hverdagsdomener i lokalsamfunnet til en videre forståelse av samfunnet, som også inkluderer arbeidsplasser, frivillige organisasjoner og menneskers roller som borgere og forbrukere.

Flere teoretiske perspektiver om samfunnsdeltakelse har lagt tunge føringer for avhandlingen. Analysen er innrammet i en diskusjon som knytter seg til medisinske rehabiliteringsmodeller og samfunnsvitenskapelige, orienterte tilnærminger til funksjonshemming. Det er også en avhandling der relevansen av ICF og den canadiske konkurrenten, Disability Creation Process (DCP-modellen), belyses. På papiret, har begge disse klassifikasjonene mange fellestrekk med ergoterapi, særlig DCP-modellen. Dette framkommer i likartede syn på aktørens kapasitet til å utføre aktiviteter og roller under ulike typer av deltakelse og begrensninger. Den viktigste forskjellen er at ergoterapi har et mer utviklet språk og interesse for hva aktørene trenger å gjøre, ønsker å gjøre, og er forventet å gjøre. Dette er også den teoretiske begrunnelsen for å vektlegge sosial anerkjennelse og hva mennesker potensielt evner å klare (”capability”) i analysen av konkrete deltakelsesprosesser.

Informantenes fortellinger om deltakelse i samfunnet illustrerer betydningen av sosial anerkjennelse i hverdagen og i samspillet med andre. Dette kommer også til uttrykk i informantenes sosiale identiteter, deres oppfatninger av seg selv i samhandling med andre, samt i synet på deltakelse i samfunnet i paritet med øvrige borgere. Resultatene gir støtte til sentrale tankeganger i det som ofte betegnes som en nordisk relasjonell tilnærming til funksjonshemming. Også der forstås funksjonshemming som et resultat av sosiale barrierer og en invalidiserende miljø, i tillegg til at funksjonshemming ses som situasjonsbetinget.

Ett av de mest interessante resultatene fra denne studien er informantenes vekt på sysselsetting som hovedvirkemiddel for deltakelse i det norske samfunnet. Dette er et syn uttrykt av både de som var og som ikke var i lønnet arbeid. Funnene vedrørende sysselsetting er spesielt viktige i et rehabiliterings- og sosialpolitisk perspektiv. Positive og langsiktige virkninger av sysselsetting tenderer å bli undervurdert i rehabiliteringsprosessen etter en ryggmargsskade. Å sikre at flere av dem som har en restarbeidskapasitet kommer seg i jobb eller forblir i arbeidslivet etter en ryggmargsskade krever langt bedre samordninger mellom trygdesystemet, det medisinske systemet og arbeidsgivere. Til tross for at mer enn 2/3 av personer med ryggmargsskade har vært ansatt på et tidspunkt etter skaden, så har Norge en lavere andel sysselsatte enn de øvrige europeiske landene som inngår i denne studien.

Det foreligger ingen enighet i ICF-litteraturen om hvordan man skal tolke aktivitets- og deltakelsesdimensjonene. En lang rekke måleverktøy er blitt foreslått for å måle aktivitet og deltakelse. Uten at det foreligger en grunnleggende enighet om deltakelse er en teknisk term eller et teoretisk begrep er det vanskelig å finne essensen eller innholdet i ICF. Generelle allmenngyldige modeller som ICF, opprinnelig tuftet på forestillinger om miljøbetingelser i naturvitenskap og medisin, blir særlig vanskelig når de skal oversettes til virkelige samfunn og i konkrete hverdagslivssituasjoner. Fortsatt framstår det som et paradoks at gapet mellom begrepene i den generelle ICF- modellen og begrepene i praksis er så uavklarte. Når ikke engang modellen eller forskere og klinikere, som referer til ICF-modellen, er enige om hvordan deltakelsesbegrepet bør forstås, så er det ikke gitt at andre gjør det. Mot denne bakgrunn er svarene vi har fått av informantene langt rikere enn ICF-modellen og det vi finner i ICF-litteraturen.

Hovedbidraget i dette doktorgradsprosjektet er en diskusjon om sosial anerkjennelse i sammenheng med deltakelse i samfunnet blant personer med ryggmargsskade. Det viser også nødvendigheten av å problematisere de mange ulike funksjonene lønnet arbeid har i et videre deltakelsesperspektiv. Avhandlingen kan også ses som et bidrag til en kritisk diskusjon av ICF, som er sjelden, men nødvendig for forskning og politikk fokusert på deltakelse i samfunnet.

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(REK)

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PART I

1. INTRODUCTION

Optimal participation of persons with disabilities in society is a major goal of all health strategies. It is also increasingly recognized as a human right, e.g., in the United Nations Convention on the Rights of Persons with Disabilities (UN 2006; WHO 2011; Bickenbach 2012) which calls upon member states to implement policies that are more ambitious and disability-friendly than those of the past. However, despite increased research interest, our knowledge about participation in society by persons with spinal cord injuries (SCIs) is still limited in Norway and elsewhere.

The title of this doctoral dissertation suggests that the concept of participation is not self-evident. Despite the standards established by the World Health Organisation (WHO) and its International Classification of Functioning, Disability and Health (ICF), there is no consensus in the ICF literature regarding how to approach participation. This may appear paradoxical at first because of the impressive number of researchers involved in the operationalization of participation. However, a closer look at this research literature reveals that a large segment of the research community is more interested in standardization and measurement than in the content of the concept and theory development. It is my hope that this thesis may contribute to a discussion of a broader range of participation issues in both private and public participation domains and in both theory and practice.

This thesis has two main goals: *to study the meaning of participation in society among persons living with an SCI, with a special interest in the role of employment, and to explore the participation dimension of the ICF*. The first main goal is operationalized in two research questions:

1. What does “participation in society” mean to persons with spinal cord injuries (SCIs)?
2. What role does employment play in the participation narratives of persons living with SCIs?

Both of these research questions are part of a broader debate about factors that may contribute to the social inclusion and exclusion of persons with disabilities. Both research questions also encompasses the issue of how environmental and societal factors enhance or prevent opportunities for persons with disabilities to live a life on par with that of the “non-disabled”

majority of the population. It is also intertwined with how we view participation as “optimal” or “problematic”.

Norway has higher employment levels among persons with disabilities compared with the USA (OECD 2010), where most of the relevant research on SCI and employment has been conducted (for overviews, see Lidal, Huynh and Biering-Sørensen 2007; Ottomanelli and Lind 2009). In contrast with the USA, Norway has a highly developed public health care system, a generous public welfare system for persons who are unable to work, and relatively small social cleavages (see chapter 3). All of these factors may impact how Norwegians with SCIs experience participation in society compared with North Americans or with citizens of other European countries with more comprehensive welfare systems than the USA. Despite the widely shared view that employment is an important participation and integration determinant (OECD 2010; WHO 2014; Grammenos 2014), work and employment are treated primarily as demographic variables, and their importance in the lives of persons with SCIs is largely unexamined. I argue that we need more and better information about the meaning of employment among persons with SCIs to develop a realistic discussion of participation in society in both theory and practice. Although the importance attached to employment may vary among individuals over the course of their lives, employment is not necessarily given priority in individual rehabilitation plans.

Employment is part of Activity and Participation in the ICF model but has no specific status or function beyond the person’s formal employment status. The research question regarding employment is also linked to the research objective of exploring the possibilities and limitations of the ICF model.

The second main goal is operationalized as a more general theoretical research question:

3. What are the possibilities and limitations inherent in the participation dimension of the ICF framework?

Despite of its universal language, design and claims, the ICF is a model with several paradoxes with respect to how participation is presented theoretically and as a contextualizing concept. The ICF was designed to study activity and participation, but it adopts a very abstract and flexible notion of the participating person or actor. Because the ICF was at the core of this project from the beginning, it became both the standard reference and the target. In addition to an ambition to fill the gaps in the ICF with empirical data and participation

categories and domains, I also had a personal wish to engage in a discussion of the theoretical foundation of the ICF model. In contrast to those who claim that the ICF is no more than a classification of health and disability, I argue that it is part of a framework and embodies a number of theoretical assumptions about human conditions, activities, capacities and functioning (Schedin-Leiulfstrud 2005; Dubois and Trani 2009; Mitra 2014). It is also a model that is highly dependent of our understanding and interpretation of the language of the concepts used in different cultures and societies. The theoretical elaboration of the ICF is of interest because its leading advocates attribute significant potential to the ICF model beyond what is revealed in the official manual (WHO 2001). This is evident, for example, in controversies about the social agency problem and the view of actors' potential in the ICF model (Nordenfeldt 2003, 2006; Mitra 2014; Bickenbach 2014). The ideas behind the ICF model are also of interest because most classifications that involve human behaviour are based on a number of assumptions about the "world" (Franzosi 2004; Imrie 2004). From this perspective, it is less surprising that the ICF is formulated in seemingly neutral language (referred to as "etiologiical neutrality") but more surprising that the assumptions and language of the ICF has not led to more critical discussions in the research literature.

A growing body of research questions meta-theoretical models of participation with weak or no clear links to person's everyday lives and practices (Pollio, Henley and Thomson 1997; Hemmingsson and Jonsson 2005; Borell et al. 2006; Peterson et al. 2010; Ripat and Woodgate 2012). Most of the participation literature linked to the ICF model is based on quantitative studies that are more interested in measurement and the standardization of instruments than in the in-depth analysis of persons' social participation outside a clinical environment. The same problem is apparent in the ICF's main competitor, the Canadian Disability Creation Process (DCP) model (see chapter 3).

To overcome the problems of general models of human action, several health and rehabilitation researchers advocate using an "insider perspective" to substantiate abstract theory and concepts with human experiences (Hammel et al. 2008; Van de Velde et al. 2010; Bellanca, Biggeri and Marchetta 2011). This research has also been useful because it explores ideologies that are embedded in everyday life (Asaba and Jackson 2011) but easily forgotten in official health classifications or standardized measurements of activity in daily life (ADL).

Thus far, the outcome of this "insider perspective" has been uneven in the research literature. On the one hand, we see the development of numerous overlapping connotations of

participation. On the other hand, this focus has led to a more comprehensive discussion of participation in major domains of modern society. This development is also welcomed by the World Health Organisation (WHO) and by the WHO experts involved in the development of the ICF model (Cerniauskaite et al. 2011).

Hammel et al. (2008) and van de Ven et al. (2005) have developed a more explorative approach to participation for persons with SCIs. Joy Hammel's study in the USA adopts a theoretical framework that views participation from a social and cultural context, whereas the Dutch study by Leontine van de Ven et al. (2005) adopts a social psychological framework that emphasizes meaningful activities and coping strategies in everyday life. Until recently, SCI studies with a broader focus on participation in different societal domains, including both everyday participation and participation in a broader range of citizenship roles, have been rare.

The question of participation barriers is also relevant in a general discussion of integration, as is the issue of how persons with SCIs are part of what Hans Zetterberg calls "the small world" ("den lilla världen") and "the large world" ("den stora världen") (Zetterberg 1989.)¹. Participation barriers may be present in the physical landscape, in everyday living environments, and in the manner in which public domains are designed and organized.

In this dissertation project, participation is understood as inherently "social". In contrast to ego-oriented actions (such as toilet use and sleeping), participation is geared towards others. "Others" include not only other persons but also the cultural norms, roles and practices that affect human behaviour and actions. Humans may be seen as social beings formed by society, but they are also creative actors with the will and ability to define themselves as unique entities. Social recognition and respect from others are important because they enable the individual to be a full person and provide confirmation of individual behaviour and actions. The matter of what counts as "socially acceptable participation" is critical in any assessment of individuals and groups; it may have consequences for how we evaluate work that is unpaid, social activities conducted in informal social networks, or the work required to maintain our own bodies and daily functioning. To understand the importance of these roles, it is important to pay attention to the social recognition processes that influence person's participation and behaviour.

1.1 The dissertation project's status as part of a European project

My dissertation project is anchored in two European projects. The first project, which is the empirical source of the dissertation papers, is “It takes two to tango - revisited” (also called the European Tango Project). This project was conducted in 2008-2010 and is based on qualitative in-depth interviews with persons living with SCIs in Norway, Switzerland, Finland, Germany, Ireland and Northern Ireland. The second project, ILIAS-SCI, comprises national surveys of the labour market participation and integration of persons with SCIs in Norway, Switzerland, the Netherlands and Denmark. The first wave of this survey was conducted in 2012.²

Because knowledge about the employment and living conditions of persons with SCIs remains scarce in Norway, I refer to data from ILIAS-SCI in 2012 as the background for the qualitative empirical papers included in the dissertation. The background for these papers also includes the information about employment and living conditions found in Schedin-Leiulfsrud and Solheim (2016).

The original European Tango Project had a number of goals that can be summarized as follows: to generate new and relevant empirical material regarding the understanding of participation and integration in society among persons with SCIs; to identify factors that facilitate/hinder participation/integration in society; to develop the relevant concepts of the ICF; and to gather examples of best practices for rehabilitation and policy purposes (see paper 3).

The main difference between the European Tango Project and the studies by Hammel et al. (2008) and van de Ven et al. (2005) is that the European Tango Project takes a broader approach to participation and integration in society. In the European Tango Project, society includes everyday life experiences and experiences within different public domains, such as the health care system, the labour market, state welfare agencies, the legal system and public opinion. In this respect, persons with SCI are valued as individuals but are equally important as “experts” on how members of this population face different types of barriers to their participation in society.

My main contributions in this PhD project are broadening the discussion of participation in society to include the role and functions of employment (past and present) and showing the relevance of social recognition as a component of concrete participation experiences and

beliefs among persons with SCIs. Despite my interest in the theoretical and methodological issues related to the ICF model, I am more interested in participation in practice than in highly generalized ideas of what ideal participation is or should be. The same may also be said about my approach to social recognition and capability: I am more interested in what persons need to do, want to do and are expected to do than in meta theory and universal human rights unless it has a link to persons everyday lives. This research focus is in line with my own background in occupational therapy but has been rare in SCI research on participation.

1.2. Outline of the thesis summary

The thesis comprises four papers. The first paper is a response to the first research question regarding the understanding of participation in society among persons with SCIs. Papers 2 and 3 respond to the second research question regarding the role of employment in the participation narratives of persons with SCIs. The fourth paper discusses the possibilities and limitations of the participation dimension of the ICF.

Chapter 2 provides the reader with an overview of the theoretical framework of and important concepts in the four papers and the thesis summary.

Chapter 3 presents background data from ILIAS-SCI and official statistics about social participation in society. These data include Norwegian and European statistics on labour market participation among persons with disabilities and persons with SCIs.

Chapter 4 discusses how the interviews were conducted and analysed, ethical considerations and methodological considerations.

Chapter 5 includes short summaries of each of the four papers.

Chapter 6 comprises a discussion of certain main results.

Chapter 7 provides final remarks and reflections regarding the relevance of the project for research and clinical practice.

References used in the thesis summary are provided at the end of part I. Part II includes the four papers. Part III includes the appendixes. The interview protocol is described in appendix

1. Additional information of particular relevance to the thesis summary is presented in the appendices.

2. THEORETICAL FRAMEWORK OF THE STUDY

This is a study inspired by an “insider perspective” how persons with SCIs view themselves and others in terms of participation and integration in society. Adopting an insider perspective gives the informants a strong voice and ensures sensitivity to their problems and everyday realities. It also implies an ambition to speak on behalf of the informants, which is not to say that the researcher aims to be a “megaphone” for persons with SCIs or for any other particular interest group. Rather, in this project, I as a researcher am interested in the actual experiences of individuals with SCIs as persons and as citizens (see also chapter 4).

Although this study reflects an open mind to the concept of participation, it is also influenced by previous scholarship and research.

Additional relevant concepts in this project include “integration”, “impairment and disability”, “empowerment”, and “capacity and capability” (see 2.2.). Other concepts, such as those referring to established health classifications (i.e., the ICF and DCP models) and social recognition are addressed in more detail in section 2.4 and in other parts of the thesis summary.

“Studies of disability” is not a very informative label for the type of studies, theories and models included in this project. “Disability studies” is more limited than “studies of disability” (which includes medical rehabilitation research) and is traditionally seen as an umbrella for theoretical models that explain discrimination against and the social exclusion of persons with disabilities (Gustavsson 2004; Shakespeare 2006; Tøssebro 2009). A traditional criticism levelled by disability scholars against medicine and medical rehabilitation research is that it assumes a “deficit” in individual functioning or role performance (Pfeiffer 2002). However, in recent years, we have seen a shift in the language used in medicine and medical rehabilitation, which now includes concepts such as “empowerment”, “capacity” and “capability”. This shift illustrates a change in rhetoric but not necessarily a qualitative shift in the research focus or clinical practice of medical rehabilitation.³

2.1. Concepts

The *ICF* and its rival, the *Disability Creation Process (DCP) model*, are both health classifications that emerged from the WHO's efforts to revise the predecessor of the ICF, the *International Classification of Impairments, Disabilities and Handicaps (ICIDH, WHO 1980)*. In the case of the ICF, the terms "activity" and "participation" are used interchangeably (WHO 2001). In the DCP model, participation is viewed as social because all humans engage in numerous roles in society to survive and thrive (Levasseur, Destrosiers and St-Cyr Tribble 2007). Both models highlight the interaction between the person and the environment (material and social) in which activities and participation take place. Participation may include all of the types of activities that determine health conditions in both models. Although the models overlap, the DCP model has a more explicit focus on life habits and life domains (Levasseur, Destrosiers and St-Cyr Tribble 2007). In addition to providing a health classification, the ICF is presented as a policy instrument for assessing the activity and participation potentials in the general population (Cerniauskaite et al. 2011; see 2.4.1.)

Participation. There is no consensus in the research literature on how to operationalize participation in society. A common understanding found in medical and rehabilitation models, including occupational therapy models, is that participation is of interest when assessing the patient's everyday activities. In this interpretation of everyday life, the focus is primarily on the individual's roles and engagement in the family and the local community, whereas society is often seen as a general system and is less problematized. For example, this interpretation is in a standardized view of work and employment that shows limited interest in the importance attached to work or in other types of participation that take place outside of the private sphere.

An alternative understanding found in the ICF and DCP models focuses on society as a system with a physical and social environment. Instead of focusing on how person A or person B participates in different activities, the interest is in the system in which persons participate. This perspective focuses on the system or ecological environment and is designed to study the combination of daily activities and social roles. From this perspective, participation is seen primarily as a positive outcome measure of person's ability to play essential social roles. Conversely, a negative outcome regarding the execution of social roles is described as a "disability situation" (Fougeyrollas et al. 1998). In this type of reasoning, participation may also be treated as a continuum that ranges from optimal to low in different

participation domains and avoids labelling individuals with fixed statuses such as “handicapped” or “disabled” (WHO 2001; 2.4.1 in the thesis summary).

Integration normally refers to the relationship between parts and a larger whole. Technically, this term may be used in natural sciences, medicine and health sciences – for example, in descriptions of the integration of body and mind or, more generally, in the integration of bodily functions. Unless otherwise specified, the term “integration” is used in this work to refer to integration into society and to how persons or groups are part of the society in which they live. In the case of persons with disabilities, integration refers to their inclusion in society and the recognition that they have the same rights and opportunities as others (van de Ven et al. 2005; Tøssebro 2010, 2013). The Global Disability Action Plan 2014-2021 (WHO 2014) is an example of a program to “equalize” opportunities for persons with disabilities to enhance their participation in and integration into society.

The concept of integration has clear connotations regarding society and the social system, whereas participation refers to person’s actions directed towards others. These actions may include interactions with other persons or with norms that dictate how to behave in different roles and situations. Some may argue that integration is a process whereby actors must integrate themselves to be acknowledged as full members of society. In this interpretation, the focus is on equal treatment based on social status (for example, gender, class, race or ethnicity) and on equal treatment with respect to substantial rights and recognition in everyday life (Michailakis 1997). In social sciences, integration is traditionally discussed with reference to the norms and values that regulate the configuration of people’s lives, organizations and society.

Because of my research questions and an interest in how persons and actors understand participation in society, I focus primarily on integration in society as an outcome of more or less “successful” participation in society. With a different research focus – for example, one on social discrimination in the labour market – it may have been appropriate to make a sharper distinction between integration and participation. Specifically, with a focus on social discrimination in the labour market, it would be more meaningful to distinguish participation (by persons and actors) from integration (by the system and institutions that influence the social inclusion and exclusion of persons and groups in the labour market). I refer to the conventional understanding of integration as the relationship between the system and its parts in certain sections of this dissertation related to the public welfare agency (The Norwegian

Labour and Welfare Administration, NAV), which is an example of a social security system that enhances integration by providing economic support for persons who are unable to work and addresses social exclusion from the labour market on a long-term basis through individually targeted action plans (see chapter 3).

Spinal cord injury (SCI) refers to spinal cord damage that results in a loss or reduction of sensation and motor control. SCIs caused by fractures, dislocations, crushes or compressions of the vertebrae or by objects (for example, bullets or a knife) that suddenly injure the spinal cord are commonly labelled “traumatic”. In contrast, non-traumatic injuries are the results of tumours, spina bifida (a spinal injury present at birth) and, in developing countries, tuberculosis (WHO 2013). It is estimated that up to 90 percent of spinal cord injuries worldwide are caused by traumatic injuries, primarily traffic injuries and falls (WHO 2013). For an overview of the incidence of traumatic injuries worldwide, see Lee et al. (2014).

Data from the Norwegian Spinal Cord Registry in 2014 show that the share of traumatic injuries is dropping but remains substantially larger than the share of non-traumatic injuries (34.5 percent). Less than half of SCIs (42.5 percent) were caused by traffic accidents and falls, and 13 percent were caused by sports (Strøm et al. 2016). Persons with paraplegia (paralyses of the lower part of the body, including the legs), persons with tetraplegia (paralyses of all four limbs), and persons with spina bifida (a congenital defect of the spine and backbone) are included in the Norwegian Tango Project. Persons with spina bifida often share similar medical conditions as persons with paraplegia when it comes to paralyses of the lower part of the body. Spina bifida may be associated with cognitive impairment but none of the persons in the Tango project have brain damages or cognitive disabilities.

Disability is a concept that a number of schools within the field of disability studies have adopted. Despite the differences among these schools, they share the idea that disability is an outcome of how society is organized. In this research paradigm, disability is viewed as social exclusion, injustice and discrimination against persons with impairments. The theoretical models in the field of disability studies vary significantly in terms of their focus and how these social injustices are explained. These differences are also relevant to whether we view disability as structural discrimination or as a process in which norms and cultures are expressed through actions, interactions, social roles, social identities, recognition and misrecognition.

In medical terminology, *impairment* is traditionally viewed as an individual problem that requires professional help to be resolved. Consistent with this view, disability is primarily understood as a deficiency on a scale from optimal participation to a low level of participation, which is equated with a handicap (as explained in the DCP model described above). Impairment used to play a smaller role, and primarily refer to individual problems in earlier versions of the social model of disability, but has been recognized as an important element of the disability tradition since the 1990s (Shakespeare 2006).

One of the problems with referring to impairment or disability as a concept that belongs exclusively to one of the two paradigms is that researchers in medicine and rehabilitation science and advocates of the ICF and DCP models now refer to “disability”. This development may be seen as a realization by medicine and medical rehabilitation science that the understanding of health and disability must be broadened. Nonetheless, the understanding of “disability” in the ICF and DCP models focuses on functioning, which is very different from the ideas of social exclusion and power struggles described in disability studies. The ICF and DCP models primarily refer to individuals with disabilities.. In most versions of the social model of disability they consequently use “disabled people” in order to avoid to place the problem in the individual (see 2.3.).

The understanding of *empowerment* in this project is consistent with the definition found in most dictionaries, that is, “to give power or authority to someone” (*Webster’s New Reference Library* 1984). This may be a management practice that provides employees with the information, power and tools necessary for taking initiative, making decisions and solving problems (ibid.). It may also take the form of a policy to motivate and stimulate vulnerable groups or citizens to take charge of their own lives. In the management and social policy literature, empowerment is not merely the will to empower individuals but also the intention to hold them accountable for their actions. Empowerment is also interwoven with the concept of “social recognition” in social policy and disability discussions (see 2.4.2.).

Work and *employment* are frequently used interchangeably in disability and health research (Barnes 2000). Work is in principle a term that denotes most activities conducted by human beings. Nonetheless, even in some of the broadest definitions of activities, we find references to work as a job, in contrast with play and activities of daily living (Kielhofner 2008, p. 101). Employment, as it is defined in the official statistics of Norway and by Eurostat, refers to wage work whereby persons sell their labour to an employer in exchange for a salary and to

those who have a private business of their own, with or without persons working for them. In official statistics, employment may also apply to persons who are not currently employed but are enrolled in training or rehabilitation programs subsidized by the state with the goal of becoming employable and returning to the labour market. In Norwegian and EU statistics, the term “economically inactive” typically connotes persons who are neither employed nor actively seeking a job. Thus, productive work may also represent work without payment or an employment contract, including work within the family, work that assists friends or other persons in need of services, or volunteer work. This is of special relevance in studies of what counts as valuable participation in society (see also papers 2-3).

2.2. Theoretical departure and development of the project

The core of occupational therapy is to assess meaningful activities that occupy persons’ time as individuals or as members of families or communities. These activities are referred to as “occupations”. Under this view, occupations “occupy time and bring meaning and purpose to life” (WFOT 2016).

It is commonly understood in occupational therapy that occupations “include things persons need to do, want to do and are expected to do” (WFOT 2016). Gary Kielhofner’s (2008) “Model of Human Occupation” (MOHO) views participation as personally and collectively influenced by the actors’/patients’ capacities to conduct activities and play roles (“performance capacities”), their way of life and habits (“habituation”), their will (“volition”) and the environment (“environmental factors”).

According to the MOHO, it is insufficient to focus on the person-environment relationship without also actively focusing on the actor’s/patient’s way of life, will and motivation, and personal preferences (Kielhofner 2008). This view is also expressed in the “Canadian Occupational Performance Model” (COPM: Carswell et al. 2004; Parker and Sykes 2006) and in Australia’s “Occupational Performance Model” (OPM) (Chapparo and Ranka 1997). All of these models view the person from a “holistic” perspective, whereby body, mind and spirit are seen as interacting elements. Involvement in an “occupation” (activity/participation) provides “a sense of reality, mastery, competence, autonomy and temporal organization” (Chapparo and Ranka 1997, p. 2). According to this view, health “is not the absence of disease: rather it is the competence and satisfaction in the performance of occupational roles, routines and

tasks” (ibid.). Consequently, the patient’s own assessment of important activities in his or her life situation is used to guide the COPM rehabilitation program (Carswell et al. 2004; Parker and Sykes 2006) and in the OPM (Chapparo and Ranka 1997).

To substantiate the MOHO, occupational therapists such as Kielhofner (2008) developed increased interest in ethnographic studies and in the phenomenology of everyday life and practice (Pollio, Henley and Thomson 1997; Borell et al. 2006; Peterson et al. 2010; Asaba and Jackson 2011; Ripat and Woodgate 2012).⁴

The advantage of theoretical models that are grounded in practice is that the patient’s everyday experiences are understood in depth, particularly when therapy includes longer periods of rehabilitation activities and home visits in the patient’s environment. The disadvantages of this professional perspective are that it may result in a limited view of persons as patients or clients and it tends to be very person-centred at the expense of more generalized and commonly shared experiences.

Because this project focused on participation in society, it was necessary to broaden the perspective from the community and everyday domains – which are typically found in occupational therapy models - to a broader notion of society.

One scholar who inspired my view of participation but has no obvious presence in my dissertation papers is Hanna Arendt. Her writings cover a broad range of topics, and her theoretical writing is difficult to interpret as one coherent theory. In my selective reading of Arendt, I have primarily been inspired by her claim that we have to activate all of our critical capabilities and potentials to live an active and “flourishing life”. This view accords with occupational therapy in that she argues that human beings are perfectly able to reflect upon their own lives, both privately and publicly, and that their voices must be included in any meaningful discussion of participation (Arendt 1998, chapter 13).

According to Arendt, the optimal realization of the human condition is living an active life (“vita active”). Vita activa, or a life of activity and participation, is divided by Arendt into three categories: labour, work and action. In her view, these are the basic activities for being a citizen and existing in the world. Labour refers to the economic system and the human condition of life; work refers to our activity and ability to be creative human actors; and action refers to our activities and participation in a number of different social arenas (Arendt 1998, chapter 2). In Arendt’s analysis of *The Human Condition*, we are seen as Persons from

birth to death, with individual biographies filled with life-events, and Life is seen as the “Highest Good” (chapter 44).

What makes Arendt especially interesting for my project is that she combines a theoretical discussion of activity and participation with an insistence that we must recognize differences in living conditions and that persons have multiple voices and interests with respect to their participation in society. She agrees with those who say that we cannot leave labour (work and employment) out of a discussion of the human condition but opposes a theory that reduces human action to economic transactions and roles. Even if Arendt does not present a theory of human beings’ need for social recognition, many scholars have read her work as a testament to social recognition in human interaction and participation (see 2.4.).

Arendt’s theory and analysis of human conditions is highly normative. Her voice is not expressed in a language of “etiological neutrality” but rather reflects an ambition to be critical and to take part in discussions as both a critical citizen and a participant.

2.3. The medical/rehabilitation model and disability studies

The difference between those in favour of a more traditional scientific language based on objectivity and a professional distance from interest groups and those who are more concerned about the negative impact of discrimination is also found in health and disability studies. In numerous studies of disability, this difference has been reduced to a distinction between two camps: the *medical model/rehabilitation model* and the *social model of disability*. Advocates of the medical model often describe the “social model of disability” as a normative and politicized program to abolish discrimination. Although both camps may agree that discrimination based on disability is negative, they differ in their views on how we should best understand and conquer disability.

A major problem in comparing models from two camps is that the comparison tends to ignore and simplify the broad range of perspectives within each model and the in-between positions. In an overview, David Pfeiffer (2002) lists nine interpretations of the disability program found in disability studies, as follows: 1) *The social constructivist version*, which is exemplified by Irving Goffman and his interaction analysis of social stigma as defined by “normal” persons; 2) *The social model of disability*, which is found in the UK and framed in a

language similar to that of social class, oppression and identity-based politics (Oliver 1990; Watson, Roulstone and Thomas 2012, eds.); 3) *The impairment version*, which is based on the assumption that the impairment is essential to comparisons between persons with and without disabilities and argues that the impairment is related to the person, whereas the disability is located in the environment and in social roles (this view is close to that of the DCP model that emerged from the revision of ICIDH); 4) A politicized version of *the oppressed minority*, whereby people with disabilities are treated as second-class citizens; 5) *The independent living version*, which gives weight to fundamental rights, rejects the idea that disabled persons are deficient and argues that society must change to abolish socially created barriers, and emphasizes advocacy and organization; 6) *Disability as a social and cultural construct* (post-modernism and post-structuralism) that must be decoded and deconstructed, with a primary focus on examining the social constructions of concepts and basic assumptions to offer a more pluralistic view of disability as a social identity; 7) *The continuum version*, which claims that we live in a continuum ranging from disabled to non-disabled (this idea is found in both medical and psychological models that assess patient participation in different environmental domains (Whiteneck 2010) and in the ICF (WHO 2001) and DCP models (see 2.4.1); 8) *The human variation version*, which argues that persons with disabilities share a number of commonalities with other oppressed groups but are weakened by the fact that the disabled community is so varied and fragmented; and 9) *The disability as discrimination version*, favoured by Pfeiffer, which argues that disability rights are civil rights and that disability must be based on individual freedom to choose. This version focuses on the rights of individuals with disabilities and concludes that they must be involved in research about their lives and living conditions.

Pfeiffer's list is interesting because he anticipated new versions of the disability program in versions 7-9, which are also found in the ICF (WHO 2001). These notions of disability have a greater interest in individual people than in disabled people as a collective. They also shift the focus of disability approaches towards an understanding of individuals who have a voice and the capacity to define their own interests.

Pfeiffer's criticism of disability studies prior to 2000 is biased by his personal project and by his view that disability studies must be useful for advocacy and organizing. His list is also selective. For example, it is interesting to note that what is commonly referred to as the GAP model of disability, which was introduced by Ivar Lie in the late 1960s, is omitted from

Pfeiffer's list.⁵ The GAP model is commonly described as the *Nordic Relational Model of Disability* (NRMD) and focuses on the mismatch between individual capabilities and the necessary requirements for "optimal" social participation. This research tradition places a strong emphasis on normalisation, equality and equal opportunities ("likestilling") rather than on a specific social identity for persons with disabilities (Gustavsson, Tøssebro and Traustadottir 2005). Nordic researchers have been especially interested in evaluating services and the environment (including the physical environment and social institutions and structures). Nordic disability research has also traditionally been more concerned with social integration and anti-discrimination measures than with social oppression (Tøssebro 2009; Shakespeare 2006, p. 25-26; Gustavsson, Tøssebro and Traustadottir 2005; Lindquist 2007). Additionally, the Nordic model is based on a view of disability as situational and relative to the activity and participation arena (Gustavsson, Tøssebro and Traustadottir 2005; Lindquist 2007; Tøssebro 2009).

These views resemble core ideas found in official policies since the 1960's and 1970's in Norway, with a strong belief in politics and social reforms. At the same time do we see a shift in public discussions from the 1990's onwards from discourse of "normalisation" and integration towards a discourse of individual rights. As a consequence of this shift we see an increased focus on full participation, accessibility, equality, empowerment and autonomy in both Norway and Sweden since the 1990's (Lindquist 2007, p. 21).

NRMD is not part of one coherent theory, but an umbrella of relational approaches of disability as it is found in *realist perspectives* such as ICIDH and ICF, *critical realism* with a focus on social reality as multi-levelled, and in approaches of human interaction understood as phenomenological systems in *system theory* (Gustavsson 2004). In addition to these three approaches, Anders Gustavsson add a fourth approach, *the critical interpretation approach* with a special interest in disability at different levels of the life world and of human meaning making.

In contrast to Pfeiffer with a focus on the disabled person, Gustavsson (2004) highlight a Nordic tradition of disability studies framed in constructionist approaches, the environment, and an emancipatory agenda, and an insider-perspective. In the Norwegian case, NRMD may be described as a "soft version" of the social model of disability in that researchers, policy makers and activists agree that it is society that enables or disables people. In the Nordic countries, this model is based on collaboration and dialogue with the state, political parties

and experts and practitioners in medicine and rehabilitation rather than on an oppressed minority, as the British Social Model is.^{6 7} In the Norwegian case, the policies of the largest disability organization (“Norges Handikapforbund”) have traditionally been geared primarily towards equality and equal opportunities (“likestilling”) and traditional Norwegian values. An openness and willingness to discuss social identity issues related to, for example, disability and the “queer” identity (Kvistum 2016) have only recently emerged. In this respect, it is still the commonalities rather than the differences that are noticeable among individuals and groups.

What used to be distinct paradigms in disability and health research have become more jumbled since the late 1990s. The concept of disability has gradually been incorporated into medicine and health science, in recognition that health limitations and disease are not only individual problems. The medical profession also widely accepts that health and impairment are affected by the society type, social policy and human rights.

As Pfeiffer’s list indicates, the British Social Model of Disability (BSMD) is just one among several social approaches to disability and social exclusion. Although the BSMD played an important role until the end of the 1990s, it appears to have lost some of its impact in disability research (Shakespeare 2006, Ch. 3). It is also interesting to note that some of the fiercest criticism of the BSMD has come from disability researchers, such as Tom Shakespeare (2006), who emphasizes the importance of bringing the body back into the discussion (see also Shakespeare 2012 regarding disability as a health issue). Shakespeare also criticizes the Social Model for being one-dimensional and ignoring the multiplicity of factors and mechanisms (social, psychological and biological) that influence human behaviour and human action. It would be misleading to say that this model is dead; rather, it appears to be a less-politicised version of the Social Model that focuses on social exclusion and discrimination (Grue 2016).

2.4. Theoretical models of specific relevance to this project

Several theoretical approaches were initially explored in this project to analyse social participation and social integration: the ICF model, social recognition perspectives, and activity and capacity perspectives. These theoretical approaches also inspired the dissertation work.

The ICF was important in the first phase of the project but gradually became less important as a theoretical framework in the empirical part of the project. The social recognition perspective became more relevant when analysing the meaning of responses to participation and integration questions in the qualitative interviews. The activity and capability perspective, as it is called here, is not one but several theoretical models. It bears some resemblance to social recognition perspectives and the ICF but is also part of a new mantra in rehabilitation philosophy that emerged after the millennium and has a broader interest in the interactions between participation and the environment.

2.4.1 The ICF model and the DCP model

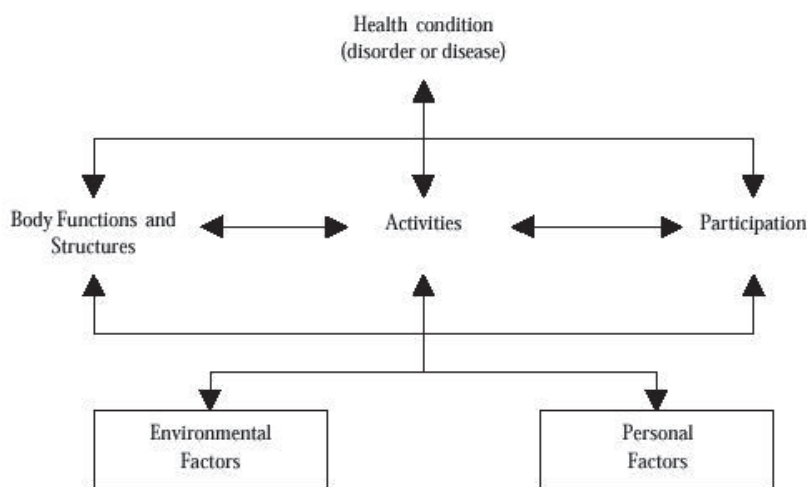
In the ICF model, “disability” refers to impairment, activity limitations and restrictions in participation in general. From this perspective, disability has many causes. It represents a continuation of the ICIDH, i.e., as a “bio-psycho-social-model” (Bickenbach 1999, p. 1176). The ICF differs from the ICIDH in terms of its more explicit focus on environmental factors that may restrict actors’ ability to participate and be active (“actors” refers not just to individuals but also to groups). Research is conducted all over the world to further develop the ICF model and facilitate its implementation for different categories of patients, including standardized protocols and measurements for persons with SCIs (Biering-Sørensen et al. 2006).

When it was officially launched, the ICF model was presented by the WHO as a brand new model. This classification received overwhelmingly positive evaluations, and within few years, it became the standard reference in rehabilitation medicine, physical therapy, occupational therapy and occupational health. An article search in the major medical rehabilitation journals from 2001 to 2013 confirms the impression that the WHO standard has many followers and has received little general criticism; those who have criticized the ICF model have focused primarily on omitted topics or specific measurement instruments.⁸

For a considerable length of time, journals such as *Disability and Society* either ignored the ICF or viewed it as a continuation of the ICIDH. In reality, the ICF may be described as both a new paradigm and a continuation of the ICIDH (WHO 1999). In contrast to the ICIDH and most medical models of health and handicaps that existed prior to the late 1990s, the ICF does not reflect a body and mind perspective that is based on functional deficiency, disorder or

disease. What is new in the ICF is a model of disability and health that has human activity/participation at its core. Instead of viewing activities as an outcome of body functions (body and mind), the ICF presents activity/participation as dynamically interacting with body functions and structures.

Figure 1. The International Classification of Functioning Disability and Health Model (ICF) – Interactions between the components of ICF



Source: WHO 2001, p. 18.

Activity and participation are technically separated in the ICF, but decisions regarding how to use these concepts are left to the expert or practitioner. Activity and participation are described in nine ICF chapters: 1) learning and applying knowledge, 2) general tasks and demands, 3) communication, 4) mobility, 5) self-care, 6) domestic life, 7) interpersonal interactions and relationships, 8) major life areas and 9) community, social and civic (WHO 2001, p. 39-42). The most developed chapters are those that refer to bodily functions and self-care (chapters 1-5), whereas the least developed chapters are those regarding major life areas and community (social/civic) (chapters 8-9). The fact that the ICF is flexible with respect to the use of the activity and participation dimensions is also explained in terms of unclear and contradictory operationalization in the ICF manual. As a consequence, several scholars have been concerned about the distinction between the two concepts (Piscur et al. 2013).

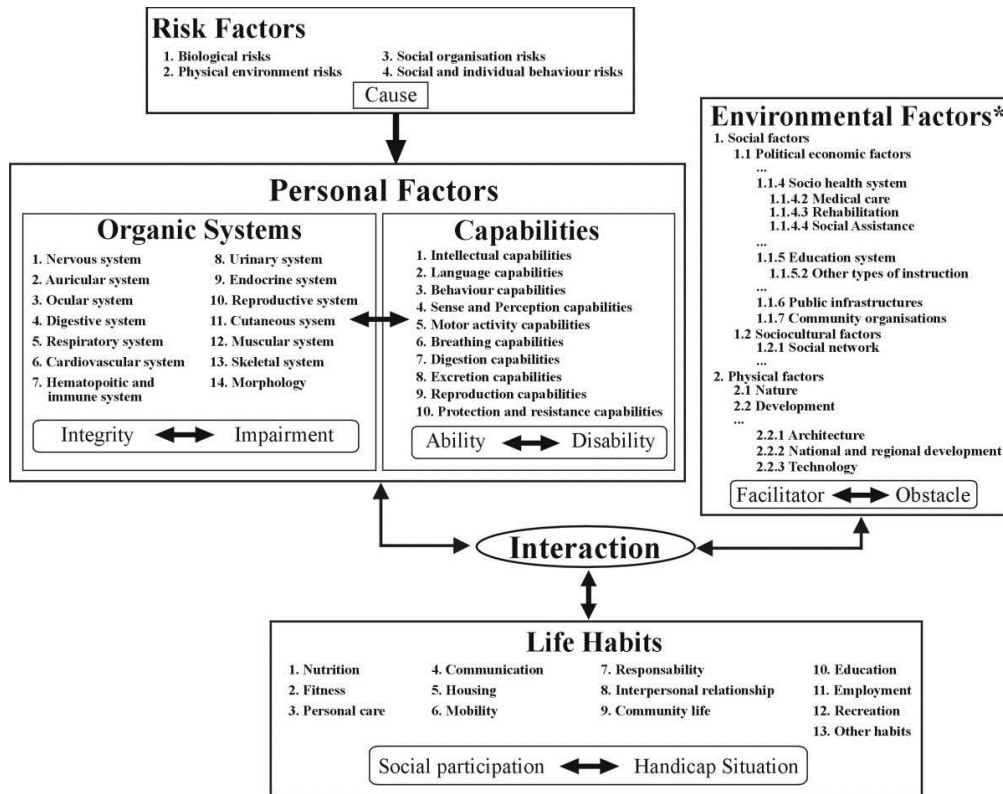
The ICF model is based on an approach whereby participation is understood as a dynamic interplay and relationship with environmental and personal factors. In contrast to a static view of a person's general social status or functional level, the ICF model views an ability/disability, at least on paper, as situational and relative to the participation arena. Similar to the Nordic Relational Model of Disability (2.4.1), the ICF allows an approach whereby a person's participation may differ significantly depending on the participation type and domain. The ICF is also grounded in an understanding that the health conditions of a population may affect human activities. Notably, the participation dimension is placed on the right-hand side of the ICF model but is undifferentiated from the activity dimension (see Figure 1). This leaves us with a number of possibilities for viewing participation more narrowly (i.e., in direct relation to activity of daily life assessments) or as situated in a social context (i.e., in relation to the social environment in which the activity is conducted).

Environmental factors are operationalized in the ICF model in five main chapters: 1) products and technology in a person's immediate environment; 2) the natural environment and human-generated changes to the environment; 3) support and relationships in the person's environment or daily activities; 4) attitudes, including norms, beliefs and value systems, in the environment; and 5) services, systems and policies found in various sectors of society (WHO 2011, p. 43-44; Schneidert et al. 2003; Reinhardt and Post 2010; Reinhardt et al. 2011).

In contrast to the ICF model, which has activity at its core, the DCP model has a more explicit focus on the person and their capabilities in community life. It also focuses more explicitly on the person's integrity, which is understood as a matter of body control and autonomy, and does not equate a lack of control with impairment (see Figure 2).

Congruent with a late version of the ICIDH model the DCP model views participation within a framework of daily activities and social roles. In this understanding, participation is described as social participation, in interaction with personal factors and environmental factors in the physical and social environment. This understanding acknowledges that participation based on what is important to the person must relate to the person's age, gender and sociocultural identity.

Figure 2. Disability Creation Process (DCP) Model



Source: Levasseur, Desrosiers and St-Cyr Tribble (2007, p. 234).

In the DCP, participation (in the framework of “life habits”) is on a continuum from social participation to handicap situation (see Figure 2), whereas in the ICF model, participation is a matter of a person’s ability to be in control of their self-care, household, interpersonal relationships and social roles.

The argument behind the DCP model is that risk factors (biological, environmental, organizational and behavioural) determine personal factors, which interact with environmental factors to shape our everyday life domains (life habits). Under the DCP Model, daily activities and social roles interact with environmental factors (e.g., political/economic factors, socio-cultural factors and physical factors) and with facilitators/obstacles. Thus, the

DCP model resembles the ICF model; the main difference between them appears to be the DCP model's more explicit emphasis on risk factors and the person's capability and life habits.

It is no surprise that the ICF and the DCP models resemble each other because both are the result of revisions of the ICIDH (ICIDH-2, in WHO 1999). It is also not surprising that a great number of those who worked on the revision of the ICIDH in Canada present the DCP model as highly competitive with the ICF in medicine and rehabilitation but with a more direct focus on the person's life domains (Fougeyrollas et al. 1998; Levasseur et al. 2007).⁹

One of the difficult questions that arises in discussions of the ICF and DCP models is whether we approach them mainly as classifications or as theoretical models that include a classification. In most cases, it is emphasized that the ICF is a classification (WHO 2001; Bickenbach 2014) or at best a very tentative version of a theory in progress (Reinhardt 2011). The problem with referring to the ICF exclusively as a classification is that it is built on a number of theoretical assumptions about human behaviour and the human condition. This problem is also evident in criticism of the ICF's theoretical framework from scholars who argue that agency, action and capability are overlooked in the ICF (Nordenfeldt 2003, 2006; Mitra 2014). Other criticisms of the ICF are that it needs further clarification of the nature of impairment, the content of bio-psycho-social theory, and the meaning and implications of a universal standard as the basis of disability policies (Imrie 2004). The standard response to such criticism is, that although the ICF is not a theory, the agency perspective is fully compatible with the ICF model (Bickenbach 2014). With this type of defence, it is as if the ICF model is immune to criticism. Or perhaps it is the other way around: with a meta-view of the activity and participation dimensions, it is easy to respond to any criticism with the claim that the ICF is or may be in accordance with the views of the critics.

Like most universal standards the challenge is not restricted to theoretical design of the model and the concepts. It is also sensitive to the language and interpretation we do of the concepts in different cultures and societies. This may be illustrated by Norway, Denmark and Sweden, with in theory similar words for participation ("deltagelse" in Norway and Denmark, "deltagande" in Swedish) translating the ICF term differently. In the Norwegian and Danish ICF manuals, participation refers to the more general understanding of taking a part or share (Sosial and Helsedirektoratet 2003; Sundhetsstyrelsen 2005). In Sweden, the ICF translation of participation (Socialstyrelsen 2003) brings in the element of being concerned or involved

(“delaktighet”), on pair with being involved in a project, a group, event or cause. Neither of the two translations are wrong with respect to the theoretical rationale of the ICF, but they illustrate a dilemma of operating with a theoretical interpretation of an essentially technical understanding. As the Swedish translation, in contrast to Norway not was performed by a technical translator but a disability researcher and sociologist, we may suspect that this has been a deliberate choice to emphasise the relational side of the model and involvement (beyond a general understanding of “involvement in a life situation” in the ICF).

The words and concepts we use to describe participation tend to live a life of its own in the ICF literature with no consensus whether to distinguish between activity and participation, or if the “qualifiers” of both factors (capacity and performance) are integrated in the overall understanding of the participation concept (Arvidsson, Granlund and Thyberg 2014).

In the European Tango Project, we were primarily interested in exploring and identifying participation and integration dimensions in a context of appropriate life domains.¹⁰ As a result of an open concept of participation, we found ourselves with rich data material coded according to the ICF but limited theoretical guidelines regarding how to analyse and interpret our data in an ICF framework. In retrospect, it is interesting to observe that the social recognition perspective did not emerge as a result of the ICF-inspired coding but rather from the in-depth reading of each of the Norwegian interviews (see chapter 4).

2.4.2. Social recognition perspectives

Friedrich Hegel is often quoted as an important inspiration in modern discussions of social recognition. Hegel’s argument is that we need to recognize others as subjects to recognize ourselves (McQueen 2015). Hegel is also the main inspiration for Charles Taylor’s (1994) famous essay on social recognition and its opposites, “non-recognition” or “misrecognition”. In Taylor’s view, both “non-recognition” and “misrecognition” can be oppressive and limiting and can reduce the person’s social worth and being (Taylor 1994, p. 25).

Taylor (1994) discusses the creation of individual identity and self-realization as an on-going negotiation process that takes place with “significant others”. In my papers, I mainly refer to the understanding of Axel Honneth and Nancy Frazer regarding social recognition. Honneth (1996), who is inspired by both Hegel and Taylor, distinguishes among three types and

spheres of recognition that are necessary for self-realization and the development of our identities: love, rights and solidarity.

According to Honneth, *love* comprises the relationships in which we invest our emotions and physical needs and is exemplified by family, lovers and close friends; *rights* are bounded by moral responsibility and moral relations developed through interaction with others; and *solidarity* refers to recognition of our traits and abilities and is particularly important because it largely defines how we view ourselves as persons. Love, rights and solidarity are also important elements maintaining social status for individuals, families and groups.

Honneth's social recognition scheme may be used both to analyse recognition processes based on self-respect and self-esteem and to assess processes based on self-confidence that has been shattered by abuse, social exclusion, stigma and prejudice. In line with both Hegel and George Herbert Mead, Honneth argues that misrecognition or injustice cannot be reduced to a single cause, such as culture, economy or biology. Rather, to understand misrecognition and injustices, Honneth advises us to analyse the various principles, mechanisms and spheres wherein social recognition occurs (Danermark and Gellerstedt 2004; Shakespeare 2006, p. 81-82).

Although many of the discussions regarding participation and integration that I reference in my papers refer to social recognition as a "right", the participants – particularly the female informants - are also concerned about social recognition in terms of how they perceive themselves in society:

"I feel I have to prove as much or even more that I am able to do it. A medical doctor told me... you have many children because you have to prove yourself more than others. He meant that I was the type of person who wanted to achieve, and more than that" (Bente).

"I have pretty bad self-confidence, and consequently, people do not walk around and appreciate me all the time. I feel I have to pay them. I feel I need to be extra funny, extra, extra, extra in everything I can come up with personally" (Fanny, also quoted in paper 3).

“I am not at all denying my disability, but it becomes a bit too much. I feel that it is problematized. After I have been to places like that (ASL, a reference to medical rehabilitation facilities), I feel as though I am coming home with problems that I did not know I had. It is a bit tiring. Is this something to problematize?” (Ida).

“It is an example based on misunderstandings. Getting applause for something that is natural for me and being underestimated in general. It is tiresome to be looked upon as different and often to be pitied...it proves that they do not understand me at all. I am fine. To explain things like this is tiresome. I feel that I am misunderstood” (Ida).

These quotations are interesting illustrations of the misrecognition of traits and abilities by others. The informants’ accounts also describe misrecognition as misunderstood sympathy or a strategy to make them feel more helpless and impaired than they perceived themselves to be. Although most of the informants expressed a belief that discrimination based on social and physical barriers continues to be a problem, too much understanding, sympathy and recognition from others may in some cases generate a misperception-based type of recognition.

Ida is a good example of a person who argues in favour of both the recognition of disability and the principle of normality (i.e., not being different from other persons). These two concepts could be viewed as opposites but may actually form the optimal balance between the two concerns (i.e., that other persons recognize the practical challenges associated with impairments but nonetheless respect those with impairments as persons who are equal to other citizens)

Nancy Fraser warns against the use of recognition as the only dimension in studies of social injustice (Fraser 1995; McQueen 2015). In her view, it is insufficient to consider ethical self-realization in a cultural context. If we follow Fraser, recognition must also include universal rights in a world where individuals and groups are socially marginalized and misrecognized. In her interpretation, misrecognition should be seen as subordination that denies certain persons full social participation and integration in society. Fraser discusses participation as a matter of “parity” among all adult members of a society; a more fair distribution of material and economic resources is necessary to achieve participatory parity. Her idea of participation parity – i.e., participation in society in a manner that is no different from the participation of

other people - is also frequently mentioned by the Norwegian informants with reference to organizations, human rights and social citizenship (paper 1).¹¹ Nancy Fraser is more explicit in her references to social participation than to integration. If we follow her idea of participatory parity as a relative measure, it is also reasonable to assume that integration in society is relative to the situations of other citizens or groups with whom we compare ourselves. If this is a correct interpretation of her argument, we are advised to examine participation in relation to opportunities to live a life on par with the lives of others and to recognize persons and important institutions in our social participation efforts.

Fraser discusses the possibility of overcoming social injustices through affirmative actions and social transformation. Affirmative action refers to changes within the political system to correct injustices. In Fraser's view, social transformation requires a more fundamental change in the society, language, institutions and economic systems that produce these injustices. Fraser argues in favour of a radical transformation of society that breaks down group cleavages and promotes solidarity. Affirmative action, in her view, tends to reproduce the old structures and institutions and risks the stigmatisation of disadvantaged classes. Fraser also problematizes the dilemma of recognition politics based on a collective identity that may force individuals to conform to group culture and deny "the complexity of person's lives, the multiplicity of their identifications and the cross-pulls of their various affiliations" (Fraser 1995, p. 112).

Whereas the "social model of disability" is primarily concerned with universal aspects of disability and oppression, we find a more contextual view of discrimination and injustice in Honneth and Taylor's writings on recognition. In their view, social recognition must be understood as "dialogical, situated and generated through practice" (McNay 2008, p. 4). Following these principles would require us to assess the interview quotes as part of an on-going dialogue with others in the specific situations and contexts that influence how each informant views him- or herself as a person.

This is not to say that individuals alone can change the way others recognize them. All of the recognition theorists mentioned above would agree that social recognition is part of our language of disability as expressed in private and public rhetoric, official legislation, or public debate.

When reading Fraser, one interesting question that arises is how to approach the idea of group identity, given what Shakespeare (2006) has described as the multifaceted identities of persons with disabilities? Are we referring to individuals or groups with specific identities or to more fluid identities that vary depending on social climates, situations and events?

Honneth's (1996) idea that our view of ourselves and of others is negotiated and re-negotiated based on norms, trust, recognition and misrecognition is easily found in the informants' narratives. This is particularly visible in their notion of "normality", that is, not being different from others. It may also be expressed through internal status markers and a social distance from persons with brain injuries (see paper 1). The examples of how the informants in my study negotiate or strive to be "normal" and "no different than others" are interesting because it is easy to think of this as a basic human right value. One problem with a recognition theory based on the ideal of universal recognition is that we easily conflate recognition as a universal moral value with how social participation works in real life and in concrete face-to-face interactions (McNay 2008, p. 8). This risk also exists with individual-centred models that are more concerned with formal rights and recognition than with substantial rights and recognition in everyday life (Michialakis 1997, p. 28).

What may be viewed as basic human rights of equality and integration in society (WHO 2014) may be perceived more critically in concrete face-to face-interactions. A good illustration of this was found among the SCI informants in my study who actively distanced themselves from the notion of "integration in society" because this concept suggested that they were similar to immigrants who needed to adjust to the majority (see paper 1). In this interpretation, the comparison of the informants with immigrants represented a type of stigma. (In the words of Per, "Why should we be treated as different from the rest of the Norwegian population?")

In the disability literature, it is possible to find examples of those who frame disability in terms of more or less permanent roles, identities, interests and struggles for social recognition (Barnes and Mercer 2003) and those who view disability and social recognition as "situated" and an outcome of how persons actually live their lives (Danemark and Gellerstedt 2004; Gustavsson 2004, Shakespeare 2006).

Irving Goffman's concept of "social stigma" is an example of misrecognition in face-to-face interactions. In Goffman's view, actors play a number of games to portray themselves and

their actions in a favourable light. This behaviour may be based on conscious actions and strategies, unconscious habits, or simply a developed sense of how to comply with the rules of the game. One strategy, which is exemplified in the interview quote from Bente, is to be active and leave others with the impression of one's status as a "high achiever" (this pattern is also found among other Norwegian informants). Another strategy, represented by Fanny, is to play on irony and be extra funny in all types of situations and encounters. In Fanny's case, irony and strategies to distance herself from predefined roles and stigma represent important elements in her coping and everyday life.

Although I do not devote much space and attention to Goffman's analysis in this dissertation, several interesting observations are possible. In contrast to the very general notion of roles found in the operationalization of the ICF and DCP models, Goffman (1963) shows that roles and role performance are played out in intricate ways, with numerous rules and alternative strategies for playing the game. This approach to participation is very different from that of the DCP model, which employs a scale ranging from high to low levels of participation to assess "handicap situations". It also differs from most interpretations and applications of the ICF and DCP models, which are based on fairly fixed sets of roles and behaviour. In Goffman's interpretation, participation is instantly "negotiated" in ways that may result in a spiral of stigma and misrecognition or in more positive outcomes, in which participants redefine their sense of disability as unimportant in their daily interactions (paper 1).

A common criticism of Goffman is that he is better at observing – illuminating how individuals, contrary to their beliefs, act according to roles, statuses and manuscripts – than at providing a method and tools for analysing face-to-face interactions (Lemert 1997, p. x). Another criticism is that he is better at describing social interactions and interaction rituals than at explaining actors' social identity and their interpretations of meaning. According to Charles Lemert, this criticism is unfair because Goffman wrote his best work on talk, semiotics and conversation analysis (Lemert 1997, p. xxxv). Goffman has also been a source of inspiration for Norwegian disability researchers interested in persons with cognitive disabilities (Kittelsaa 2008) and in descriptions of everyday interactions, coping, and identity-building in kindergartens (Ytterhus 2001).

Honneth's departure, which views social recognition as the basis of social life and human interaction, is not new. Rather, it is a central idea found in symbolic interactionism, which understands the individuals personal and social identity creation as a never-ending process

shaped through interaction with others and symbols (including language, norms and symbols). To be someone, to make sense of the world and to find meaning, we must think of the environment in which we live as more than our surroundings. In this more social psychological view, all persons bring social norms and social practices into their perceptions of themselves, others, and how others see them (Hewitt and Shulman 2011). In light of my research questions, the social psychological side of participation was played down. However, what is important and can be learnt from symbolic interactionism is that who we are, how we view others, and how we believe others view us in various types of participation do not reside in static roles or fixed identities. How we see ourselves, resist stereotyping from others, and carve out personal space may differ considerably from situation to situation and over time (Hewitt and Shulman 2011).

2.4.3. Participation in light of social inclusion and exclusion

Participation in society is intertwined with the concepts of social exclusion and social inclusion. In French and European discussions since the 1970s, social inclusion and exclusion have referred primarily to the effects of success or failure with respect to integrative institutions in society. Social exclusion has often been used as a synonym for poverty, but for our purposes, it is more interesting to examine social exclusion from a perspective of participation in different domains of society.

Hilary Silver (1994) identifies three paradigms of social exclusion: the *solidarity paradigm*, the *specialization paradigm*, and the *group monopoly paradigm*. The solidarity paradigm approaches social exclusion from a perspective of shared values and rights. In this tradition, social inclusion may be expressed either in the justification of differences between groups or in universal solidarity beyond group interests. The specialization paradigm approaches social exclusion from the perspective of discrimination against individuals, which is of interest with respect to both limitations of rights and the provision of opportunities for individuals to participate in various types of social exchanges. The monopoly paradigm approaches social exclusion from a perspective of power and hierarchy wherein dominant groups systematically discriminate against the dominated. Possible means of breaking the power of dominant groups and enhancing social inclusion include citizenship and opportunities for equal membership and participation (Rawal 2008).

These paradigms are also found in the ICF and the disability literature. The solidarity paradigm is interested in both group solidarity and collective solidarity. The specialization paradigm, which places a strong emphasis on individual freedom and antidiscrimination, mirrors Pfeifer's (2000) version of disability and the implicit human rights perspective found in the ICF model (Cerniauskaite et al. 2011). The monopoly paradigm, with its focus on class and social divisions, resembles core ideas about disabled persons in "the social model of disability" found in the UK in the 1980s and 1990s (Oliver 1990).

2.4.4. Activity and capability perspectives

One of the main criticisms of the ICF model comes from those who argue that it lacks sufficient action and human agency. The main question here is how to view the nature of activity and participation. Should activity and participation be understood as the essence of being a Person, as we see in Hanna Arendt's work and in occupational therapy (Kielhofner 1997, 2008)? If so, what counts as activity and participation? Does it include all types of activities or only those deemed important and meaningful for the person conducting the activities?

Despite all efforts to bring the "voices of the actors" into the model, most criticism of the ICF model involves whether the Person should be viewed as a patient/client, an informed actor, or a person with a long-term disability.

General theories about human action, such as Nordenfeldt's (2003, 2006) action theory, present a view of the person as an informed actor who is able to define his or her life according to how he or she is expected to cope in different types of action situations. In this model, it is the action – "what happens when actors act" – that is of interest in studies of participation based on failures and success. In Nordenfeldt's view, the ICF is based on an unnecessary distinction between activity, understood as what is measured in clinical assessments of body and cognitive functions, and participation, understood as the roles the person performs in ordinary, everyday life. Nordenfeldt thus proposes that the concepts of activity and participation should be replaced with the concept of action. In line with his utilitarian perspective on action, he also proposes that we pay more attention to actors' abilities to do things rather focusing on disability as a negative outcome. Nordenfeldt's criticism of the ICF model has led to controversy with rehabilitation doctors and others who

support the ICF model. His critics' main argument has been that Nordenfeldt's view of patients' potential for action is no different from theirs (i.e., to conduct a rehabilitation process successfully, it is necessary to evaluate what patients are able to do without any intervention and what they are potentially able to do in society). This argument is in line with Kielhofner's Model of Human Occupation, which provides the person with "dispositions and self-knowledge concerning one's capacities for and efficacy in occupations" (Kielhofner 1997, p. 209). Knowledge and awareness of present and potential abilities and a sense of effectiveness in achieving outcomes is at the core of this model (ibid.).

The emphasis on a person's/actor's potential ability rather than their disability is also found in journals such as the European Journal of Disability Research, *Alter*, expressed in a language of capability. The concept of capability is not part of a developed theory or model but rather a mission to challenge the view of disability and replace it with a strong notion of the person's participation potentials (Mitra 2014). Some advocates of the capability approach, inspired by the economist Amartya Sen, argue that this concept also opens up the possibility of a theory of "dis-capability" (Bellanca, Biggeri and Marchetta 2011). In their view, disability refers to "someone who has a limited capability set compared to his/her objectives, ambitions and system of values" (ibid., p. 158). Disability, as it is understood by Bellanca et al., represents two pathways. The first is that of the limitations of the capability set, and the second is "a pathway of creative adaptations, able to disclose new abilities, opportunities and potentialities" (ibid., p. 158).

As observed earlier, few attempts have been made to incorporate the actor's capacity or capability into models initially developed and inspired by the ICIDH. In the DCP model, capability is seen as the "intrinsic ability of an individual to accomplish a physical or mental activity regardless of the environment" (Levasseur, Destrosiers and St-Cyr Tribble 2007, p. 234). In this model, participation (which is equated with social participation) refers to daily activities and social roles that ensure the survival and development of the individual in society.

Neither alternative that highlights the importance of actors and social action is without problems. How do we know whether actors are acting in accordance with the theoretical logic suggested in rational actor models or the theoretical logic whereby participation/integration can be determined by empirical measurements? A major problem with both the ICF and DCP

models is that participation is easily evaluated as a measurement ranging from low to high. The question of which participation roles are essential for the individual is less important.

Once we start to look at the quality of different participation roles, it becomes problematic to apply just one type of human interaction. Alan Page Fiske (1991) refers to four elementary forms of human behaviour: communal sharing, authority ranking, equality matching and market pricing. His argument is that each form includes different types of social roles, norms and behaviour. Similar to Zetterberg (1989), Fiske claims that the roles we perform in communal life with families and friends require a different set of personal involvement and recognition than the roles we play as consumers in the marketplace (which are based on market pricing). Similarly, it is reasonable to assume that participation roles that are based on equality between partners differ considerably from those that are based on unequal power (authority). This theory may be interesting to apply if we want to explore person's roles in families or personal networks, and it is of particular interest in this project with respect to the informants' understandings of the nature of employment roles and their roles as citizens, family members and friends (this issue is elaborated in the discussion portion of the summary).

2.5. Summary

Because this dissertation project was driven by an interest in the perceptions and meaning of participation, I ended up with many more possible ways to analyse the interviews than originally anticipated.

A number of core ideas have informed this work.

- Without a theoretic framework for understanding participation, it is very difficult to conduct meaningful analyses of participation.
- The question of integration in society for persons with SCIs may be answered with reference to human rights, the rights of social citizens or official statistics that show gaps in labour market participation or other types of social participation. This issue may also be addressed from the perspective of the individual and how he or she experiences his or her life in terms of recognition, misrecognition or non-recognition from the community and society in which he or she lives.

- The shift in language from disability, described as impairment, towards capability and empowerment is important because it leads to myriad new questions in medical rehabilitation research. The focus on capability may help us see the whole person from a much broader perspective than if we view the person as merely a patient or a client.
- Discussions that reduce the concepts of activity and participation to roles fail to consider the complex and dynamic nature of everyday interactions. Individuals do not merely play roles. Rather, individuals are also capable of defining and redefining the roles they play. In line with this notion, it is not possible to define in advance terms such as “meaningful life” or “full participation” because their meanings are contingent on the person and his or her life situation.
- It is generally agreed that we need recognition from others to develop a self. Social identification based on principles of sameness or distancing may complicate solidarity with other categories of disabled persons.
- The study of participation and integration in society is broader than a study of persons in their everyday life roles. In addition to a view of participation and integration in everyday life, we must have a concept of society that refers to membership in a civil society (social citizenship) and in the labour market (employment). All of these social spheres are relevant in a study of participation and integration in society.
- Society is not a single system; rather, it comprises different domains with different sets of norms, roles and types of individual involvement. Although the notion of “involvement in a life situation” may cover all of these spheres, it tends to be viewed in terms of persons’ everyday life. The roles we engage in with family and friends (based on communal sharing or equality) differ from the roles we play in hierarchical organizations (such as firms, schools, or hospitals) or in the marketplace (Fiske 1993). Participation in all of these roles is important to integration in society.

3. RESEARCH AND DATA RELEVANT TO OUR UNDERSTANDING OF THE PARTICIPATION OF PERSONS WITH SPINAL CORD INJURIES IN SOCIETY

Most of the research on persons with an SCI includes limited information about the society, health and welfare systems, labour market and living conditions under which participation in society takes place. To live a life with a chronically illness may lead to disability in a disabling environment, but it is not self-evident that all persons living in a disabling environment perceived themselves as disabled or part of a disabled persons as a category. Chapter 3 presents prevailing understandings of participation in the SCI and the ICF literature, in addition to social policy and human right links to participation. The main bulk of the chapter refers to societal factors, including the welfare provisions, labour market and barriers to participation. In addition, chapter 3 includes information about life conditions for persons with SCIs in Norway that may be relevant to how we discuss participation in the context of SCI and disability research.

3.1. Alternative views of participation in the SCI and ICF literature

Most SCI research on participation refers to activities that take place in social and community life. In line with the ICF model, the issue of barriers and facilitators is a central element of personal and environmental factors, which are referred to as contextual factors in the ICF model. In a review of 23 social and community participation articles, Barclay, McDonald and Lentin (2015) found a pattern in which adequate personal care, support, equipment and treatment were mentioned most often as facilitators. Examples of frequently mentioned barriers in their review included transportation, lack of accessibility, issues with health care and rehabilitation providers, and bodily pain.¹²

The inconsistency terminology or usage participation concept in the ICF is in part a question of which stakeholder is speaking (e.g., persons from the disability community, scholars and policy makers in the WHO system, health professionals) and in part a question of definitions, operationalization and measurement (Jette et al. 2003; Hammel 2008). A common criticism levelled against the ICF model by segments of the disability community is that participation has been primarily defined by scholars and policy makers (Hurst 2003). It is therefore no

surprise that most of the articles on the participation dimension of ICF since 2001 have addressed operationalization and measurements (Van de Velde 2010; Heinemann et al. 2010; Dijkers 2010).

If we consider the ICF and rehabilitation literature after the millennium, participation is normally used as a general term (either alone or as social participation); with reference to a specific domain (mainly community participation), designated roles (for example, employment and family roles) or activities (Noreau et al. 2005); or simply to refer to social involvement (Lund et al. 2005). References to a specific domain, role or activity may be seen as specifications of the general idea of participation, which is covered in both participation and social involvement in a life situation (WHO 2001, p. 14).¹³

Everyone working in rehabilitation and social service programs is more or less obligated to have an idea of what participation is or ought to be. In the words of Marcel Dijkers (2010, p. S 5):

“It is the domain of functioning that is beyond impairment and performance of activities. It is more or less what we mean with instrumental ADLs... community re-entry or participation, social or societal integration, community living or (re) integration, independent living, normalization, psychosocial functioning or integration, handicap, social health or inclusion or adjustment or disablement, social role valorisation, and a number of other terms varying by professional domain and by whether we want to emphasize a process of normalizing or the resulting status.”

The problem from a rehabilitation perspective, according to Dijkers, is not the lack of a standard definition of participation but rather its conceptualization and measurement. In short, the lack of a concrete notion or a common basis in defining the concept complicates its measurement. Dijkers’ overview of attempts to measure participation is of interest both as a critique of the validity and reliability of most existing instruments and as a realization that our understanding of participation needs data based on systematic observations and qualitative methods (Dijkers 2010, p. S 12).

In contrast to other activities conducted by human beings, participation includes an element of taking part or having a share in an activity or event (Merriam Webster Dictionary 2015). Standard definitions of participation as “engagement in a life situation” (WHO 2001, p. 14) refer to taking part in an activity, enterprise or event but are less concerned with how we

interact, share or join with others in the activity, enterprise or event. One problem with this definition is that it is difficult to detect what is behind the life situation(s) that frame our engagements, identities and preferences. Many researchers, including those who initially designed the ICF and DCP models, would in theory accept Hammel's view of participation as active and meaningful engagement through which persons are "being a part of an activity, a context, a social scene and/or a social group" (Hammel et al. 2008, p. 1450). It is unclear whether their understanding would also include Hammel's broader view of participation, which encompasses personal control and choice, access and opportunity, personal and societal responsibilities, and a sense of social connection (ibid., p. 1450ff). This potential discrepancy is also my own motivation for approaching participation from a broader perspective, one that includes the environment in which persons participate, find meaning, gain self-respect or fail to live a rich and "flourishing life".

Unless we view participation as a simple outcome or status after a rehabilitation program, it is often a component of the "process of normalizing" (Dijkers 2010, p. S 5) to gain optimal personal autonomy and independence after an injury. This process is intertwined with the process of social integration and being a part of society. Being a member of a society is an important part of participation. Karin Margrete Hjelle and Kjersti Vik (2011) describe this concept in terms of *opportunities* to work, to develop a career, to join a profession or to have access to public services, linking participation to *autonomy* and the ability to make decisions and be in control of one's own life.

In social science-oriented research, the notion of participation is often accompanied by the idea of empowerment, i.e., enabling individuals to utilize their potentials as humans, as in the human rights field (Bickenbach 1993; UN 2006; WHO 2011; WHO 2014). The notion of empowerment is also seen in the current Nordic public activation policy, the main idea of which is to optimize the remaining potential of individuals to work regardless of their functional impairment and disability (Johansson and Hornemann-Møller 2009; Lindquist 2007).

3.2. Participation from a social policy and human rights perspective

From a policy perspective, participation is related to citizen activities that educate, facilitate or comply with the law or political programs. The “Convention on the Rights of Persons with Disabilities” is a good example of this perspective because its ambition is to promote, protect and ensure the full enjoyment of human rights (article 1) and rights to accessibility, independent living and to be included in the community (article 19); and to promote mobility (article 20) and the right to participation in public life, cultural activities, recreation and sport (article 29 and 30). The Guiding Principles of the Convention are in line with essentially universal ideas of human rights and principles, such as “full and effective participation and inclusion in society” and “respect for difference and the acceptance of persons with disabilities as part of human diversity and humanity.”

Although most citizens would probably support the Convention and its guiding principles related to “full and effective participation and inclusion in society”, it is not a given that these principles match the everyday experiences of persons with disabilities. Like many of the underlying principles of the Convention, individuals may bring in a wider repertoire of beliefs, concerns and experiences than is generally represented and acknowledged in human rights legislation or classification tools such as the ICF (WHO 2001).

3.3. Participation in a Norwegian and European welfare context

In the context of the European Tango Project, Norway and Finland differ somewhat from the other nations in the organization of the welfare state. In particular, the welfare systems of Norway and Finland are primarily based on universal health and welfare provisions and on generous economic compensation schemes (Esping-Andersen 1990).

In contrast to more conservative welfare regimes, such as those in Switzerland, Germany and Ireland, which are to a significant extent based on family support and insurance from one’s employment before the injury, the pillar of the Norwegian and Finnish welfare systems is the state, not the family or employer. Persons with disabilities are generally less dependent on individual insurance arrangements in Norway than they are in Switzerland (OECD 2006).

If we look at programs for persons with disabilities, including follow-up systems (“monitoring systems”), we observe a pattern wherein all of the Tango Nations, with the

exception of Ireland, are well above the OECD average. Norway's total scores are on par with those of Finland, Germany and Switzerland. The UK and USA have some of the least developed disability policies, with total scores well below the OECD average (OECD 2010, p. 103).

Norway scores high on benefits coverage and generosity but low on vocational programs and sickness benefit monitoring (OECD 2010, p. 103).¹⁴ Whether the low scores are viewed as a problem depends on perspective and interest. From the perspective of the welfare state, it may be important to have an effective monitoring system to achieve better control and reduce costs. From the welfare recipient's perspective, generous benefits and low degrees of state oversight may increase the freedom to leave the labour market but may also create a barrier to potential labour market participation.

Eurostat data from 2011 shows that 24.1 percent of persons in Norway with a self-reported disability in the previous six months were at risk of poverty and social exclusion, compared to 12 percent of persons with no disability. (The average figures for the EU were 29.9 percent among people with disabilities compared to 20 percent among those without disabilities.) The Norwegian figures resemble those reported in the other Tango Project countries mentioned above, with a gap between persons with and without disabilities that is just above the EU average (Eurostat 2014; Grammenos 2014).¹⁵ The EU measures of poverty are relative to the population in each nation, which means that those in relative poverty in Norway may be economically better off than those in other European nations.

Eurostat data from EU-SILC 2011 also show that a lower percentage of persons report activity limitations in Norway (14.9 percent) than in the other Tango nations. The figures for persons aged 18-65 years were 25.4 percent in Denmark, 25.1 percent in Finland, 24.6 percent in the Netherlands and 22.5 percent in Switzerland (Eurostat 2014).

3.4. Employment for persons with disabilities in Norway and Europe

The percentage of persons with disabilities who were in employment was 45.5 percent, compared with 77.0 percent of those without disabilities according to the Norwegian Labour Force Survey in 2010. This is a substantially larger employment gap than the EU average (based on 28 EU members) for 2011; a gap that may increase somewhat if we have had fully

comparable data with respect to age and operationalization with the European Labour Force Survey in 2011. Despite the problems of getting fully comparable operationalizations of these data, the Norwegian employment rate for persons with disabilities is substantially lower than the rates for Sweden, Finland and Iceland but similar to what we find in Denmark (see Table 1).

Table 1 Employment rates for persons with activity limitations (disability) and the general population in Europe (age 16-65). EU-SILC 2011

Country	Persons with activity limitations	General population
Norway*	45.5	77.0
Denmark	46.7	78.1
Finland	60.8	73.2
Sweden	66.2	75.7
Iceland	66.9	84.0
The Netherlands	42.7	80.1
Switzerland	69.0	81.6
Germany	51.5	72.1
United Kingdom	47.6	75.4
Spain	44.3	60.5
France	56.2	66.1
Italy	45.6	58.9
EU-28	47.3	66.7

* Labour force data only available in Norway for 2010 and persons aged 16 - 64 (Source: Eurostat 2014 and personal communication with Statistics Norway¹⁶).

If we extend the analysis to include the entire OECD area, we see that the Norwegian employment figures for persons with disabilities are close to the OECD average (43 percent in the late 2000s). In addition to the other Nordic nations, Estonia, Switzerland, Luxembourg and Germany all had higher employment levels than Norway for persons with disabilities in the late 2000s (OECD 2010, p. 51, Figure 2.1). The USA, which is an important reference in research on SCIs and employment, had lower employment levels for persons with disabilities than in the EU and the OECD area in the late 2000s. Although the USA has more far-reaching anti-discrimination laws than the Nordic countries, there is a larger employment gap between persons with and without disabilities in the USA than in any Nordic country (OECD 2010, p. 51, Figure 2.1.).

The OECD figures must be interpreted with caution because operationalization may differ among countries (some countries base their numbers on self-reported disabilities, whereas others consider medical conditions). Eurostat's operationalization of disability (activity limitations) is better harmonised since 2008 than in previous years and may differ somewhat from national labour force surveys and level-of-living surveys.¹⁷

Normann, Rønning and Nørgaard (2013, p. 228ff) report lower levels of labour market participation among persons aged 16-64 years with lower levels of education in all of the Nordic countries in 2010. This picture is particularly pronounced in Norway, where participation rates among persons with low levels of education and poor health were 32 percentage units lower than those of persons with low levels of education and good health. Poor health also reduced employment levels among persons with higher education in 2010 (except in Denmark), although the employment gaps were less dramatic than those for persons with lower levels of education.

Expenditure levels for social policy measures targeting the working-age population differ little between Norway and the other Nordic countries, but fewer resources are used for activation measures in Norway. This pattern has existed since the millennium. In Norway, persons with disabilities get more financial support to return to employment in the first years after an injury but significantly less support over their lifetimes compared with the other Nordic countries (Rønning et al. 2013).¹⁸ For an overview of persons with a disability's employment and living conditions in Norway compared to other nations see Rune Halvorsen and Bjørn Hvinden (2013).

3.5. Employment and social conditions for persons with SCIs in Norway and a comparative outlook

Based on information from the Norwegian Spinal Cord Registry from 2011-2014 (Halvorsen and Pettersen 2014) and the author's own estimations, approximately 3.900 persons of working age (18-67 years old) in Norway have SCIs (Strøm et al. 2016).¹⁹

A review by Ottomanelli and Lind (2009) of articles published between 1978 and 2008 estimates that the average employment rate after SCIs is 35 percent. The SCI employment figures for Europe (on average 50 percent) are considerably higher than those found in articles for the USA (35 percent on average), Australia (43 percent on average) and Asia (41 percent on average), but these figures are highly unreliable due to different samples and operationalization (ibid.).²⁰

The results of a Norwegian retrospective study conducted by Ingeborg Lidal et. al. (2009) show that 35 percent of persons with SCIs were employed in the late 2000s. Annelie Schedin-Leiulfsrud and Erling Solheim (2016) analysed employment among members of the Norwegian Spinal Cord Injury Association (LARS) and found an employment rate of 44.5 percent among persons in the 18-67 year old age group (N = 298). They also found that most of the respondents (69.5 percent) had been employed post-injury.

Comparable data explaining employment after SCI are also available for Switzerland, Denmark and the Netherlands in 2012 (Post and Reinhardt 2015).²¹ In 2012, the Norwegian employment figure for persons aged 18-65 years old with SCIs (44 percent) was somewhat lower than the figures for the Netherlands (51 percent), Switzerland (54.5 percent) and Denmark in 2012 (54 percent).²² The 2012 results from the ILIAS-SCI Survey confirm a pattern found in previous SCI literature that showed small and non-significant gender differences in employment rates (Post and Reinhardt 2015; Schedin-Leiulfsrud and Solheim 2016).

The summary by Marcel Post and Jan Reinhardt (2015) of the ILIAS-SCI noted that employment levels dropped from 84-88 percent pre-SCI to 52-55 percent post-SCI, with a decrease in average working hours from 37-39 hours per week to 23-27 hours per week (the highest average hours post-SCI were found in Norway). This summary of the results also showed a high potential labour capacity among respondents not currently employed in Norway (54 percent expressed a desire to work, and 71 percent felt they were able to work).

In the Norwegian case, most of this employment potential is found among those who were employed post-SCI but are no longer active in the labour market. The most frequently offered reasons for not being employed are poor health and the lack of resources to maintain a job. Reasons related to a lack of interest in the types of jobs available or a lack of economic incentives to remain employed also play a role, but they are seen as less important among the Norwegian respondents (Schedin-Leiulfsrud and Solheim 2016).

Schedin-Leiulfsrud and Solheim (2016) compare those in employment with those who are not in employment and find a significant difference in the importance these groups attach to employment (with high mean scores for those in employment and lower mean scores for those out of employment). Those in employment were less inclined to agree that most employers would not hire them but agreed that employers discriminate against persons who use wheelchairs. Those in employment also rated their quality of life somewhat higher than those who were not employed or self-employed.

Post and Reinhardt (2015) and Schedin-Leiulfsrud and Solheim (2016) report significant associations between employment rates and education levels, functional independence (ADLs), and secondary health conditions (bodily pain levels) in Norway. After education, the best predictors for remaining employed are pre-SCI employment status and the possibility of remaining in the same type of job or with the same employer post-SCI (Schedin-Leiulfsrud and Solheim 2016). This finding is consistent with the findings for persons with disabilities in Norway (Tøssebro and Wik 2015). It is difficult to acquire a regular job post-SCI without support from an employer, although a higher education level increases a person's chances of post-SCI employment considerably (Schedin-Leiulfsrud and Solheim 2016). It is particularly challenging for young persons who lack the relevant education and employer support to be integrated into the labour market (Bergmark, Westergren and Asaba 2011; Tøssebro and Wik 2015; Schedin-Leiulfsrud and Solheim 2016).

Most of the ILIAS-SCI respondents were independent in self-care (96 percent were able to eat or drink independently, and 75 percent reported that they could manage their own hygiene independently). Eight out of ten respondents (80 percent) reported secondary health complications in the previous six-month period (including bladder, bowel and sleep problems and wounds). Eighty-three percent stated that they had pain issues (with an average pain level of 4.7 out of 10). (ibid.)

Two-thirds (68.5 percent) of the ILIAS-SCI respondents reported that they were very happy or happy in their personal relationships with others, and only 7.5 percent indicated that they were very unsatisfied. Most respondents also reported a good quality of life, even if it was lower at the time of the study than pre-injury. In addition, the ILIAS-SCI data show that 27 percent of respondents actively participated in volunteer work, out of which 17 percent volunteered for organizations for disabled persons and 16 percent volunteered for other types of organizations (ibid.).

The results presented above and unpublished raw data from the Norwegian ILIAS-SCI Survey support a view of most persons with SCI as fairly active citizens (Schedin-Leiulfstrud 2012). Nine out of ten (89 percent) were able to drive a car by themselves. Only one out of ten (10.5 percent) reported that they had had no visits from family and friends in the previous four weeks. Most respondents reported that they had engaged in sports and physical activities or attended social events or outdoor activities in the previous four weeks. However, despite mainly positive participation results, we also find that 35 percent of the respondents had not performed sports or physical activities or attended social events in the previous four weeks. Almost one-half (49.5 percent) of the respondents reported that they participated less in social activities than most persons their respective age groups, 42 percent indicated that they participated at the same level as others in their age groups, and 8.5 percent stated that they were more socially active than most persons their age (ibid.).

Although these results highlight important problems among persons with SCIs in Norway, they are probably less dramatic than those found in many other countries (OECD 2010). The results are also more encouraging than the negative picture portrayed by the WHO (2013), wherein SCIs were primarily associated with family breakdowns, social isolation, stress, etc. In order to get better information of the actual living conditions for persons with an SCI we clearly need better cross national data (Gross-Hemni et al. 2016; Strøm et al 2016).

3.6. Barriers to and facilitators of participation

A core idea found in both Ivar Lie's work with the GAP Model in the late 1960s and Vic Finkelstein's development of the British Model of Social Disability is the notion of working towards a society without barriers:

“Once social barriers to the reintegration of persons with physical impairments are removed, the disability itself is eliminated. The requirements are for changes to society, material changes to the environment, changes in environmental control systems, changes in social roles, and changes in attitudes by persons in the community as a whole” (Finkelstein 1980, p. 33, in Shakespeare 2006, p. 43). The focus on breaking barriers has gradually become an important element of social policy in many Western nations and in discussions of “universal design” (Shakespeare 2006, p. 44). It also resonates with the barriers and facilitators included in the ICF model.

Most SCI research has addressed impairment and activity limitations rather than social participation. Most ICF research related to activity barriers refers to the physical environment, transportation and accessibility, and secondary health complications (Whiteneck et al. 2004; Vissers et al. 2008; Hammel et al. 2015). Among those who refer to participation, it is common to distinguish between community participation and social participation. Community participation has a direct link to a person’s everyday life in his or her local environment. Social participation refers to a broader range of participation with other persons (family, friends, peers) and social roles outside of the community but rarely focuses actively on public roles and domains related to employment, volunteer organizations or social citizenship roles.

Within this narrower understanding of society, we may identify environmental factors or individuals who impact social and community participation. Examples of barriers or facilitators that may impact social participation are transportation, technology, financial resources and the physical environment. Examples of barriers/facilitators that may impact a person’s autonomy in community engagement are access to health services and assistance and commonly held attitudes in the local environment (Barclay et al. 2016, p. 5).

An alternative approach to studying participation barriers is to focus on individual’s intentions and tendencies to avoid certain types of participation. The Nottwil Environmental Factors Inventory (NEFI) model, which was developed by researchers in Nottwil and their partners in the United Kingdom and the USA, aims to study participants’ perceptions of barriers and their attempts to overcome these barriers to identify successful and unsuccessful participation (Juvalta et al. 2015, p. 619, figure 1). The results presented by Sibylle Juvalta et al. (2015) show that the study participants were able to distinguish between environmental factors in the ICF that influence work/employment and those that influence social life/community life. The results also show that study participants had difficulty distinguishing

between environmental factors that influence social life and those that influence community life. Whether this difficulty is an outcome of the ICF measures or the research model remains an open question. One possible explanation for respondents' difficulty with making meaningful distinctions between barriers in social life and barriers in community life is that it is an inherently difficult distinction. Another possible explanation is that the current ICF model is not designed to make this type of distinction between community and social life based on the available environmental parameters.

3.7. Summary

Life after a major trauma such as an SCI is often addressed in terms of maintaining social status post-injury (Plaum et al. 2006). Most barriers to community participation mentioned in the SCI literature refer to environmental factors related to limited access to resources or transportation or a lack of accessibility. Barriers to social participation are identified in negative attitudes and in encounters with health care providers, social services or employers.

Standard explanations for why persons with SCIs are not employed include their physical inability to perform, their fear of losing pension benefits, and physical barriers, such as workplace inaccessibility/environmental factors (Young 2009; Ottomanelli and Lind, 2009; Lidal et al. 2007). Some authors also mention the person's own coping strategies and motivation or the importance of a supportive supervisor (Femke et al. 2013). Persons with higher educational levels before the injury generally have higher odds of both returning to work and remaining employed than those with lower educational levels (Krause and Reed 2009). Non-participation in the labour market is often explained as a mix of personal, social and medical conditions related to lack of energy, health considerations, pain, personal experience of the bodily impairment as a disability (Valtonen et al. 2006) and musculoskeletal and urogenital problems (Lidal et al. 2009). Non-participation may also be explained from the perspective of employment conditions and work strain (Tomassen et al. 2000; Fekete et al. 2014; Ferdiana et al. 2014).

Norwegian data support a view that the lack of energy and health considerations may explain why persons with SCIs opt out of the labour market (Schedin-Leiulfstrud and Solheim 2016). These data also support findings in previous studies that persons with higher educational levels tend to have substantially higher levels of labour market participation than those with

lower educational levels and job skills (ibid.). The gender differences in employment are small but nonetheless disguise the fact that men and women tend to work in different sectors and types of jobs (ibid.). In Lidal's Norwegian study, post-SCI economic inactive rates were higher for elderly persons somewhat higher for females, and higher for those with a higher level of injury. Valtonen et al. (2006) report that employment participation is affected by individual- and injury-related factors but did not find that age, age at the time of the injury or neuropathic pain affected women's labour market participation as much they affected the participation of their male counterparts.

Most participants in the Norwegian ILIAS-SCI Survey reported that they had a car and were able to drive. Although a large proportion of persons with SCIs are active and participate in Norwegian society, we still find a substantial share that is less active and less socially integrated.

4. RESEARCH METHODOLOGY

This chapter includes a description of the data sources, how the data were analysed, reflections on the methods used and ethical considerations.

My study and PhD project is based on a literature search; in-depth qualitative interviews of persons with SCIs in Norway (papers 1 and 2) and in five additional European countries (paper 3); and a theoretical essay on the ICF (paper 4). I have also conducted a nationwide SCI survey (ILIAS-SCI) regarding working and living conditions in Norway (Schedin-Leiulfsrud and Solheim (2016)²³, but this survey is used only as background information in chapter 3.²⁴

Chapter 3 also includes descriptive statistics from a previous collaboration with Erling Solheim based on data from the European Social Survey and information based on a paper co-written with colleagues in the field of spinal cord injury rehabilitation in Norway (Strøm et al. 2016).

4.1. Literature search

Several web-based searches with the key words “participation”, “integration”, “work”; “employment”, “disability”, “socio-economic status”, “spinal cord injury” and “ICF” have been performed since 2010. Complimentary searches have been conducted with “ICF”, “society”, “social citizenship”, “recognition”, “human rights” and “work”, as well as the ICF in combination with the DCP, COPM, OPM(A) and MOHO models, to obtain an overview of articles. This process helped me to develop a view of the relevant literature on participation and employment with a direct link to SCIs that is broader than that found in targeted journals such as *Spinal Cord Disability and Rehabilitation*, *Archives of Physical Medicine and Rehabilitation*, and *Journal of Rehabilitation Medicine*. The literature search was also instrumental in revealing a more general picture of the reception of the ICF model and related discussions about participation and employment. Most of the articles I ultimately reference to in the papers and the thesis summary were published in *Disability and Rehabilitation*, *Disability and Society*, *Spinal Cord*, *International Journal of Social Welfare*, *Journal of Social Work in Disability and Rehabilitation*, *Work: A Journal of prevention, assessment and rehabilitation*, *Social Science and Medicine*, *Archives of Physical Medicine and*

Rehabilitation, European Journal of Disability Research and Scandinavian Journal of Disability Research.

In addition to PubMed, Web of Science and Google Scholar, I searched for US-published PhD dissertations that addressed SCI and employment after the year 2000 (search words: “work, employment, and SCI” + “society”). Very few of these doctoral dissertations are discussed or cited in articles published in the journals.

Most of the literature on SCI and participation is written by researchers in North America and in Central Europe (primarily Germany, Switzerland and the Netherlands). The Norwegian and Nordic SCI literature has mainly been published in English-language international journals. One researcher who has also studied SCIs and labour market participation in Norway is Ingeborg Lidal and her colleagues at Sunnaas Rehabilitation Hospital and Copenhagen University Hospital (Lidal 2010). Despite an increased interest from qualitative researchers in the participation dimension, my project is the first attempt to study the meaning of participation and integration in society for persons with SCIs in Norway.

In addition to the articles and books I found through literature searches, I have also received literature advice from collaboration partners and supervisors. Active engagement in reading the literature implies that the articles and books were an important source of new references. As a researcher, reading the works of others is a source of new (or not so new) insights and an introduction to and an incentive to read publications referenced by other researchers.

4.2. “It takes two to tango – revisited”

The European “Tango project” was originally a Swiss project. Norway was included in 2008, Finland in 2009, Germany, Ireland and Northern Ireland were added in 2011. The Norwegian portion of the research project was based on collaboration among researchers in Trondheim and Nottwil (Switzerland) and the European Spinal Cord Federation (ESCIF). All of the researchers who conducted the interviews in Finland, Germany, Ireland and Northern Ireland were employed by Swiss Paraplegic Research. The Norwegian part of the project was “conducted as an autonomous research project directed by the author in collaboration with St. Olav University Hospital and NTNU Social Research, Ltd.

The European project was initially inspired by the Dutch study published by Van de Ven et al. (2005) entitled “It takes two to tango – the integration of persons with disabilities into society”. The common element in both Van de Ven et al. and the Nottwil-based follow up project (“It takes two to tango – revisited”) was the focus on an “insider perspective” (Reinhardt et al. 2008). Rather than working with predefined models of participation, the idea was to explore and substantiate various aspects of the concept based on informants’ experiences. In the original paper by Van de Ven et al. (2005), this idea was approached from a social psychological perspective of meaningful activities. In the Nottwil-based study, this perspective was broadened to focus on both participation and integration in society. Instead of limiting the research question to meaningful activities for persons with SCIs, the broader study encompassed how persons with SCIs describe participation and integration in society. The idea behind this focus was to learn from the informants personal experiences in addition to their view of the situation for persons with SCI more generally. The main difference between this approach and that of Van de Ven et al. (2005) was that this approach allowed for questions about “generalized experiences”. Asking respondents about “generalized experiences” regarding, e.g., barriers and facilitators for persons with SCIs, provides a wider perspective than a focus on individual experiences of everyday life. Asking about generalized experiences was also an attempt on our part to include societal and environmental factors in the narratives.

The European Tango Project was originally intended to compare persons with SCIs who were “well integrated” with those who had a “low degree of participation/integration” in society. This ambition, however, was soon abandoned because of the difficulty of finding informants with low participation/integration in Switzerland. It was also quickly understood that this research study design posed a number of ethical dilemmas, including a potential risk of social stigmatization of those with a low level of participation/integration. Instead, the issue of what constituted high/low levels of or successful/less successful participation/integration was transformed into a research question.

The original European Tango Project had a number of goals that may be summarized as generating new and relevant empirical material about how persons with SCIs understand participation and integration in society; identifying factors that facilitate/hinder participation/integration; developing ICF-relevant concepts; and developing examples of best practices for rehabilitation and policy purposes. Six research topics were viewed as

particularly relevant in what became the European Tango project: 1) the understanding and meaning attached to participation and integration in different European countries; 2) the differences between the two concepts of participation and integration into society; 3) the identification of personal and environmental factors that the informants experienced as facilitators or barriers to participation and integration; 4) the strategies used to achieve participation and integration; 5) how these strategies are developed; and 6) the identification of strategies that can be made accessible to other persons (Reinhardt et al. 2008). The first research topic is covered in the articles included in this dissertation. Questions 3-6 will be addressed in a six-country paper on participation and integration strategies. Coping strategies are also briefly discussed in papers 2-3.

4.3 Sample and interview setting in Norway

The Norwegian data collection was organised in two waves in 2008/2009 and in 2010 respectively.

In the first part of the Norwegian data selection process, persons who had been injured for at least five years and were at least 18 years old were contacted. (In addition, I included a woman who had been injured two years earlier to increase the number of female informants.) Potential informants were recruited in a hospital ward. If they agreed to participate, they received a written information disclosure that included a declaration of agreement (all potential informants were informed that their participation would not affect their stay on the ward – see appendix 1). These informants were admitted to the SCI ward for observation stays lasting between 2 days and two weeks. The informants were asked to participate in the project in their capacity as ordinary citizens rather than as patients (see also 4.7).

Thirty-three persons were asked to participate, and only two chose not to participate. One refusal was related to a general scepticism toward all types of research, whereas the other was related to time constraints (the person had a hectic program of medical examinations and tests during the stay and was to be discharged within two days). The informants were generally very positive about participating and willing to share their experiences. Although some of the questions concerned the post-SCI rehabilitation period, the interview focused on their lives, with potential relevance for other persons with SCIs.

At the end of the first phase of the data collection I realized that men and middle-aged persons were over-represented among the informants. To obtain a broader range of experiences, more women and younger persons were recruited during the second phase of the data collection (in 2010).

Table 2 show some of the main features of the Tango sample with the Norwegian ILIAS-SCI material as a reference.

In line with data from the Norwegian Spinal Cord Injury Registry and ILIAS-SCI two thirds of the informants are men. The mean age is 48 with a range from 23-67 years. Most of the informants have lived with a spinal cord injury for many years (mean = 18 years), but the sample include persons that have only been injured for 3-5 years as well as one person injured 43 years prior to the study. Half of the Tango informants were married or cohabiting at the time of the study, which is somewhat lower than we find in ILIAS-SCI. One third of the informants have tetraplegia, the remaining two thirds have paraplegia or spina bifida injuries.

The Tango informants were under represented among those in employment at the time of the investigation (35.5%) compared to ILIAS-SCI (44.0), but with a somewhat higher share with a history of employment post SCI (81%).

The Tango informant's occupational class (based on current or previous employment) resemble that of the ILIAS-SCI with an over representation of persons in middle class jobs (based on the European Socio Economic Classification). The percentages in middle class and working class jobs presented in Table 2 have to be interpreted with great care. Both studies may however potentially support a view of spinal cord injured as a more resourceful group than shown in their overall participation rates in the labour market.

Table 2. The Norwegian Tango Project participants' characteristics vs. ILIAS-SCI

	TANGO-NO	ILIAS-SCI-NO
Females/Males Ratio		
Females	35.5%	34.5%
Males	64.5%	65.5%
Age and time since injury		
Age – at time of the study. mean (range)	48 (23-68)	49 (21-66)
Age- at the onset of SCI (excl. spina bifida). Mean (range)	28 (3-57)	30.2 (1-65)
Time since injury (excl. spina bifida). Mean (range)	19 (3-41)	19.6 (1-62)
Family status at time of the study		
Married or cohabiting	51.5%	59.0%
Single, divorced or widowed	48.5%	41.0%
SCI¹		
Paraplegia	58.0%	65.0%
Spina bifida	10.0%	2.5%
Tetraplegia	32.0%	32.5%
Complete/Incomplete Injury	61.0% /49.0%	48.5% / 51.5%
Employment status		
In employment Pre SCI (yes)	64.5%	65.0%
In employment Post SCI (yes)	81.0%	69.5%
In paid work at time of the study	35.5%	44.0%
Students at time of the study	10.0%	4.0%
Pensioned at time of the study	55.0%	52,0%
Socio Economic Class (ESeC) present or last job²		
Middle Class	(17) 55.0%	39.0%
Working Class	(9) 29.0%	22.0%
Unclassified (never in empl./missing information)	(5) 16.0%	30.5% +8.5%
(Ratio middle class/working class jobs)	(1.8)	(1.8)

¹ *Paraplegia* = paralysis of the lower part of the body, including the legs. *Tetraplegia* =paralyses of all four limbs *Spina bifida* = a congenital defect of the spine. It often causes paralyses of the lower limbs and it may be associated with brain injury (none of the persons in this study have brain damages or cognitive disabilities).

² *Middle class* refers to classes I and II in ESeC (professionals and managers higher and lower grade, technicians, higher grade), class IIIa (higher grade non manual work), class IV (employers not included in class I) and class V (supervisors). *Working class* refers to class IIIb in ESeC (routine non manual employees) and classes VI and VII (skilled and unskilled workers and agricultural workers). For a more detailed description of ESeC, see Rose and Harrison (2010). The ratio middle class/working class is calculated by the percentages in middle class divided by the percentages in working class jobs (past and present).

The gender and age composition and injury type (tetraplegia/paraplegia) fit relatively well with available statistics from this rehabilitation unit both in 2008/2009 and in 2010 (Halvorsen and Pettersen 2014), and the socio-demographic factors of the informants fit relatively well with the ILIAS-SCI.²⁵

The Norwegian papers (papers 1 and 2) also include persons with spina bifida because they were relevant to the questions asked. Although there is a potentially interesting difference between those born with SCIs and those who acquired SCIs as adults in terms of employment, certain cases tend to fall between the two extremes (e.g., those who acquired SCIs as children, youths or students) or lack previous job experience. Because of the author's interest in the SCI population, persons with spina bifida were included when their experience was relevant to the questions asked. Questions such as "when they received" their SCIs were not asked to persons with spina bifida.

The Norwegian interviews took place in different rooms at a SCI rehabilitation unit. Only two interviews took place in the person's own room on the ward. The informants could choose whether they would be interviewed in their own rooms or in another room on the ward. None of the informants had any objections to the location of the interview. One interview was conducted by phone because the person was discharged shortly after admission. This person wanted to participate and agreed to be phoned (at work) the following week.

4.4. Sample and interview settings in the other five European countries

In the other five countries, the recruitment process was adapted to the researchers' available SCI networks. Peer counsellors from the Swiss Paraplegic Association contacted participants in Switzerland. In Finland, employees of a rehabilitation centre recruited participants for the study from among persons who visited the centre for outpatient therapy. Thus, persons who lived far from or outside the urban areas could also be reached. The participants in Germany were recruited through wheelchair sports clubs, disability organizations, and the German Association of Persons with SCIs. In the Irish Republic and Northern Ireland, board members of Spinal Injuries Ireland and Liveability, respectively, recruited participants for the study. In all five countries, the sampling was also based on a "snowball procedure" whereby informants helped the researchers to find new informants (Reinhardt et al. 2008).

In paper 3, all informants with spina bifida are excluded to provide a sample that was consistent in terms of injury type (persons with spina bifida were not interviewed in Germany, Ireland or North Ireland). In addition, only the 20 informants who were interviewed in the first round of the project in Norway are included in paper 3.

The national samples differ in size and demography, with 11 informants in Switzerland, 15 in Finland, 15 in Germany, 8 in Ireland and 5 in Northern Ireland. As a consequence of these differences, it was not meaningful to conduct systematic national comparisons among the six nations.

Table 3. Sample characteristics (frequencies, mean and range)

Country	NOR	FIN	CH	GER	IE	NI	TOTAL
Gender							
<i>male</i>	16	12	4	11	6	4	53
<i>female</i>	4	3	7	4	2	1	21
Age, years, mean (range)	49.9 (28-68)	37.3 (20-51)	51.1 (20-75)	49 (37-65)	44.5 (33-53)	43 (32-59)	46.1 (20-75)
Time since injury, years, mean (range)	18 (5-50)	15.9 (5-30)	18.5 (3-38)	22 (3-46)	22.6 (11-31)	16.6 (3-30)	18.5 (3-50)
Age at injury, years, mean (range)	32 (13-57)	21.3 (2-36)	34.6 (17-63)	27 (18-49)	20.9 (17-25)	24.2 (19-30)	27.5 (3-63)
Level of injury							
<i>Paraplegic</i>	12	4	8	12	5	3	44
<i>Tetraplegic</i>	8	11	3	3	3	2	30
European Social Economic Class (current job, or last job for those no longer in employment)							
Middle Class (Higher/intermediate managerial and professionals, routine non-manual, supervisors & self employed).	11	9	5	10	6	4	45
Working Class (Lower level sales/services, skilled and unskilled workers, farm workers)	9	3	3	4	2	-	21
-of which in employment	6	4	6	11	8	2	37
Never been in employment	-	3	1	-	-	-	4

4.5. The Norwegian interview protocol - core version and extended version

The European Tango Project employed a common interview guide, and identical core questions were asked in each interview in the six countries. The informants were given the opportunity to develop their answers in what could be described as a semi-structured interview design. Questions addressed not only about the participants current situations but also positive and negative experiences that affected their participation and integration later in life. The interview protocol also included questions about the participants' life situations at the time of their injuries, during their primary rehabilitation periods, and after discharge from the rehabilitation unit.

The Norwegian interview guide included the core questions asked in the other countries but was supplemented at the end of the interview with additional questions regarding the participants' everyday lives. The main questions in this supplemental module asked participants to "please describe a typical day" and "a typical weekend". This was a deliberate extension of the protocol and was motivated by my professional interest as an occupational therapist in how persons organize their everyday lives and prioritize certain activities and roles. In retrospect, it also resulted in more in-depth information about the participants' everyday lives and life situations than I would have received without this extension. The supplemental module also allowed for a number of follow-up questions related to topics mentioned in the core questions. Based on previous clinical experience, I assumed that direct and concrete questions about the participants' everyday lives would provide me with valuable information about each informant's life. In addition, in this extra module, I paid extra attention to questions regarding the participants' life situations before and after the injury and their employment histories. This information was based on their narratives and accounts.

In addition to more follow-up questions than in the other countries, the Norwegian leg of the study featured longer interviews and richer data as a result of the interview extension. The Norwegian interviews lasted 50-100 minutes, with an average of 70 minutes per interview.

4.6. Data analysis of the European Tango material

Each interview was transcribed verbatim and supplemented, by the author, with an interview protocol that included a summary of the informant's personal history, how he or she defined

participation and integration in society, follow-up topics, and specific information about the interview situation.

The most demanding part of the European Tango project was the initial coding of the interviews. Because the project had already been conducted in Switzerland, where they used a computer-based coding system (MaxQDA), it was expected that the other countries involved would use the same computer-based coding system. To systematically code the interviews, it was also decided that our focus on the “meaning of participation in society” and “the meaning of integration in society” should be limited to information obtained in response to the core questions. Information from the extra module of the Norwegian interviews was thus excluded.

Two researchers from Swiss Paraplegic Research and I primarily performed the joint coding. Although the number of interviews conducted in each country was not very large, it was a tremendous task to code a total of 74 transcribed interviews. The Norwegian interviews were coded together with two co-researchers who spoke both English and Swedish (in addition to German, Swiss German, and Finnish), which made it easier to compare and discuss our results.

After the individual coding, the researchers compared their results, and possible differences were discussed until a consensus was reached and new robust categories were found. Our results were constantly compared with our previous coding. The interviews were coded at different stages, and patterns were sorted and discussed continuously with my co-researchers. In cases of potential disagreement or uncertainty as to how to code the material, the European project leader was automatically consulted. Although I participated only in the coding of the Norwegian interviews, we constantly discussed and compared results of the coding in other countries during this period.

The Norwegian interviews included in the Nottwil database were coded three times over a 12-month period before sufficient agreement was reached. Re-coding was not prompted by initial disagreement with the coding; rather, it was driven mainly by new insights into categories and dimensions that developed as all of the interviews were coded. In accordance with Glaser and Strauss (1967) and Glaser (1978, p. 37-38), we assumed that theory could be induced and could emerge after the data collection began. The problem was how to address the deductive work and “derive from induced codes conceptual guides as to where to go next for which comparative group or subgroup, to sample for more data to generate the theory” (Glaser 1979,

p. 37-38). This difficulty forced us to conduct second and third rounds of coding to reach a joint coding standard. It also forced us to implement more selective coding to avoid drowning in the data material and to eventually reach a point at which additional rounds of analysis added little in terms of new insights.

This methodology was inspired by grounded theory in that it involved rigorous open-ended coding of the material, was data-driven, and revealed the interconnections among categories.²⁶ Because the ICF model does not include an integration dimension, we simply added this dimension to the ICF model and coded it according to the same principles as the participation dimension in code trees with main categories and subcategories and with appropriate codes for the environmental domains.

Although the computer-based program was supposed to save time, it actually resulted in more time spent. We were able to produce potentially interesting ICF categories but had limited theoretical guidelines to direct our analysis of the data. Consequently, I shifted my focus from systematic mapping towards a more abductive approach, with an interest in subcategories that were not necessarily found or developed in the ICF and in categories in the material that puzzled me. To explain surprising findings, I went back to a more in-depth reading of each interview to explore the various functions of employment, the importance attached to social recognition, etc. In retrospect, it is interesting to observe that the social recognition perspective did not come about as a result of the ICF-inspired coding; instead, it arose from an in-depth reading of each Norwegian interview and from abductive reasoning based on interpretations of the narratives found in the interviews, theory and research on social recognition, and my own reading of the data in light of theory and previous research over a considerable time period.

MaxQDA was used primarily in the six-country paper (paper 3) to analyse the European material and to assess how informants associated participation with different dimensions and social realms (see paper 3). In the Norwegian papers (papers 1 and 2), MaxQDA coding was primarily used as a research tool to develop a systematic picture of the data and to frame the topics of discussion. The in-depth reading of cases played a more important role in papers 1 and 2 than it did in paper 3.

Kajsa Ruoranen et al. (2015) wrote a paper on participation and integration based on the MaxQDA coding of all countries except Norway, but ultimately this was – in their words – an aggregated coding in line with qualitative content analysis.

What can be learnt from this experience is that it is very difficult to generate theoretically based classifications without a minimum of hypotheses and assumptions regarding the topics under investigation. If we had chosen to pay more attention to the DCP model instead of limiting ourselves to the ICF, we might also have added interesting dimensions, such as integrity-impairment or ability-disability (see Figure 2 in chapter 2).

4.7. Ethical considerations

The project plan and the interview protocol were approved by a Regional Ethical Committee of Health Research (REK) prior to the start up of the Norwegian Tango Project in 2008/9. All articles based on data from the Norwegian Tango material were written before the end of 2014. The most recent approval of the Tango project from REK is included in appendix 3.

All participants were notified about the aim and purpose of the project and informed that they were being interviewed as ordinary citizens to obtain their opinions regarding participation and integration in society. Almost all of the participants were very positive and eager to answer the questions and share their experiences.

The Norwegian informants differed from those in the samples in the other five countries in that most of the Norwegian informants were interviewed in a hospital environment. In addition, they were interviewed by an occupational therapist (with more than 20 years of clinical experience with SCIs). In contrast to the Finnish informants, who were also recruited from an SCI ward, the Norwegian informants were not interviewed by a stranger but by an “insider”.

A number of strategies were used to create a necessary distance from my established status as a health professional. Whenever possible, I tried to interview persons who were not recent patients of mine. A second strategy was to present myself as researcher engaged in a research project in collaboration with European researchers and the Norwegian and European Spinal Cord Injury Associations. A third strategy, already briefly mentioned, was to present the project as a study of the participants’ everyday lives and their participation and integration in

society. With this focus, it became more obvious to both parties that this study addressed the study participants' own life situations and the life situations of persons with SCIs in general. A fourth strategy was to highlight the lack of research in this field and promise that the results would be presented at SCI meetings and be of practical use in clinical practice.²⁷ A fifth strategy was to avoid personally "sensitive questions" and invite the informants to be my guides and experts on SCI. "Sensitive subjects", such as sexuality, economy, politics and religion, were deliberately not addressed in the follow-up questions. However, some of the informants spontaneously mentioned sexuality or gave detailed accounts of troubled childhoods.

My impression is that most informants appreciated being asked and enjoyed responding to the questions posed in the interviews because they hoped their responses would benefit persons with SCIs in the long run. Several informants also perceived this project as an opportunity to gain recognition. One informant said it was "incredibly important to inform that spinal cord injured persons are living like people in general". Certain informants felt that the questions about participation and integration overlapped and were difficult to answer.

Rapley (2004, p. 108) refers to two common ideals in the interview setting, the "neutral interviewer" and the interviewer who is eager to communicate trust, reassurance and likeability. I identify with the second ideal. However, as interviewers, we must make decisions about what types of questions require follow-up. It is difficult to play the role of a "neutral interviewer" or to pretend that the questions asked are "neutral" (Gubrium and Holstein 1997; Rapley 2004).

Regardless of whether it was emphasized that the informants were recruited as ordinary citizens, it is possible that the informants in Norway participated out of a sense of loyalty. The low number of refusals among the Norwegian persons who were invited to participate may lend support to this suspicion. However, similar response rates occurred in the other countries, where participants were recruited from patient organizations or among those interviewed at an SCI ward by a student.

The moral dilemma posed by having one foot in an international research project and the other foot in a hospital ward is that this position may have induced some of the informants to be more open and vulnerable with respect to the information they chose to reveal. Conversely,

in some cases, it may have made it more difficult for me to obtain information compared with a “stranger” with no or weak ties to the health care system.

Working from an “insider perspective” does not necessarily imply that one is an ambassador of a group (although this may be the case); rather, it informs the analysis of data gathered in different social contexts. What is relevant in one social setting, such as an interview situation, is not necessarily transferable to scientific discussions, which are defined by the research question and previous discussions in the scientific field. As a researcher who aims to give a fair account of the data from the informants, I faced a delicate balance in determining what to present in a scientific setting without violating the original data and their original meaning.

4.8. Methodological reflections

In this study, the informants are approached as experts not only with respect to their own lives but also with respect to how persons with SCIs are living in general and how the society in which they live responds to SCIs. Persons with SCIs are individuals with both unique experiences and experiences in common with other persons with SCIs. They may also be viewed as part of a larger collective, such as the population of disabled persons in Norway. This is of particular relevance because our focus may shift between generalized experiences and highly individual experiences of participation in society.

Concepts such as disability, participation, integration and recognition can be found in the research literature, independent of the informants’ own perceptions. Because these concepts are parts of theories and models with languages of their own, their use in the research literature may differ from how our informants perceive them. For this reason, the European Tango Project was originally designed to substantiate the ICF model and to generate new categories emanating from concrete everyday experiences. This is also the reason why my PhD project ultimately focused on employment and social recognition rather than remaining within an established ICF framework.

Inspired by Bryant and Charmaz (2007) grounded theory was used not only to “ground” the interpretations of the material in a systematic way but also as a tool to analyse values, beliefs, feelings, assumptions and ideologies. In this way, grounded theory was used not only as a methodological tool to help to reveal meaning structures (inductively) but also as a “door

opener” for examining the established theoretical notions of participation for persons with disabilities. Both dimensions are also represented in the grounded theory tradition (Reichertz 2007).

The reference to grounded theory is a common denominator in the protocol of the European Tango Project and in articles based on the European Tango material. It may be an adequate label for how the material was coded and how we tried to identify topics that tended to cluster around key dimensions of participation in the interviews. The challenge regarding grounded theory, however, is not the way data are coded and analysed but how the material is used and theoretically operationalized (Glaser and Strauss 1967, p. 1). Papers 1-3 in this dissertation are based on coding inspired by grounded theory but supplemented with qualitative readings of each interview as a case and with an analysis that uses concepts and narratives from the general literature. The label of grounded theory may therefore be rather misleading.

In the European Tango Project, the implementation of a systematic cross-country study of the everyday lives of persons with SCIs was problematic because gender and age selection varied among the countries. The six-country database is also limited with respect to the number of informants. Nonetheless, the informants were able to talk about themselves and, most importantly for our purposes, to reveal common and generalized experiences of living with SCIs in these countries.

Comparative research is “...well suited for the goals of exploring diversity, interpreting cultural or historical significance, and advancing theory” (Ragin and Amorosso 2011). According to Ragin (1987, p. 1), comparisons allow us to recognize empirical regularities and to evaluate and interpret cases in the light of substantial and theoretical criteria. Contrary to my expectations – I expected to find national differences in the informants’ understandings and interpretations of participation in society – the results suggest a number of commonalities with respect to participation barriers. The most noticeable difference relates to the emphasis the informants placed on employment and the lack of alternative participation arenas, which appears to be more pronounced in Norway than in the other nations.

4.8.1. Possible limitations in the study design of the Norwegian Tango Project

Asking questions about how persons live their lives today and in the past potentially involves several problems. First, informants may tailor their responses to present themselves in a more favourable light in an effort to normalize their personal status. In addition, persons' often tend to forget events that took place a long time ago or to recall those events based on selective memory. However, although the stories the informants told may have been biased, nearly all of the informants were able to give detailed accounts about their life situations immediately before and after their SCIs. It is also my impression that most of the informants answered the questions very openly and that few tried to "glorify" their lives or life situations. After the interviews, many of the informants revealed that the questions had made them more aware of their own participation and integration in society.

Very little has been written about women with SCIs and their participation, and the results regarding differences in labour market participation between men and women are inconclusive. Despite an active attempt to find gender differences in participation patterns, such differences were mainly found with respect to personalized coping strategies and in the female informants' emphasis on achieving more than women in general, which in itself is an interesting finding. Another plausible explanation for why I was not able to find a systematic gender pattern in this study is that the research questions and research design had no specific focus on gender or on "sensitive issues". With a more explicit gender perspective and a focus on everyday life rather than on participation and integration in society, it would have been easier to identify gender-specific issues.²⁸

A final comment regarding the methodology used relates to the difficulties of asking general questions about participation in society. It is reasonable to assume that this information is more reliable in concrete everyday practice than in highly generalized statements about society.

5. SUMMARY OF EACH PAPER

Paper 1: Annelie Schedin-Leiulfstrud: “Social Participation in Theory and Practice: The perspectives of persons with spinal cord injuries”. Manuscript submitted to *Alter – European Journal of Disability research*.

The aim of this article is to explore the concept of participation in society as it is understood among persons with SCIs in Norway. The paper is based on qualitative content analysis and the in-depth analysis of each of the 31 interviews conducted in 2008-10.

Personal autonomy, socializing with others, and living an active and normal life are values shared by the informants and are important values in rehabilitation and disability research. The informants’ views of participation in society are expressed along two main narratives: one of normality and employment and a second of social recognition, human rights and contribution to society. The idea of being ordinary citizens is more important to the informants’ views of themselves than being persons with disabilities or members of minority groups. This is accompanied by an emphasis on individual rights and a strong society that can break down participation barriers.

Paper 2: Annelie Schedin-Leiulfstrud, Jan D Reinhardt, Anne Osterman, Kaisa Ruranen and Marcel W. M. Post (2014): “The value of employment for people living with spinal cord injuries in Norway”. *Disability and Society*, 29 (8): 1177-1191.

The aim of this article is to study the value of employment for persons with SCIs in Norway. The article is based on qualitative content analysis and the in-depth analysis of each of the 31 interviews conducted in 2008-10.

Most informants describe work and employment as the most important vehicles for participation and integration in society. Employment is described using a language of moral duty and contribution to society, albeit with qualifiers. Remaining in a routine job or a job beneath one’s skill level was seen as inferior to receiving a disability pension by those who felt they had made productive contributions to society. Jobs sponsored by the government were seen as inferior to regular jobs. Alternative types of work were generally regarded as

less important than employment, even among participants who were no longer in the labour force.

The article illustrates several dilemmas related to the role of employment. In particular, employment is seen as important, but the majority of persons with SCIs in Norway are not in the labour force. Given the public norm that employment is the key to participation and integration in society, it is particularly problematic that alternatives to employment are limited and given so little social recognition in Norwegian society.

Paper 3: Annelie Schedin-Leiulfstrud, Kaisa Rouranen, Anne Osterman and Jan D. Reinhardt (2016): “The meaning of employment from the perspectives of persons with spinal cord injuries in six European countries. *Work - a journal of prevention, assessment and rehabilitation*, 55 (1): 133-144.

The aim of this article is to examine the meaning of employment as it is understood within the framework of participation and integration in society among persons with SCIs in six European nations. We ask how SCIs relate to employment, the functions of employment, and obstacles to employment. The study is based on 74 semi-structured interviews and qualitative content analysis.

Participants in all six countries emphasized the importance of employment, regardless of their current employment status. Three functions of employment are identified: 1). Employment is important for personal and collective identity, self-respect and social recognition from others. 2). Employment enables the structuring of time and distracts from impairment and pain. 3) Employment is an important social arena that facilitates interaction with other persons.

The status of voluntary work and domestic work did not fully replace that of employment in any country. This perception is reflected both in participants' views and in the design of disability compensation schemes.

Paper 4: Annelie Schedin-Leiulfstrud (forthcoming): “International Classification of Functioning, Disability and Health in the context of participation” in Eide A H. Josephsson S, Vik K. and Ness N – E. (eds.). *Participation as professional concept and everyday lived experience. The role of health and welfare services*. Routledge. Accepted 11. September 2015.

The main aim of this essay is to explore the participation dimension in the ICF model and its potential usages. In contrast with those who primarily approach the ICF model as a neutral classification, this essay argues that the ICF is built on a number of assumptions about the person/actor engaging in participation and the environment in which participation takes place. The ICF is based on a model of consensus among experts, practitioners and disability advocates who aimed to develop a positive view of participation in the environment in which participation occurs. The individual’s abilities and disabilities are emphasized in this model. According to this view, participation is determined both by the person’s bodily and mental capacities and by the environmental factors – physical and social – that enhance or restrict participation.

The ICF model is particularly interesting because it leads to a view of disability as highly “contextual” and “situational”, which makes the traditional distinctions between disabled persons and the majority population less meaningful. However, most ICF research articles on participation in the fields of medicine and rehabilitation are more concerned with measurement and standardization than with the idea of participation as “contextual” and “situational”. One of the main problems with most of the available ICF instruments is that they are more suited to mapping a person’s participation numerically than to assessing the relative importance of different types of participation and participation situations.

Three steps are considered especially important in the development of the ICF model. The first step is to incorporate a more developed view of the person/actor engaging in participation. The second step is to develop a framework of participation roles and domains that recognizes the differences between community-based roles and roles as citizens, consumers and workers. The third step is to further explore the possibility of incorporating theoretical models of human action from the social sciences and occupational therapy fields.

6. DISCUSSION

The discussion is organized around three topics: the empirical part of the study addressed in papers 1-3; persons with SCIs in Norway in the context of previous disability studies; and the potential and limitations of the ICF, which is the topic of paper 4. In addition, at the end of the discussion, I include several comments on the contributions of the thesis to research and rehabilitation practice.

6.1. The empirical part of the study

This project is based on the assumption that persons with SCIs – “the insiders” – could help the research community develop an appropriate language of participation in society. From the very beginning, it was expected that the interviews would inform us not only about the participants’ everyday lives and participation in society but also, and even more importantly, about the “generalized experiences” of persons with SCIs in society.²⁹

As a consequence of our research interest, we have paid closer attention to the determinants that contribute to participation than to the social psychology of participation expressed in the original Tango Project (Van de Ven et al. 2005). As will be illustrated in the case of Ove, below, both approaches may be useful and may supplement each other.

One of the main challenges in a project based on information from “insiders” is deciding what to include in and what to exclude from the concept of participation. Participation in society may refer to “the small world”, “the large world”, or a combination of both (Zetterberg 1989). This variation is also shown in paper 1, where the concept of participation in society has connotations for person’s everyday lives and for their various public roles as citizens, workers and members of volunteer organizations.

Our everyday life takes place in the “small world”, with family, friends and persons who see us and treat us in personal relationships. In contrast, “the large world” involves our roles and identities as citizens, workers or customers. However, processes that take place in “the large world”, such as higher levels of unemployment caused by a downturn in the economy or changes in the tax system, legislation, health care provisions or sick and disability schemes, may contribute dramatically to how persons are able to live their everyday lives. The idea of a

person's "additional capacity" or underutilized ability to participate is also in line with the ICF's language highlighting a person's ability and capability and promoting the optimal use of the potential labour force (Cerniauskaite et al. 2011).

The interviews reveal a number of commonalities based on "generalized experiences" with how to live life with an SCI. This was shown in common references to living "a normal life" and being treated no differently than others ("normalizing") and in a strong belief in employment as the primary vehicle for participation in society. Normalizing may be seen as part of a process to downplay the significance of the injury and focus on commonalities with others. Normalizing may be an efficient personal strategy for participating and integrating on one's own terms rather than being categorized and victimized by others. In addition, several of the informants, particularly those younger than 40-45 years, were hesitant to involve themselves or identify too much with the spinal cord community because the association could damage their attempt to be no different from others.

The Norwegian informants' strong notion of employment fit well with the public rhetoric and social policy that views employment as a productive vehicle for individuals to participate in society. The informants also expressed a strong belief in employment as duty. References to employment were made with respect to the past ("I have done my duty"), the present or the future (for example, "I would ideally like to be employed and contribute to society, but I am currently unable to work").

The strong emphasis on employment is interesting because work and employment were not included in the initial questions about participation in society. From a rehabilitation perspective, this emphasis is an important finding because post-SCI employment has traditionally been downplayed in the medical rehabilitation process. Rather, the goal of rehabilitation is to resume everyday functioning on par with one's pre-SCI life. In medical rehabilitation programs, questions about employment tend to be placed on hold.³⁰

As mentioned in chapter 3, the employer is one of the main determinants of long-term labour market participation after an SCI (Schedin-Leiulfstrud and Solheim 2016). If the employer is not involved as a partner and employment is not actively included in the rehabilitation plan, the chances of remaining in the labour market decrease (ibid.). Even if the newly injured person invests in new education or pursues higher education, education alone does not guarantee a return to employment unless it is paired with specialized skills that potential

employers demand. This finding has been reported in previous research (Tøssebro and Wik 2015). Another problem with the lack of interest in post-SCI employment is that employment has a positive correlation with overall quality of life and a positive effect on coping with pain (Schedin-Leiulfstrud and Solheim 2016).

Once we start to discuss what counts as “successful” or “optimal” participation in society, we quickly end up in one of two traps. The first trap is that this discussion depends on a belief that certain types of participation are considered successful or optimal, whereas other types of participation are considered the opposite of successful. The second trap entails departing from objective measures of participation and adopting a scale that ranges from optimal participation to “disability” without considering how the meaning of success may vary depending on the person and social context (see the DCP model, presented earlier). One possible method of overcoming some of the problems with successful participation/integration is to refer to “parity” with other groups (Fraser 1995), for example, persons of the same age or gender. Referring to parity in interviews and surveys may give us an idea of the informants’ understanding of social participation.

Most measures of participation mentioned in chapter 3 indicated that the majority of the informants in the Norwegian Tango Study and in the ILIAS-SCI Survey felt that they were active and participating in both “the small world” and “the large world”. As a consequence of being unemployed or being older with activity limitations, several Norwegian Tango informants described having lower levels of social participation and shifting towards activities and events in the “small world”. Only two of the 31 informants described a life situation in which they felt socially excluded and marginalised, with few friends and a life hampered by disability (see paper 1). This result may be at least partially related to an overrepresentation of well-integrated persons or the lack of “sensitive” topics in the interview questions.

The two persons who deviated in the Norwegian Tango Study by living a life with a low degree of participation are also of interest in this study. Anna and Simen, mentioned in paper 1, have limited employment experience, small social networks, and a strong self-perception of being marginalised and outsiders. Each reported that the SCI was a major obstacle that impacted his or her current life, which was characterized by a dearth of friends and a lack of energy to participate in public activities. In both cases, we find a pattern of being excluded by relatives and friends and of self-exclusion. Equally important, neither Anna nor Simen (nor any others who claimed that they had lost participation arenas after their injuries) revealed a

life of absolute exclusion. In contrast to most informants, who discussed social integration in terms of a group identity or society with limited understanding or recognition of disability, Anna and Simen mainly referred to discrimination and social exclusion on an individual basis.

Based on the experiences of my Norwegian Tango informants, it may be appropriate to speak about exclusion from certain social domains rather than full social exclusion. It may also be useful to think of participation in society in terms of what the person has achieved, how they live their lives, and what they would like to do in the future.

Comparisons of what we have achieved and how we live our lives or ideally would like to live our lives may reveal major traumas, particularly for newly injured persons with an active life style. The SCI as a trauma and the fight to return to a “normal life” is the main story revealed in interviews and clinical practice. The excerpt below, from an informant eager to provide us with “insider information from the ILAS-SCI Survey, illustrates this story.

Here are some comments and reflections about being disabled early in the life without having a taste of life itself, just a small bite of starter. As a person, you get uprooted and placed somewhere outside the expected life course (“livsveien”). Your social status and personality change, and the surroundings and local environment change you anyway. You become affected. You have what we refer to today as an identity crisis, a loss of your identity; it has dropped on the floor, been broken, crashed. Where are the parts? The platform, my foundation has been destroyed; I am about to sink, I am in open sea, I see no safe harbour in which to anchor, and I have to repair the platform all by myself in an open sea” (Ove, injured in his early 20s, now in his 60s and reflecting back on his life).

Ove’s description of his SCI as a traumatic event is not unique but is nonetheless a story about his personal experiences and fears, which were reinforced by a rehabilitation milieu in the 1970s that invested limited resources in psychological treatment: “Words such as self-perception, self-confidence and self-consciousness were never mentioned”. The first six months after his injury were described as “lonely”; he lacked any idea of how to return to his local environment. Ove’s story is important because he describes how he perceived himself and the rehabilitation period after his SCI. Ove’s story is also a reminder of the importance of

incorporating integrity and social recognition into the discussion of participation in society by persons with SCIs.

“A person with bad or no integrity in society loses their purpose in life. As human beings, we have a deep and basic need to be seen... To feel integrated, and to be perceived as integrated, a lot of time and effort are used to make things appear normal and ordinary. You disguise your differentness and outsidersness in words and in actions... What is the significance of the three interrelated concepts of identity, integrity and dignity for rehabilitation? They have to be included in the rehabilitation work because they are part of the rebuilding...of the whole person, with life-long effects. To have the possibility of being part of something larger than yourself is vital.”

Ove’s emphasis on identity, integrity and dignity refers to the rehabilitation process and to life itself, to our need for social belonging and our need to be a part of life and a world larger than ourselves. It is not a fair game; unlike a high-profile athlete who has just broken a foot and becomes the focus of a television program labelled “The fall, the injury and the road back”, Ove feels that he must work hard – all of the time –to maintain his personal integrity and dignity.

For those who have always desired an alternative life, an SCI may offer a second chance or the possibility of a fresh start. The fact that a traumatic injury may represent a second chance for certain persons is interesting because it helps us imagine alternative life paths. Examples of such a second chance include escaping what appeared to be a destined career in a family firm, getting a new education, or cultivating hobbies or activities that were not prioritized before the SCI.

Being born with an SCI (spina bifida) differs from being injured in one’s late teens or early 20s, which in turn may differ from being injured after one has already worked for 15-30 years, established a family, and lived a long life without an SCI. Ove is an example of a person who was injured early and never managed to establish a life with a family and children. Ove’s journey back to society and the local environment is very different and more problematic than the journeys described by informants who were well-established in their jobs and had families and children. It also differs from the journey of a person who has

always lived with an SCI, although the efforts to be accepted and respected as a “whole person” may be similar.

A common thread in many of the informants’ stories was that the time and energy required for their personal care were not fully understood by persons in their surroundings. This lack of understanding not only affects their dignity and respect but may also prevent persons with SCIs from regularly interacting with friends, relatives and peers (see paper 1).

Ove’s remark, “To feel integrated, and to be perceived as integrated, a lot of time and effort is used to make things appear normal and ordinary”, reflects a common understanding among the Norwegian Tango informants. This understanding is a strong norm that can determine success or failure in terms of participation in society. Like most “insiders” who have grown up and learned how to live a life in Norway, my informants dislike being objectified and told how to live their lives (see paper 1).

Most of the Tango informants argue that Norway is far from the disability-friendly society portrayed in official politics and rhetoric. This view was expressed in general criticisms of the government for not doing enough, of employers for not actively recruiting persons with disabilities, and of people in general for being ignorant or misinformed about what it means to live with an SCI. Although this view is based on criticism of important integrating institutions, it is combined with a strong belief in the power of the welfare state to gradually improve persons with SCI’s rights as social citizens and their accessibility in terms of transportation and infrastructure. Basic human rights, as formulated in the United Nations Convention on the Rights of Persons with Disabilities (UN 2006), are part of the respondents’ narratives regarding participation and integration in society, although the convention is rarely referred to explicitly.

6.2. Persons with SCIs in Norway in the context of previous disability studies

The participants in the Norwegian Tango Project refer to participation within a framework of normality and autonomy and to equality and accessibility as essential for social integration in society. The informants’ understanding of social participation is firmly rooted in activity/engagement, in social interaction with other persons, and in a narrative in which

participation is based on the integration criteria described above in addition to an emphasis on contribution to society.

Elements of the three paradigms of social exclusion described in Silver (1994) are found in the Norwegian interviews. The informants' concern with whether they are contributing to or have contributed to society fits with Silver's "solidarity paradigm". For some informants, this desire to contribute is expressed in terms of solidarity with other persons with SCIs or with disabled people in general, but for most informants, it represents solidarity with society as a whole in their roles as social citizens, workers or members of volunteer organizations. Several informants had experienced personal struggles with insurance companies or the public welfare system (NAV), which placed them in a type of limbo, not knowing whether to stop or continue working after their SCIs. What Silver refers to as the "specialization paradigm", or social exclusion based on individual discrimination, is emphasized less often than the solidarity argument mentioned above. I expected to find a strong emphasis on social exclusion among persons with SCIs, not unlike the emphasis found in the social model of disability, but the picture was more nuanced. Rather than viewing persons with SCIs as socially excluded by the majority society, the main narrative found in the interviews is one of participating in society as "ordinary citizens".

6.3. The ICF Model

Despite all the efforts that have been invested in the ICF project worldwide, we observe a pattern in which the ICF is treated like a container to be filled, with few theoretical guidelines regarding what should fill it. This criticism may seem unfair if we examine the ICF manual (WHO 2001, appendix), which is based on a hierarchy of participation activities and domains, from general chapters and categories to very specific groupings. Nonetheless, the WHO must live with this criticism as long as the ICF is presented either as a pure classification or as a classification tool that may be used in full or in part depending on the research interest and purpose.

My own approach to the ICF has been a mix of curiosity and scepticism. Like several colleagues in the field of occupational therapy, my main criticism of the ICF model is that it tends to objectify the person or actor involved in the activity or participation and to strip the person from meaning and agency. The ICF may help us write a report about the person's

functions and abilities, but without basic knowledge about the person's capabilities, will and preferences, it is difficult to provide an accurate assessment. Ole and most of my Norwegian Tango Project informants work hard to be defined as successful in terms of participation in society, but how do we know whether the participation is optimal from their point of view? This question is particularly relevant if the main norm is that persons with SCI are expected to be "normal" or no different than others. Moreover, with reference to both Ole and Ida, how does the ICF model ensure that the medical system sees each of them as a full person and does not treat them as victims or objects disconnected from their own identity and self-perception? Once we move from the ICF model to the concrete operationalization of participation, it becomes difficult to avoid seeing the person as partial and decontextualized.

As briefly indicated in chapters 2 and 4, I see some potential in the ICF model that may be useful in future research and theory development. This potential may be formulated as five requirements for a more dynamic model of social participation. The first requirement is that the ICF should be treated as more than just a meta-model of human behaviour and functioning. With the abstract and general notion of participation in the current ICF model, it is very difficult to use the ICF list of participation roles and domains. The second requirement is that we develop an ICF language that better enables us to distinguish between the activity and participation dimensions. One simple way to start would be to acknowledge that activity is a general concept regardless of situation and social context, whereas participation always takes place in a social context that may affect the way we portray ourselves and play our participation roles. A third requirement is that we acknowledge that our participation in the environment follows not one but several principles of human interaction. Earlier, I referred to several elementary forms of human behaviour that differentiate among various types of social roles, norms and behaviour. Alan Page Fiske's (1993) differentiation between participation roles based on communal sharing and participation roles in the labour market or as consumers is one possible way to rethink the social domains in the ICF. Fiske's typology is also interesting because he makes a distinction between human interactions based on equality and situations in which we play hierarchy-based roles as clients, patients or citizens. Some may criticise the foundation of Fiske's typology of human behaviour or Hans Zetterberg's (1989) distinction between "the small world" and the "large world". My point is simply that we need a clearer notion of the different spheres of society to enable a more concrete and accurate analysis of participation roles. A fourth requirement for developing the ICF as a model of

participation is a more realistic picture of the actors that is not reduced to individual or personal traits (personal factors) but instead differentiates persons with SCIs in terms of their social status and living conditions. This requirement contradicts the official view that persons with SCIs have similar problems regardless of their culture and social status (Bickenbach et al. 1999). The importance of socioeconomic and cultural differences has gradually been acknowledged in the SCI research (Gross-Hemni et al. 2016). Consequently, we now find attempts to develop core data sets regarding the socioeconomic status and living conditions of persons with SCIs.³¹ A fifth requirement is that the persons involved in the development of the ICF take potential criticism more seriously. The ICF model will be more credible if it can be shown that it allows for an understanding of activity and participation that partly or fully recognizes a person's abilities and capabilities.

It may be difficult to think outside the box once you are inside a research community and a model that steers your research questions and your understanding. I am nevertheless confident that the ICF model may be developed in at least two alternative directions that are compatible with the original formulation of the ICF. The first alternative is to acknowledge the previous and current work in what has been referred to here as the DCP model. This may, at least in theory, lead to a greater interest in the issues of personal integrity and ability. In addition, the idea of habitat and habits (participation roles and areas) is more developed in the DCP model. A second alternative is to incorporate the current ICF model into more developed models of human activity and participation roles (Stamm et al. 2006). This alternative has primarily been discussed in terms of how the ICF model may provide established occupational therapy models using 1) environmental factors, 2) emotional, mental and body functions, and 3) "occupation"/participation codes such as ICF codes b1529 ("self-care, unspecified"), d859, ("work and employment, other specified and unspecified"), and d9209 ("recreation and leisure, unspecified") (Stamm et al. 2006, p. 15, Table 2). It is notable that occupational therapy, with its developed theoretical vocabulary of activity and participation, has not proposed an active response in which one or more occupational therapy models are supplemented by the ICF, rather than the other way around. A main problem in the established occupational therapy models and in the ICF is that they are based on an undifferentiated view of society and the environment in which activity and participation take place. Three out of five chapters in the ICF's environmental dimension (support and

relationships, attitudes and services, and systems and policies) are neither fully utilized nor developed from a participation perspective.

6.4. Possible implications of the study

Asking questions about participation in society creates the risk of opening a Pandora's box in which the questions asked trigger new questions in an endless process.

The ICF model is a good example of a Pandora's box. It has a seemingly simple architecture in which each component is placed in a hierarchy of main and subcategories of interest in studies of participation. The problem is that once we start to discuss the ICF, it produces more questions than answers. The model has a strong grasp of the medical and rehabilitation research in the field of SCI that has gradually become the standard for assessing a person's capacity to perform and their potential capacity for activity and participation. The results from my Norwegian Tango Project support the idea of placing engagement in a life situation at the core of the participation dimension of the ICF. The Norwegian informants' emphasis on human interaction and social rights may be a good indication that both of these aspects of participation need to be further developed and problematized in the ICF framework.

Although the importance of employment may vary across different societies, it seems very problematic to place employment alongside a number of other participation domains without any guiding principles regarding the participation roles in the various environmental domains.

Many occupational therapists have been eager to find support for their own models of "occupation" in the ICF model. However, the use of occupational therapy models or alternative models of participation add agency and action to the ICF model has yet to be accomplished.

The dissertation lends strong support to the notion that clinical rehabilitation must incorporate employment as an active element of the rehabilitation plan. An obvious risk of de-emphasizing employment in the rehabilitation process is that the person may exit the labour market earlier than necessary. Both society and persons with SCIs would probably benefit from a more integrated approach to employment and education after an SCI.

Despite the problem areas identified in this thesis, it provides good reasons to focus on what seems to work with respect to participation in society among persons with disabilities. Unless we as health professionals adopt a reasonably balanced view of the distinction between societal problems and ordinary everyday challenges, we may cause persons to be more disabled than they need to be.

The contrast between the negative picture presented by the WHO (2013) and the Norwegian situation is particularly striking with respect to participation in society and the life situations of persons with SCIs. As mentioned in the background chapter (see 3.5), the majority of persons with SCIs in Norway are happy in their personal relationships. In addition, the proportion of persons with SCIs who are married or cohabiting is on par with that of the Norwegian population as a whole.

7. CONCLUSION

Participation in society, as it is understood by the informants in this study, includes personal autonomy, socializing with others, and living an active and normal life. These values also resonate in Norwegian rehabilitation and disability research. The informants' views of participation in society are also expressed in terms of social recognition, human rights and contribution to society, as well as a strong emphasis on employment and normality.

Social recognition processes take place in everyday life, in interactions with others in community life and in various social roles as social citizens. The importance of social recognition is expressed in a language of "normality", or being no different than other citizens. This is also revealed in narratives regarding the informants' social identities; that is, their perceptions of themselves in interactions with co-workers, health care providers and family and friends. For most of the informants, persons in general are a more important reference group than persons with disabilities or minority groups. The informants also emphasize individual rights and a belief in a strong society to break down participation barriers. In congruence with a Nordic relational model of disability, participation in society is perceived as situational and relative to the participation context. This view is also in line with the ICF model, wherein participation, at least on paper, is relative to the concrete activity/participation environment and to the roles and actions performed.

One of the most important findings of this study is the importance attached to employment as a means of participating and being fully integrated in Norwegian society. This view is expressed by both those in employment and informants no longer in employment. To optimize the capabilities of persons with SCIs to remain in employment in the long term, more and better coordination between employers and the health system is required. In addition, it is important to recognize problems with pain and secondary health complications and the time required to perform elementary body functions as special challenges in relation to long-term employment. Even if more than two-thirds of persons with SCIs have been employed at some point post-SCI, Norway has a lower proportion of persons with SCIs in long-term employment than the other European countries included in this study.

The importance of employment and social recognition to individuals, families, communities and society is well known. Nonetheless, it is rare to find research in the disability and SCI literature that incorporates these dimensions into a discussion of participation from an

“insider perspective”. Most discussions of the ICF model either treat it as a standard reference with few reservations or criticize and reject it on general grounds. The in-between position presented in this thesis – one that is critical but curious about potential applications – is less common but necessary in research and policies that address participation in society.

The contribution of this thesis is that it broadens the discussion of participation in society from theory, concepts and models to everyday practice. This thesis does not deny the importance of standardized measurement instruments of participation in the ICF and in clinical practice; rather, it serves as a reminder that the concept of participation in society, as understood by “insiders” reflecting upon their own private and public life, is richer and more nuanced.

Gender and generational differences are less visible than expected in the informants’ perceptions of participation in Norwegian society. More research should be devoted to possible gender and generational differences in participation. Research on productive coping strategies that enhance participation in society is also needed to overcome participation barriers.

ENDNOTES

¹ In Zetterberg's analysis, the "small world" comprises family, relatives, friends, the home community and the person's social network, whereas the "large world" includes public administrative agencies, business organizations and different types of markets. Zetterberg's idea is that social roles and participation differ between the two "worlds". In his view, "the small world" is based on principles of emotions, altruism and informal relationships, whereas "the large world" is based primarily on power and profit. It is in the large world that Zetterberg sees human collaboration based on competition, evaluations of skills and competence, bureaucracy, and private property relations.

² Australia conducted a slightly modified version of the original ILIAS-SCI Survey in 2015, and additional ILIAS-SCI surveys are planned in Belgium in 2016 and in China, the United Kingdom and the Czech Republic in the near future.

³ Evidence that a shift in language is not necessarily accompanied by a change in practice is revealed by the annual program of the International Spinal Cord Organization (ISCOS), which provides limited space for research on post-injury empowerment and participation in society (<http://www.iscos.org.uk/2016-annual-scientific-meeting>).

⁴ For an overview of the COPM and other occupational therapy models discussed in reference to "optimal participation", see Rochette et al. 2006.

⁵ These are also ideas found in a Swedish white paper published in the mid 1960's according to Rafael Lindquist (2007, p. 19).

⁶ This model is also consistent with Jan Grue's (2011) discourse analysis of the Norwegian Association for Disabled People, which had an official rhetoric resembling that of the social model but espoused an organisational practice based on members' medical diagnoses/impairments and promoted active collaboration with experts and practitioners in medicine and rehabilitation.

⁷ This is also in congruence with the policy of the Norwegian Spinal Cord Injury Association (LARS) with a history of strong collaboration with the SCI units in Oslo, Bergen and Trondheim (Stura and Fjellheim 2016).

⁸ In this regard, we find a number of attempts to operationalize the ICF with core data sets for different patient categories; assessments of specific instruments and their reliability; construct validity and measurement potential; attempts to increase conceptual clarity and comparability in surveys; correlates and determinants of physical activity; an interest in domains that contribute to disability in activities of daily living; and applications of the ICF model to quality of life, tools for vocational rehabilitation, children and youth, the coding of medical certificates, physical therapy intervention trials, environmental barriers and activity/participation restrictions, etc.

⁹ An interesting question is why the ICF and not the DCP model became WHO's new international standard. The answer may be hard to find, but several explanations may help in this regard. The first possible explanation is that the DCP model represented too much of a continuation of the ICIDH and was initially too detailed and complex to use. A second possible explanation is that the DCP model met significant resistance from European colleagues and critical voices within the disability movement. This resistance is based on the criticism that a model of health conditions should have a focus that is broader than individual functioning and disability. A third explanation, which should not be ignored, is that the architects of what ultimately became the final and "winning" version of the ICIDH-2 (renamed the ICF) did an exceptionally good job that satisfied numerous interests. Helped by a clever design, the ICF was formulated both in etiologically neutral language, which satisfied the WHO and its research groups, and with a positive view of actors that could be used in studies of both disability and health and social policy. A fourth explanation for why the DCP model has not received

much attention outside of Canada may be that much of its discussion is written in French, not English. The scholars within each camp view themselves as the owners of the classification, and no significant discussion has occurred between the parties.

¹⁰ Because my research colleagues worked in official branches of the WHO system, the DCP model was never discussed in the early phase of the European Tango Project. The ICF became the reference model because it led to a broader interest in participation and integration in society. The European Tango Project also encompassed a mission to fill an essentially raw and empty model with meaning that would be relevant to future studies of people with SCIs.

¹¹ *Social citizenship*, in this study, refers to rights and duties as defined within a nation state. The standard concept of citizenship includes several legal entitlements, including the civil, political and social rights of citizens. These are legal entitlements that have developed over centuries, and the social right to maintain a life with basic social security defines different types of historical welfare states. It also represents a social status whereby the members of a nation state are free to express their opinions and to vote in political elections in accordance with the applicable laws and possess the legal right to protection. In contemporary social policy discussions, we see a shift from social citizenship as a right toward a view of citizens as active participants in a society. This view is also expressed in social and labour market policies that demand the utilization of activity potentials among unemployed citizens (OECD 2010). *Human rights* differ from social citizenship in that they are universal and less binding on the nation states that have agreed to implement the principles set forth by the United Nations (UN) regarding human freedom and basic social rights. The UN Convention on the Rights of Persons with Disabilities, which calls upon member states to provide more disability-friendly policies than in the past, is of interest because it also monitors the situations of people with disabilities (UN 2006).

¹² Their review included 17 quantitative articles, 5 qualitative articles and 1 article based on mixed methods from the databases OVID, MEDLINE, AMED, CINAHL PLUS and PSYCHINFO.

¹³ For more detailed overviews, see Witsø (2013, p. 22-23) and Kvam (2014, p. 17-18).

¹⁴ The OECD index (OECD 2010, p. 103) is based on scores from 0-5 on 9 items. The Norwegian scores are reported in parentheses after each item: benefit system coverage (5); minimum disability benefit (3); level of full disability (2); disability benefit generosity (4); disability benefit permanence (2); medical assessment rules (4); vocational assessment rules (2); sickness benefit generosity (5); sickness benefit duration (4); and sickness benefit monitoring (2). For more information about each of these items, see OECD (2010, appendix).

¹⁵ According to the EU and Eurostat definitions, people at risk of poverty or social exclusion experience at least one of three conditions: a) the risk of poverty after social transfer, or what may be described as income poverty; b) severe material deprivation; or c) living in a household with very low work activity/intensity (Eurostat 2014).

¹⁶ Information provided by Tor Petter Bo and Berit Otnes at Statistics Norway, based on earlier analysis.

¹⁷ A good illustration of this difference is found in the report by Tom Morten Normann and Elisabeth Rønning (2008), which compare the EU-SILC in Norway with the Norwegian Labour Force Survey (“AKU”) and Level of Living Survey (“Levekårsundersøkelsen”). The report by Normann and Rønning (2008) shows that the Norwegian Labour Force Survey (AKU) reports a higher percentage of people with activity limitations compared with the EU-SILC. The main difference between them relates to the number of people with moderate activity limitations. Normann and Rønning explain this discrepancy as the result of more items and different filter questions in the AKU compared with the EU-SILC. Normann and Rønning also report a higher percentage of people with activity limitations in the Norwegian Level of Living Surveys than in the EU-SILC as a result of differences in

operationalisation and technical design. Their interpretation, which is based on an analysis of medical diagnoses and activity limitations in daily life in the Norwegian data, is that the people depicted as having activity limitations in the EU-SILC are somewhat more impaired.

¹⁸ Norway has a labour market integration policy that is best described as a Janus face. For those in the labour market, there is an agreement among employers, labour unions and the government to support an “inclusive labour life” program (the IA Agreement). This agreement and program has gradually developed through letters of intent since 2001 and in more ambitious agreements since 2010 (Government.no 2014). The main aim of these policies for people already in the labour market is to prevent and reduce employee absenteeism arising from illness; to improve employment participation levels and the working environment; and to avoid social exclusion and marginalization from the labour market. This collaboration among labour stakeholders is based primarily on principles of early intervention and measures at the workplace level (Government.no 2014); the program is not geared toward people who are outside or weakly integrated into the labour market. Consequently, the program does not necessarily help people with disabilities, immigrants and young people with limited employment experience when they apply for new jobs. This agreement between the stakeholders in the Norwegian labour market is also uneven, with better coverage in the public sector and among larger private firms than among smaller private firms, which have fewer obligations. The aims of the Norwegian state-financed support system with respect to sickness and disability are to offer appropriate medical and rehabilitation measures, to establish a plan for a future career in the labour market and to provide compensation for income lost because of the medical impairment. The type of activation measures implemented to help people return to work within 12 months differs considerably depending on the person’s education, job situation and job prospects.

One of the critical elements in the activation process to help people return to work is that the employer is not legally bound to find new work for an employee who is no longer able to perform his or her previous job. This issue is not necessarily a problem when physical adjustments to the workplace are necessary to facilitate tasks or when the employer has alternative job options. However, it may be a problem if the employer claims on financial or business grounds that there is no longer a need for the person’s services. Because employees in Norway, particularly those in the private sector, have limited protection in cases of economic downturns and restructuring, lay-offs for people with disabilities may increase the risk that they will become welfare recipients.

¹⁹ This estimation is based on the average number of new SCIs in 2011-2013 (72 + 7 per year for people aged 18-65 years). Multiplying 79 people by 49 cohorts, we get 3.871 people. Based on the information available for people aged 18-65 years of age in the Norwegian ILIAS-SCI Survey in 2012, approximately half of these people receive a full (disability) pension, one-quarter receive a pension combined with employment/education, and the remaining 28 percent are fully employed or are students. In order to get better information about this we need better data than currently available in the Norwegian SCI registry.

²⁰ Several commentators, including Yasuda et al. (2002), Lidal et al. (2007) and Murphy et al. (2009), show that it is difficult to produce good and reliable statistics on employment rates after SCIs. This problem is common in cross-country comparisons of the employment of disabled people (Molden and Tøssebro 2010).

²¹ ILIAS-SCI is a cross-sectional SCI survey (including a web-based questionnaire and postal questionnaires) that was conducted in 2012 in Norway, Denmark, Switzerland and the Netherlands with the national SCI organisations as a target group (the Swiss study also recruited patients not included here). The sample size of the Norwegian study for persons up to 67 years, including spina bifida, was 323. The sample sizes of persons aged 18-65 years were as follows: 296 in Norway, 142 in

Denmark, 327 in Switzerland and 396 in the Netherlands. The average response rate was 50 percent (Post and Reinhardt 2015), and the Norwegian ILIAS-SCI response rate was 51 percent.

²² Based on unpublished data from the ILIAS-SCI project.

²³ This manuscript is under review in the *Scandinavian Journal of Disability Research*.

²⁴ The ILIAS-SCI Survey is based on collaboration between European researchers in Trondheim, Nottwil, Copenhagen and Utrecht in the Netherlands, the European Spinal Cord Federation (ESCIF) and the Norwegian Spinal Cord Association (LARS). Additional survey data are mainly used to illustrate the labour market situation of people with SCIs compared with the general population. The ILIAS-SCI Survey was initially intended to be part of this thesis project. However, because this survey project has a more specific focus on labour market participation and living conditions, I decided to exclude the ILIAS-SCI to develop a more coherent focus on the meaning of participation. For more information about the data and methodology of the ILIAS-SCI Study, see Schedin-Leiulfstrud and Solheim (2016) and the ILIAS-SCI Homepage (<https://www.ilias-survey.eu/en/index.php>).

²⁵ The results from the Norwegian ILIAS-SCI Survey confirm the patterns found in the Norwegian Tango project. Two-thirds of the participants (64.5 percent) were males, six out of ten (59 percent) were either married or cohabiting, and 35 percent lived alone (Schedin-Leiulfstrud 2012). See Table 2.

²⁶ Inspired by the methodology of grounded theory (GT), we worked with “selective coding”, in which core variables (or what we expected to be the core variables) were used to select new and relevant data in congruence with the core variables (also described as “theoretical sampling” in GT). According to GT, selective coding should help us delimit the study and the coding process (Glaser 1998). In our case, however, it was more difficult than anticipated to integrate the theoretical codes that could be used in a theory and hypothesis of participation and integration.

²⁷ In accordance with my promise to the informants, the findings from this project have been presented at the annual SCI conference of the Norwegian SCI association (LARS), the local branch for patients with SCI at St Olav University Hospital (“Brukergruppen ved Klinik for fysikalsk medisin og rehabilitering, St Olav”), Nordic and International Spinal Cord Society conferences (NOSCOS and ISCOS), research meetings, and meetings for health professionals. In these settings, the primary interest was what can be learnt and the clinical implications that are of interest.

²⁸ This was later confirmed in informal group conversations among women with SCIs in which I was invited to participate as a female researcher. In addition to a general agreement about having to “achieve” more than other women and peers, the conversation revealed a lack of public forums in which to discuss gender-specific experiences and challenges (SCI is a medical diagnosis with a clear majority of men, and there is little research devoted to gender-specific challenges).

²⁹ Most research within the European Tango Project has focused on the understanding and meaning attached to participation in society in different European countries, the concept of participation, and the factors that the informants experienced as facilitators of or barriers to optimal participation. Personal strategies that may enhance participation have also been analysed within the European Tango Project, but this analysis has not yet been published.

³⁰ I have discussed the loose integration among the Norwegian medical system, employers and the Norwegian Labour and Welfare Administration (NAV) in numerous encounters with rehabilitation staff and researchers. Few health professionals are surprised by the loose integration among these entities, which illustrates the problem of scant collaboration among hospitals, NAV and employers. The problem with this loose integration is particularly critical when the newly injured person has a job but no future plan for remaining in employment.

³¹ An international panel of SCI researchers led by Professor Yuying Cheng in the USA is currently working with a sociodemographic basic data set (version 1.0) with four items (marital status, number of persons in the household, years of education and primary occupation).

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PART II

Paper I

Paper 1: Annelie Schedin-Leiulfsrud: “Social Participation in Theory and Practice: The perspectives of persons with spinal cord injuries”. Manuscript submitted to *Alter – European Journal of Disability research*.

Social Participation in Theory and Practice: The perspectives of persons with spinal cord injuries

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Abstract

The aim of this article is to explore the concept of social participation based on the experiences of persons with a spinal cord injury. The material is based on 31 in-depth interviews in Norway and was analysed using qualitative content analysis (MAXQDA) combined with an in-depth analysis of each interview.

The informants' understanding of participation is primarily associated with activity, socialising and the freedom to live an active and normal life. The importance of normality, having a job and not deviating from "people in general" are seen as the primary narratives among those interviewed. The informants also emphasise the importance of social recognition, human rights and making a contribution to society. The answers reveal a stronger social dimension and agency perspective than appears in the International Classification of Functioning, Disability and Health (ICF). They also show a more complex picture of social identities and participation roles than in the ICF. Instead of a narrative comparing the disabled to the non-disabled, a complex set of social relations and identities are found in the Norwegian interviews.

Key words

Social participation, participation roles, spinal cord injury, social recognition, ICF

Running title

Social Participation in Theory and Practice

1. INTRODUCTION

The social dimension of participation has been discussed in health and social policy research since the 1960s without any consensus being reached on how to define it (Piskur, Daniels, Jongmans, Ketelaar, Smeets, Norton & Beurskens, 2014). The standard way to think about participation in both disability studies and health research, however, is in terms of the person's social relationships and sense of belonging in a context of meaningful activities in their environment (Barrow, 2008; Hammel, Magasi, Heinemann, Whiteneck, Bogner & Rodriguez, 2008). This understanding is also expressed in the International Classification of Functioning, Disability and Health the ICF (WHO, 2001).

Although the ICF is primarily a health classification, it is also based on a view of activity and participation in which "barriers" (physical/social) and "facilitators" (assistive technology but also disability-friendly policies) are seen as mediating social mechanisms. In theory, the ICF should therefore help us to identify the gap between people's actual level of functioning and the social norms associated with participation in their environments.

ICF advocates such as Jerome Bickenbach (2014) have also argued that the ICF fits like a glove with a capability approach, i.e., what people are able to do and be. Others, including Sophie Mitra (2014), have argued that the capability approach of the ICF is implicit and only loosely connected to the fact that capability is a function of resources and the ability to govern one's own life. These are also arguments found in the independent living literature (Barnes & Mercer, 2010; Fleischer, 2001). In Mitra's critique of the ICF (2014), "capabilities" are seen as a question of social justice and injustices in the real world, as opposed to the ICF model of social participation, which excludes questions about systematic inequalities in the real world.

According to Lennart Nordenfeldt (2006), the ICF also underestimates the importance of people's motivation and will as related to engagement and participation. It may also be argued that the ICF is a loose theoretical framework unless it is substantiated by a discussion of people's intentions, motivations and experiences of participation in society (ibid). In summary, it may be argued that the ICF is a general theoretical framework of functioning and disability mechanisms, rather than a realistic model of how people attach meaning to participation in society.

Despite the growing interest in practical and phenomenological approaches to activity and participation in recent years, it is fair to claim that medically oriented rehabilitation

perspectives primarily focus on individuals (body and mind) in the context of everyday activities (Hammel et al., 2008; Kielhofner, 2008). In this research, participation is primarily discussed in terms of people's autonomy and ability to make decisions about their lives. Participation is also typically discussed in terms of choice, control and a sense of personal willpower or with reference to clients' capability, control and autonomy in encounters with the medical system and welfare agencies (Barrow, 2008; Saleeby, 2007; UN, 2006; WHO, 2011).

The focus on empowerment and individual capability is also congruent with current Nordic and European public activation policies, in which the primary idea is to use individuals' remaining work capacity regardless of their functional impairment and disability (Hvinden & Johansson, 2007; OECD, 2010; Tøssebro, 2012). However, similar to the general model of the ICF and most economic models, "the person" in human rights discourse remains a fairly abstract agent only loosely related to how people perceive their lives and participates in practice.

The aim of this article is to explore the concept of social participation based on the experiences and conceptual understanding of persons with a spinal cord injury (SCI) in Norway. The primary research objective of this article is to understand people's experience of participation in society, including the complexities of the participation roles identified and experienced by the informants and to which they attach meaning.

It is argued that the ICF is based on a top-down perspective of what is ultimately included in the participation dimension. To assess the merits of ICF and alternative approaches to social participation in health and disability research, we must also include a realistic picture of how ordinary people view their participation in society. This is helped by taking a more bottom-up approach based on ordinary people's voices and experiences. Rather than treating participation as a mere description of general human activities, the focus is on participation in a social context of human potentials (capabilities) and social recognition.

2. TWO NARRATIVES OF SOCIAL PARTICIPATION: ACTIVITY/CAPABILITY VERSUS SOCIAL RECOGNITION

Despite efforts to find a common definition of participation, medical researchers and the ICF Research Branch at the World Health Organisation (WHO) have not yet reached a consensus (see the special issue in *Archives of Physical Medicine and Rehabilitation* 2010, vol. 91). One of the primary reasons for this lack of agreement is the problem of distinguishing which activities to include and in what social domains relevant participation activities occur (Heinemann, Tulsy, Dijkers, Brown, Magasi, Gordon & DeMark, 2010). However, researchers who favour a more “holistic” outlook on participation are less concerned about universal measurements and more interested in how people engage in meaningful everyday activities. This outlook is closest to that of the ICF (WHO, 2001) and the growing efforts in occupational therapy, social work, and family intervention planning (Adolfsson, 2013) to identify the concrete practices of participation conducted in everyday life (Van De Velde, Bracke, Van Hove, Josephsson & Vanderstraeten, 2010). Almost regardless of the critical exchange between Bickenbach (2014) and Mitra (2014), both parties appear to agree that the ICF may be useful as a tool to operationalise *human activity and capability in social participation*. (For a review of the use of ICF, see Cerniauskaite, Quintas, Boldt, Raggi, Cieza, Bickenbach & Leonardi, 2011.) In this respect, it is more a discussion of what is included and excluded in a capability approach in which the primary task is to empower people and to facilitate activity and engagement in everyday life and as social citizens.

An alternative to the apparently value-neutral expert perspective found in the ICF is to focus on the social recognition struggles and empowerment of vulnerable groups. This focus is at the core of many welfare and disability studies. It is also interesting to explore perceptions and societal norms in terms of “respect” (Fraser, 2000; Honneth, 2004; Lawrence-Lightfoot, 2000; Sennett, 2003). Although “empowerment” is an essential part of both narratives of participation, the focus of the social recognition literature is on the value attributions and respect expressed in interactions between people, acknowledgement of the views of other people, respect for the law, or adherence to norms, such as being a productive member of society (Fraser & Gordon, 1994). From this perspective, being recognised by others opens the door to being a fully participating member of society. Conversely, misrecognition by others may be seen as a form of asymmetrical power relations and an essential component of the processes of social marginalisation and social exclusion (Fraser, 2000; Honneth, 2004).

Although a “social stigma” may refer to something that is deviant or discredited, it also calls into question how people manage these imposed roles through resistance, denial, acceptance or embarrassment (Goffman, 1963).

Once we shift our focus towards social recognition, it is more or less mandatory to include critical questions about individuals’ abilities, rights and duties to participate as full members of society. To further understand the concept of social participation, it is necessary to explore the common experiences of participation in society and the complexities in participation roles due not only to individual factors but also to different life circumstances, resources and choices (Dubois & Trani, 2009; Mitra, 2014; Trani, Bakhshi, Bellanca, Biggeri & Marchetta, 2011). This approach to social participation is not restricted to fixed measures but instead is congruent with a relative notion of capability based on people’s objectives, ambitions and social values. From this perspective, it is not only capability but also dis-capability, the inability to live a life according to the personal and societal norms of a country’s citizens, that are of interest (see, e.g., Bellanca, Biggeri & Marchetta, 2011).

Figure 1 summarises the main dimensions to be further explored below through what are referred to here as the *activity and capability perspective* and the *social recognition perspective*. This paper also elicits the question of participation in everyday interactions with other people (individual interactions) and issues related to the realisation of social citizenship.

	Individual interactions	Social citizenship interactions
Activity/Capability Perspective (ICF)	Activities people do alone and with others in everyday life. How they perceive opportunities/activities and constraints in their everyday lives.	How they perceive opportunities/ constraints when performing activities/ actions in society in general (physical, legal, cultural, health care opportunities/ constraints).
Social recognition perspective	How they perceive themselves and are perceived in interactions with other people in their everyday lives (acceptance/stigma).	How they perceive themselves and are perceived as social citizens in terms of official norms, human rights, and respect in society in general.

Figure 1 Key aspects of participation in society

The two perspectives that are of particular interest are the *activity and capacity perspectives*, which are associated with both the ICF and most client-centred models of disability, and the *social recognition perspective*. Figure 1 also elicits the question of participation in everyday interactions with other people (individual interactions) and in society more generally.

The upper-left-hand cell in Figure 1 corresponds to a focus on rehabilitating individuals in their everyday settings, whereas the upper-right-hand cell covers infrastructure and policy measures to facilitate a disability-friendly society. Most of the environmental measures developed in, e.g., the ICF, correspond to one of these two cells. The lower cells show the importance of social recognition in everyday life as opposed to general discussions of human rights in the ICF. In the lower-left-hand cell, the focus is on recognition from other people, whereas in the lower-right-hand cell, the focus is on official norms, human rights and recognition as social citizens.

3. METHOD

This study is the Norwegian part of an ongoing European project on participation and integration from the perspective of people with SCI (Ruoranen, Post, Juvalta & Reinhardt, 2014; Author, 2014; see also van de Ven, Post, de Witte & van den Heuvel, 2010). The study is based on content analysis and an in-depth reading of semi-structured interviews.

3.1. Sample and recruitment

Thirty-three people with SCI were recruited. Two persons declined to participate (one for practical reasons, the other due to a general scepticism about research that could be used to reveal private matters). Therefore, the final sample was 31 informants. All of the informants were inpatients or outpatients (not in primary rehabilitation) at an SCI rehabilitation unit. The participants were interviewed individually and face-to-face in Norwegian at the rehabilitation unit by the author.

In the initial phase of the Norwegian data collection (2009), the recruitment was based on purposive sampling and used the criteria of age (18 to 67 years), a minimum period of SCI (at least 5 years), and a willingness to participate in the research project. Due to an under-

sampling of women and younger men in the early phase of the data collection, both of these groups were over-sampled in a later phase of data collection (2009-10). Except for the criteria above, the sample had no pre-specified quota. The sample did not include persons with mental or cognitive impairments.

3.2. Ethics

The project was approved by the Regional Committee for Medical and Health Research Ethics in line with the principles of the World Medical Association's Declaration of Helsinki. All participants were informed that this was part of a European research project and that they were being approached in their roles as citizens rather than as patients. Written consent was obtained from all participants.

3.3. Interviews

The interviews followed an interview guide with open-ended and follow-up questions, and they lasted 1-2 hours. The interviews aimed to examine the subjective understanding and language of the respondents as related to their status as persons with SCI and their participation in and integration into society. The primary question of interest in this article was *When we talk about a person with SCI participating in society, what do you think is meant by this?*³

To advance from general to individual notions of participation, the Norwegian informants were asked to define participation, to describe what was important for participation in society, and to describe their own participation. The interview guide also included questions about the participants' views of facilitators and barriers to participation in society. Asking these questions triggered reflections on the participants' current and past life situations. It also revealed their priorities with respect to participation and the social norms that they incorporated into their own narratives.

³ The same question was also asked about a person with SCI being integrated into society. The interview guide may be obtained from the author.

3.4. Analysis

All of the interviews were audio-recorded and transcribed verbatim by the author. The transcriptions were scrutinised over several stages using a structured decoding methodology to obtain an in-depth understanding of each individual case. MAXQDA software (Kuckartz, 2007) was used to structure the transcripts. The author coded two-thirds of the transcripts together with assistance from a minimum of one other researcher in accordance with the principle of consensus coding. These data were included in a joint database with data from informants from six European countries. The author worked alone to code the remaining one-third of the Norwegian transcripts.

The European transcripts were initially analysed using qualitative content analysis (Ruoranen et al., 2014). This strategy enabled the researchers involved to create categories on an inductive basis that were revised during coding to maintain reliability. This analysis also included rigorous comparisons of topics, expressions and the key words used to describe participation in society; these items were compared to our previous coding. In cases of inconsistent coding or in difficult cases a third researcher was included. This analysis enabled us to identify a) the participants' subjective understanding of participation in society, b) their understanding of participation in society compared to their situation either before the injury or in the past, and c) the domain in which the participation references took place (i.e., home/community, the labour market or the public sphere).

The analysis was initially inspired by the grounded-theory method (Bryant & Charmaz, 2007; Glaser & Strauss, 1967) and was later extended and updated with reference to symbolic interactionism (Blumer, 1986). Instead of attempting to substantiate a predefined idea of participation, we approached the concept of participation more heuristically. We were also interested in the contexts in which meaning was invested and not just in mapping activities. Blumer's idea of "sensitising concepts" (Blumer, 1986; Bryant & Charmaz, 2007) inspired us pay special attention to the various meanings attached to participation both ideally and in practice. This process also included questions about how the individuals perceived themselves in their interactions with other people in Norwegian society. It is also based on an ambition not only to be as open-minded as possible as researchers but also to be aware of previous research when analysing and exploring the different qualitative dimensions and determinants linked to social participation roles.

The results are presented in two steps. A brief picture of the participants and the sample (4.1) and an overview of topics that the participants mentioned in conjunction with their participation in society (4.2) are presented in step one. A more detailed presentation of the topics and primary narratives are presented in step two (4.3 - 4.5).

4. RESULTS

4.1. Participant characteristics

Eleven of the 31 people interviewed for this study were women. The participants' gender ratio and average age were in line with both the annual records of newly injured people at the rehabilitation unit where the study took place and with a national survey of members of the Norwegian Association of Spinal Cord Injured in 2012 (Halvorsen & Petersen, 2014; www.ilias-survey.eu). There was also a good overlap in employment status and occupational class (Rose & Harrison, 2010) between the qualitative sample and the national survey. Eight of the 11 women worked or had been working in middle-class jobs (higher and intermediate professionals/managers and office workers), 2 were university students, and 1 held a lower degree but had never worked. The class composition, based on the European Socio-Economic Classification (ESeC), was more mixed among the group of men, with 9 who had held working-class jobs (mainly unskilled and skilled workers), 10 who had held middle-class jobs, and 2 who had never been in regular employment after their injury (of whom 1 was a student).

All of the participants had a spinal cord injury. Although most of them (28) had acquired paraplegia or tetraplegia, 3 participants had been born with a spinal cord injury (spina bifida). Twenty-nine participants used wheelchairs (manual and/or electric); the remaining 2 were able to walk with technical devices.

Table 1. The Norwegian Tango Project participants' characteristics vs. ILIAS-SCI

	TANGO-NO	ILIAS-SCI-NO
Females/Males Ratio		
Females	35.5%	34.5%
Males	64.5%	65.5%
Age		
Age – at time of the study. mean (range)	48 (23-68)	49 (21-66)
Age- at the onset of SCI. mean (range)	28 (3-57)	29.0 (1-65)
Time since injury (excl. spina bifida). Mean (range)	19 (3-41)	19.6 (1-62)
Family status (current)		
Married or cohabiting	51.5%	59.0%
Single, divorced or widowed	48.5%	41.0%
Complete/Incomplete Injury	61.0% /49.0%	48.5% / 51.5%
SCI⁴		
Paraplegia	58.0%	65.0%
Spina bifida	10.0%	-----
Tetraplegia	32.0%	35.0%
In employment Pre SCI (yes)	64.5%	65.0%
In employment Post SCI (yes)	81.0%	69.5%
Employment status (current)		
In paid work	35.5%	44.0%
Students	10.0%	4.0%
Pensioned (neither employed nor a student)	55.0%	52,0%
Socio Economic Class (ESeC) present or last job⁵		
Middle Class	(17) 55.0%	39.0%
Working Class	(9) 29.0%	22.0%
Unclassified (never in empl./missing information)	(5) 16.0%	30.5% +8.5%
(Ratio middle class/working class jobs)	(1.8)	(1.8)

⁴ *Paraplegia* = paralysis of the lower part of the body, including the legs. *Tetraplegia* =paralyses of all four limbs *Spina bifida* = a congenital defect of the spine. It often causes paralyses of the lower limbs and it may be associated with brain injury (none of the persons in this study have brain damages or cognitive disabilities).

⁵ *Middle class* refers to classes I and II in ESeC (professionals and managers higher and lower grade, technicians, higher grade), class IIIa (higher grade non manual work), class IV (employers not included in class I) and class V (supervisors). *Working class* refers to class IIIb in ESeC (routine non manual employees) and classes VI and VII (skilled and unskilled workers and agricultural workers). For a more detailed description of ESeC, see Rose and Harrison (2010). The ratio middle class/working class is calculated by the percentages in middle class divided by the percentages in working class jobs (past and present).

4.2. Topics and primary narratives associated with social participation

The topics most often associated with participation in the material were ‘activity and engagement’ (mentioned by 23:31), ‘autonomy’ (19), ‘normality and normal conduct’ (17), ‘socialising with others’ (16), ‘work and education’ (16), ‘contribution to society’ (13), ‘equality and rights’ (13), ‘accessibility’ (9), ‘active individual role’ (6) and ‘organisational work’ (6). One-third of the informants found it difficult to distinguish between the meaning of participation and integration into society.

As shown in the above list of topics, the conventional notion of participation in the medical field i.e., activity and involvement in a life situation (WHO, 2001) is also emphasised by most of the Norwegian informants. This result highlights several of the core principles of human activities and actions that are ingrained in most human rights discussions, including personal autonomy and choice and the possibility of participating in everyday activities. Participation was viewed by most of the informants as a positive and active process. Integration was viewed as being included and recognised by society for the purpose of participating in different social roles on equal terms with non-disabled people.

The main narrative close to a mantra shared by all of the Norwegian informants was a desire to live a “normal” life, to participate in “normal” activities and not to deviate from the standard notions of how people in general live their lives. This narrative was primarily described in terms of either individual participation in activities and events or in terms of a society that either hampers or facilitates social participation. Accessibility was viewed as an important narrative and as a prerequisite for both participating in and being integrated into society, but it was mentioned directly by only one-third of the informants.

Their definitions and narratives focused on the importance of social recognition in everyday interactions with others and participation in society as social citizens. From this perspective, participation was not restricted to conducting activities in general. Instead, it also included concerns about how the individuals were treated in everyday interactions and a discussion of their self-perceived rights and obligations towards society as a whole.

4.3. Participation in everyday life activities and society

In the interviews, participation was translated both into a language of activity and engagement in everyday life and into part of a narrative of living an active and meaningful life. This process included taking part in activities and hobbies independently and with friends, family, neighbours and colleagues. It also included autonomy, independent living, opportunity and the choice to conduct leisure and organised activities.

For some informants, autonomy and independence were viewed as prerequisites to boost self-esteem, but in most cases, they were described in terms of the opportunities and possibilities for participating in a range of everyday activities: *“Participation is having the possibility to participate in the activities you wish to, independent of your disability”* (David). This narrative is based on the idea of being allowed to join as well as joining in a more active sense of participation.

“The fact that I am able to help myself without help from others means that I have an extremely normal relationship with things. I set the alarm so my daughter and I can wake up in time for work and school. We get to work and school, then I have a hectic day at work, fix dinner and drive to the school band rehearsal and other activities and board meetings; busy, busy, busy, like everybody else” (Kari).

Even if mundane everyday activities such as household chores comprise the bulk of what people tended to do at home, it was a relatively peripheral topic in the interviews. Rather, the focus was on being connected to others (family, friends, neighbours and colleagues) and being socially connected as a person. This included being active and engaged in social networks, holding active roles in organisations (fishing and hunting clubs, political parties), participating in cultural activities and performing job-related activities.

Family, friends and colleagues were described as important parts of a group or community, particularly among the men. For some, *“to be with other people”* (Iver) was the essence of participation and a way to counter potential social isolation. *“For me, it is important to get out and just not sit at home watching the wall, to get out among friends and colleagues”* (Rolf).

Twenty-six of the 31 informants were employed at some point after their injury, but only one-third were employed at the time of the interview (Table 1). Although most of the informants

were no longer active in the labour market, most of them equated participation in society with participation in work and employment. According to the informants, a key element of recognition in the public sphere related to having a job or having previously made a contribution as a worker (Author, 2014). Several informants discussed this contribution in terms of seeing themselves as a resource instead of as a burden to society. In line with the words of one of the female informants, a person who was not working was seen as *“a wart on society, a pain in the ass who lives off of the state. I would like to have a job and participate”* (Fanny). Despite having a high tetraplegia lesion, she saw employment as essential for both participation in and integration into society. Similar arguments were also common among other informants: *“If you have self-respect, you need to work and earn your own money instead of getting it from Social Services”* (Rolf).

All of the women and most of the men described the importance of employment and organised work in their narratives of participation in society. *“For me, participation is to participate in organisations, work, politics, family and leisure”* (Ole). Participation is to *“socialise with other non-disabled people, for example, in an organisation or at a party, and to be social in public life”* (Anders) or *“to experience the joy of the culture that society offers”* (Niklas). In the picture that emerged from the interviews, participation was linked to what people do and to their ideals of participation: *“I participate in organisations. I am deputy chairman of fishing and hunting club. I go shopping, visit people, and go to the cinema and concerts”* (Leif).

In line with the public criticism frequently echoed in the Norwegian media, informants referred to ineffective and passive laws and regulations as being major barriers to participation in both the private and public spheres. Examples given were legal regulations that limit wheelchair access to grocery stores on Sundays (under Norwegian law, only shops of less than 100 m² can be open on Sundays), age limits for receiving public aid (i.e., training and sporting equipment), and an accessibility law that should enable all disabled people access to new buildings in theory but in reality has only a limited impact. Another example mentioned was the difficulty of obtaining permission to drive motorised vehicles in national parks. In short, the informants felt that the laws intended to protect the majority in some cases could actually limit wheelchair access.

4.4. Norms, respect and recognition in everyday interactions and participation

When asked about the definition of participation, most of the informants mentioned the importance of being recognised and accepted among non-disabled people. This perspective was summarised as a *“feeling of being part of a group that enjoys your presence and getting recognition from other people”* (Christian). The social labels attached to the informants differed between persons who knew the informant well and persons who had encountered the informant only briefly. However, this may be a “self-fulfilling prophecy” because some of the informants’ old friends had disappeared because they could not cope with disability.

“People have a negative attitude. They believe you are mentally disabled because you are sitting in a wheelchair...50% of my friends disappeared after the SCI, and I cannot understand why. I don’t feel I have changed as a person. Visitors don’t know what to talk about. I don’t wish to bother other people, so it’s difficult for me to visit because I need help to enter my car” (John).

Goffman (1963) and Lawrence-Lightfoot’s (2000) claim that status and respect are related to honour and a desire to avoid shame and embarrassment was also confirmed in the interviews.

“I feel I need to be extra kind, extra funny, extra, extra, extra in everything I can come up with personally” (Fanny). This response was consistent with those of three other women who also reflected upon their ambitions to prove that they were “super-women” and able to manage a family, work and other roles.

Several informants described how prejudices against disabled people in general led to a feeling and a fear: *“Maybe they have the attitude that people in wheelchairs don’t have much in their brain”* (Anders). A response to this uncertainty and misconception was to prove that one was normal: *“I have to prove that I am mentally capable. I have to tell people that I can manage. I participate at the same level as before the injury, but people don’t believe that I do. It has something to do with people’s attitudes”* (Julie).

The car played an important role in participation with others and in terms of mobility. It was also a symbol of autonomy, ability and normality. Christine was one of several informants who described people’s surprise that she managed to get in and out of her car.

“I have been injured for almost 30 years, and I still encounter bad attitudes among people, mainly the ones I don’t know. Nobody thinks I am working or that I can manage to get in and out of my car” (Christine).

“I am not disabled when I have the car” (Kari). “People treat me more ‘normal’ when they see me driving a car by myself. There cannot be anything wrong with him because he can drive a big American van all by himself,’ they think” (Ole).

In the case of Ole and his van, we found an additional account of how people in his personal environment took interest in advanced technology, which in turn fuelled a conversation and resulted in an impression of Ole being an expert, an advanced driver with fancy equipment. Ole also gave a vivid description of how his wheelchair was sometimes forgotten by his friends: *“When I ask my friends, ‘Is it really possible to get in there with the (electric) chair?’ the response is, ‘Oh, the chair.’ Several of my close friends no longer see the chair. This proves that I am integrated. I no longer think about it.”*

Ole is socially active and does not sense a profound lack of social recognition from his non-disabled friends. Although some friends are able to disregard the disabilities, the respondents using wheelchairs also found the opposite to be true. Ulf, for example, spoke of a class reunion where he was recognised by everybody because of his wheelchair: *“I didn’t like that everybody recognised me while I didn’t recognise them. I felt that they were superior.”*

Most of the informants were more concerned about the lack of recognition in everyday interactions. One of the informants gave a detailed description of how he gave non-disabled people a lesson when his car was blocked in public spaces designated for disabled people’s cars. In his case, his experience can ultimately be summarised as a question of autonomy and being treated with respect. He admitted that it was childish, time-consuming and provocative, but he legitimised his resistance by asking, *“Why should I be different from you? This makes them feel the mentality... Maybe learning by doing, and the punishment will teach them a lesson” (Per).*

Participation was also related to the meaning associated with being helped: *“Now, I have had enough. I am an adult now and am able to say no! If I am invited to a non-accessible place where I need help to get to the toilet, I will not participate” (Dagny). “If I need help to be lifted, I don’t bother to join any longer. I don’t like to be lifted” (Ulf).* This is an illustration of how several informants reacted to an environment that despite good intentions and offers of

help, tended to put the person in a weaker and more stigmatised position. Although social recognition is an essential component in most social types of participation in activities, it may also be a barrier and potential threat against the person's individual autonomy.

4.5. Participation in society = human rights and social recognition

The Norwegian informants' views on participation showed a strong sense of human rights and social citizenship. They described participation in society as the ability to live a normal life, to avoid negative discrimination and social stigmatisation, and to break down existing barriers to participation and integration in society as a human right: *"My big hope is to live in a society without barriers and to be accepted even if we are in wheelchairs"* (Henrik). The informants also connected participation to basic aspects of social citizenship in terms of barriers to labour market participation, accessibility and ongoing struggles with public welfare agencies.

One-fifth of the informants stressed the importance of active contributions in the struggle for normality and recognition. This response included a perspective of themselves as more than citizens with special needs: *"There is also a double responsibility. If you expect to be accepted, you have to initiate contact and break down people's attitudes by showing them that I am not dangerous even if I am sitting in a wheelchair. You need to yield. You cannot expect people to contact you"* (Anders).

"No special treatment" was a frequent comment among the informants: *"I don't like that disabled people think they should be treated differently and better because they are sitting in a wheelchair. You need to be active. You need to strive, because it is a struggle to be disabled"* (Bente). Per described the situation as being "put into a box" by disabled people. *"The disabled people put you into a box... 'Now you are one of us' attitude. Why should I be a part of the disabled people? Why can't we all be a part of society?"* This statement may be interpreted not only as representing a more "individualised model" of disability but also as a more active recognition strategy to show the world that disabled people are more than victims.

The informants rarely primarily identified themselves as disabled people in general or as people with SCI in particular. They primarily spoke about the comparisons between using a wheelchair and non-disabled people living a regular life in which they contributed to society.

Some discussed negative experiences that could be used as examples of social stigmatisation that resembled the stigmas attached to immigrants and ethnic minorities, but only two out of the 31 informants saw themselves as socially marginalised. Instead, the informants referred to immigrants and disabled people to legitimise their own normality and participation in society.

5. DISCUSSION AND CONCLUSION

Persons with SCI and spina bifida constitute an interesting study group for at least two reasons. They are functionally impaired with paralyses and they often face severe health complications related to bladder and bowel control and pain that limit their overall participation level. In sum, these complications may cause a complex set of health determinants beyond the original spinal cord injury. All of the participants except two were using a wheelchair (manual and/or electric). In this respect, they fit into the general social category of people with a visible disability. They are nonetheless also internally highly differentiated in terms of education, labour market participation and personal resources (Author, 2014).

The importance of participation in everyday activities was confirmed by this study. Social recognition and respect are important because they give people confirmation of who they are in social interactions with others. They also provide an interesting perspective through which to evaluate how we believe other people see us in different types of social participation roles. In contrast to, e.g., ICF, in which technical aid is primarily seen as a facilitator, we observed that several informants claimed that a car was a strong social symbol that enabled participants to shift the focus from their functional impairment towards a discussion of participation in society.

This study's first observation is that a meaningful discussion of social participation among persons with SCI cannot be restricted to the individual or to society; they are intertwined. The second observation is that general notions of human rights are integrated into their narratives. A third observation is that issues of morals, duties and contributions play a very important role in how persons with SCI perceive their participation in society. This perspective also fits with the Nordic perspective of integration and participation accompanied by a strong public norm of "contributing to society." In congruence with official social policy, employment is

viewed as the most important vehicle for promoting the social participation and integration of disabled people into society (NOU, 2010, p. 5; OECD, 2006).

The informants' strong beliefs about employment as a way to participate in society revealed their own experiences, but their stories also showed how they believe people in general are accepted as social citizens. Informants' scepticism about being put into the same box as welfare clients can also be interpreted in terms of a general scepticism regarding passive and unworthy welfare recipients in Norwegian society in general. Despite this attitude, we observed that the informants' primary social identities are as respected citizens, with family, friends and meaningful leisure activities in their everyday lives, and as active citizens in the public sphere.

The identification with ordinary citizens can be viewed as part of a struggle to be recognised and integrated into society and to be regarded as being on par with others. Other non-disabled people may represent a barrier to social participation because of negative attitudes, prejudice and stereotyping. The welfare state is also heavily criticised for not doing enough to enable accessibility. Nonetheless, it is difficult to view these factors as part of a common struggle against the welfare state or as solidarity with non-disabled people. To paraphrase one informant, "it is an ongoing struggle to be functionally impaired, but it is also a personal struggle", including coping with physical pain and health complications, which may be a severe barrier and constraint to social participation.

Despite active efforts to identify systematic gender and class differences in this material, we found few systematic differences in terms of how the informants viewed participation in society. Both women and men underscored that equality was an essential part of participation, but this focus was still more articulated among the women. Nevertheless, the similarities between men and women could be viewed as a reflection of strong public norms and beliefs. It is also most likely the case that the women either downplayed the importance of traditional gender roles to prove their worth as active middle-class citizens or they felt that they had to live up to the ideals of "superwomen." The pressure to always live up to an image of high achievement, a high activity level and multi-tasking was also more noticeable in the interviews with the women.

To further develop the ICF, it is not enough to have a general discussion about the human rights of disabled people. The discussion must also include a more realistic framework for

analysing social participation in terms of capabilities, resources and people's choices in specific societal contexts (c.f. Trani et al., 2011; Mitra, 2014). Although some of the findings regarding the importance of personal autonomy and independent living may be confirmed in the independent living literature (Fleischer, 2001; Barnes & Mercer, 2010) and in several societies, such as the USA. These discussions are also occurring in a Norwegian context. It is also an empirical question whether future studies will illuminate meaning systems and contexts of participation other than those described in this study.

Limitations stemming from a small and selective category of informants warrant caution in interpreting the results in a Norwegian and Nordic context of disability. The results are nonetheless important because they suggest that participation takes place in a more complex social context of social participation than is typically described in current discussions of health and disability.

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Paper II

Paper 2: Annelie Schedin-Leiulfstrud, Jan D Reinhardt, Anne Osterman, Kaisa Ruoranen and Marcel W. M. Post (2014): “The value of employment for people living with spinal cord injuries in Norway”. *Disability & Society*, 29 (8): 1177-1191.

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Paper III

Paper 3: Annelie Schedin-Leiulfstrud, Kaisa Rouranen, Anne Osterman and Jan D. Reinhardt (2016): “The meaning of employment from the perspectives of persons with spinal cord injuries in six European countries. *Work - a journal of prevention, assessment and rehabilitation*, 55 (1): 133-144.

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Paper 4: Annelie Schedin-Leiulfstrud (forthcoming): “International Classification of Functioning, Disability and Health in the context of participation” in Eide A H. Josephsson S, Vik K. and Ness N – E. (eds.). *Participation as professional concept and everyday lived experience. The role of health and welfare services*. Routledge. Accepted 11. September 2015.

Paper IV

CHAPTER 2

INTERNATIONAL CLASSIFICATION OF FUNCTIONING, DISABILITY AND HEALTH IN THE CONTEXT OF PARTICIPATION

Annelie Schedin Leiufrud

1. INTRODUCTION

Over the years, the WHO has developed a number of health classifications. The International Classification of Functioning, Disability and Health (ICF) is one of three current WHO classifications (WHO 2001).

The 1990s saw increased interest among member states and experts in the WHO system and the United Nations in the contextualisation of health and disability within a disability, human rights and social policy framework (Bickenbach et al. 1999; Cerniauskaite et al. 2011). Civil society organizations, including disability organizations and disability rights advocates, contributed to the development of the ICF in an effort to change previous medical definitions.

The main aim of this chapter is to explore possibilities and limitations inherent in the participation dimension of the ICF. The claim made is that the ICF is a model with several paradoxes with respect to how participation is presented theoretically and as a contextualizing concept. As we turn our attention to paradoxes and ambiguities in the way participation is presented in the ICF, we avoid the problem of seeing the ICF as a fixed model. It is also suggested that this may enable us to open up the discussion with respect to limitations and potential usages of the ICF framework.

The ICF is presented in seemingly neutral language (referred to as “etiologically neutral”) without an explanatory theory. This presentation reflects an attempt both to unify the languages of disability and health and to translate this language into a scientific vocabulary that unifies practitioners, researchers, policy makers and clients. The ICF fits well with Mary Douglas’s description of how socially inspired classifications are often translated into

scientific classifications: “The striving for objectivity is precisely an attempt not to allow socially inspired classifications to overwhelm the inquiry” (Douglas 1987: 59).

In contrast to previous WHO classifications, such as the International Classification of Impairments, Disabilities and Handicaps (ICIDH), which are rooted in a negative understanding of deficiency and loss, the new classification emphasizes participation, empowerment and ability. This emphasis is congruent with different versions of what is commonly referred to as “the social model of disability” in terms of the goals of breaking social barriers and giving prominence to empowerment and ability (Barrow 2008). However, the ICF is primarily framed in a context of the social integration of people with disabilities, whereas the social model is framed in a narrative of their social exclusion and social oppression. Consequently, leading advocates of the social model may have a more critical view of the societal transformation that is necessary to achieve these goals (Oliver 1990; Barnes and Mercer 2010) compared with the technocratic view found in the ICF. The idea of a seemingly neutral model of health and disability may illustrate an ideological position in its own right with respect to how we explain systematic differences in participation levels within a society. For others, it may represent the “ICF’s major strength in terms of its applicability as a universally acceptable framework” (Stücki, Reinhardt & Bickenbach 2015). Whereas some view the ICF as a paradigm shift in rehabilitation research (Reinhardt 2012), others promote its use in tandem with the International Classification of Diseases (ICD-10) (Kohler et al. 2012.)

The WHO is explicit in its policy recommendation that the ICF should be a tool to establish health policies that include all people and groups, not primarily people with a medically defined impairment. With this approach, disability is viewed not on the basis of how society shapes us as individuals but on how we as actors (individuals or groups) with various impairments and obstacles are able to participate in society (WHO 2001).

Body structures and body functions are well described in the ICF model. Activity and participation are seen as outcomes of the interaction between a person’s health condition and relevant environmental factors (WHO 2001; Schneidert et al. 2003).

One of the main arguments in this chapter is that we need to develop a more theoretical discussion of the interrelationship between the participation dimension and environmental factors in the ICF model. Unless we primarily see participation as an outcome of the

environment in which it is situated, we must develop an understanding of the agency that produces participation. This argument may be viewed as an attempt to incorporate the people/groups involved in different types of participation roles. A person is not merely determined by social factors but is able to act as a reflexive entity with agency of his or her own in activity and participation. This concept is consistent with attempts to incorporate theories and models of participation from rehabilitation, social work and community-based services, which emphasize the actor's point of view and interests (Mallinson & Hammel 2010; Magasi et al. 2015).

2. THE ICF – A MODEL BASED ON ACTORS PARTICIPATING IN ENVIRONMENTAL SYSTEMS

Every classification has implications for how we understand the main concepts and the relationships among the concepts. Each classification is also based on a language and an underlying order, which enable the determination of meaningful classifications (Franzosi 2004; Sohlberg & Sohlberg 2009). Although the ICF manual published in 2001 is important, it is only an initial version of a new model of disability that will be further developed in the years to come.

The main purpose of the ICF “is to provide a unified and standard language and framework for the description of health and health-related states” (WHO 2001: 3). The main difference between the ICF and previous health classifications (including WHO's ICIDH) is the aim to classify health and impairment in terms of “functions” and how these functions relate to activities and participation in different areas of life, including work, family, friendships and community, social activities and leisure activities (see the ICF model in Figure 1).

Body functions refers to physiological and psychological functions (WHO 2001). The body refers to all aspects of the human organism, including its structures and anatomical parts, which are classified according to relevant organ systems.

Activity is understood in the ICF model as the execution of tasks or actions performed by an individual. It is based on an idea of the person's capacity to perform various tasks (which is based on a view of activity that can be measured with clinical instruments in, for example, a hospital ward). *Participation* is understood as the performance of tasks and actions in the

environment in which people actually live and requires some type of personal involvement beyond the activity itself. In the ICF framework, participation is primarily understood as the person's involvement in their life situation. Because the technical/clinical aspect of activity is easier to measure and already exists in previous classifications, it is not surprising that this aspect is more developed in the ICF literature (Noonan et al. 2009; Dijkers 2010).

In the ICF model, *function* is viewed either as a factual description of body function, activity and participation or in terms of deviances that restrict such functions and are referred to as "disability". In this model, function and disability are seen in a dynamic interplay between health conditions and contextual factors. Health condition, depicted at the top of figure 1, is technically classified as it is in ICD-10 but is interpreted as the outcome of interrelated ICF factors, namely, body functions and the ability to perform activities and participate in the local community and in society.

Environmental factors in the ICF refer to five different areas (which are described as chapters in the ICF): 1. The products and technology in a person's immediate environment; 2. The natural environment and human-made changes to the environment; 3. Support and relationships in the person's environment or in daily activities; 4. Attitudes, including norms, beliefs and value systems in the environment; and 5. The services, systems and policies found in various sectors of society (Schneidert et al. 2003).

Facilitators or barriers (described as hindrances in the model) refer to factors that enable or disable persons in their daily lives. In certain cases and countries, the hindrances are expected to be substantial (for example, a lack of technical aids to promote mobility or the absence of public and community support for disabled people). In other instances, general welfare systems and disability-friendly policies may reduce the number of obstacles in people's daily lives (WHO 2001).

Personal factors are included in the general ICF model but are more or less excluded from the operationalization presented by the WHO in 2001. Several codes⁶, measurement instruments and attempts to capture psychological-personal factor domains have been developed to fit the ICF model (Geyh et al. 2011). However, surprisingly little has been written about how

⁶ Each code is accompanied by a *qualifier* that indicates the severity of the health problem (WHO 2001, p. 21).

personal factors explain differences in functioning, disability and health outcomes for people with identical types and levels of injuries. In a similar vein, we also detect a pattern of prioritizing instruments that measure objective aspects of activity/participation.

3. ACTORS IN PARTICIPATION AND ACTION SITUATIONS

One of the main obstacles encountered when operating with highly standardized models of behaviour is what Ellinor Ostrom (2005: 32) refers to as an “action situation”: “Whenever two or more individuals are faced with a set of potential actions that jointly produce outcomes”. In Ostrom’s model of action situations, we are asked to specify the set of participants; their status and positions; possible actions and outcomes; each individual’s degree of control, information, and control over actions and outcomes; and costs and incentives. The message of the model is that various situations may trigger a range of actions by an individual. None of these specifications are made explicit in the original version of the ICF model.

Given the design of the ICF categories, it is tempting to refer to an underlying “belief” among modern, empowered clients who are in charge of their own lives (Foucault 2002; Vabø 2003). Other roles in the context of the ICF model are the person as a social citizen with a number of basic rights and the person as a client and consumer of services. In the philosophy upon which the ICF model is based, we find an underlying idea that the obstacles preventing the integration of people with impairments must be regulated to optimize the inbuilt potential of those people (WHO 2001: chapter 1; WHO 2011).

It is almost unnecessary to refer to norms and discrimination as important in a discussion of social participation (for Stinchcombe 1997; Elster 2007; this position also reflects the ICF perspective), but the definition of successful participation in society remains unclear. Is this definition restricted to the domains operationalized in the ICF manual, or are there certain societal domains that are more important than others? If certain domains are given priority, which of them should be included? Is prioritization merely a matter of the questions posed by the observer (researcher, expert or service provider)?

An alternative to the realist approach to actors typically found in the ICF literature is a more phenomenological approach that views the actors as “constructed entities”, similar to actors in a theatre with scripted identities engaging in scripted actions (Meyer 2010: 3-4).

ICF is interesting in terms of its liberal idea that societies ultimately must eliminate hindrances/barriers and identify facilitators that promote full integration regardless of disability, race, gender, religion, etc. (see UN 2006; WHO 2011; Bickenbach 2014). The underlying idea is that discrimination is unfair and violates basic human rights. Those more concerned about social policy would also say that it is unproductive and a waste of human capital to exclude anyone with a productive potential.

Whether we see the social environment as limited, with binding rules that restrict our actions (e.g., Ostrom 2005; Henrich & Henrich 2007), or pay attention to complex meaning systems (Meyer 2010: 3-4; Berger & Luckmann 1966) depends on the research topic. For example, investigations of participation conducted in a clinical ward are not automatically relevant to how we meaningfully approach participation in people's local environments, as consumers, or in interactions with the public welfare system.

4. RECENT DEVELOPMENTS IN CLINICAL RESEARCH AND PRACTICE

If the aim is to find commonalities in individual behaviour, it may be fruitful to take a realist approach. However, if the aim is to explore meaning systems, agency and identity instead of, for example, the participation of individuals and groups, it may be more reasonable to find inspiration in a phenomenological approach (see also chapter 1 in this volume).⁷

The actor's point of view is mainly explored in qualitative interviews with patients or people with disabilities to hear their voices and their descriptions of difficulties in becoming fully integrated in society. This information may be used either as a voice counter to that of the informed experts (Hammel et al. 2008; Schedin-Leiulfstrud et al. 2014) or (more commonly) as valuable data for further development of the ICF categories and domains or appropriate measurement tools (Heinemann et al. 2010; Reinhardt & Post 2010). Although the two

⁷ It is also interesting to see how established rehabilitation models that resemble ICF have gradually shifted from activity and participation framed in a realist language towards an interest in the phenomenology of everyday life and in the actors' understanding, motivation and interest in participating in various action situations. This shift clearly occurred in the development of the 'Model of Human Occupation' introduced by Gary Kielhofner and colleagues (1985, 2008). It is also evident in models such as the Canadian Occupational Performance Model (COPM), which has an interest in patient- and client-defined primary goals for being active and participating in their everyday lives after an injury (Carswell et al. 2004; Parker & Sykes 2006).

approaches are not necessarily mutually exclusive, there is an important distinction between viewing qualitative data as valuable information in its own right and viewing these data primarily as a tool to move from the generation of analytical categories and mechanisms to the development of measurement instruments and numbers (Franzosi 2004).

Numerous ICF articles and reviews illustrate the shift towards measuring activity limitations and participation restrictions. One of the main problems in measuring how activity limitations and participation restrictions potentially affect each other may be stated as follows: ‘There is so little differentiation within and between impairments, functional limitations, activity limitations, and participation restrictions that it is...impossible to create a simple taxonomy’ (Dijkers 2010: 7). One common method of measuring participation is to assess actual role performance or the time spent in actual role performance. This parameter may be operationalized through concrete activities and daily life measures or based on psychometric models for measuring participation in major life activities. One of the obvious difficulties with most available participation instruments is that participation is essentially understood as an outcome of individual factors. Consequently, for example, the centre of interest has not been what employment contributes in terms of overall participation in the community and in society but on the impact of individual attributes on participation.⁸

The introduction of the ICF has broadened the view of participation from body and mind to the interaction between the person and the environment. This expanded view is expressed through the inclusion of a broader range of life activities and ICF domains. In some cases, this view is also supplemented with questions about barriers and facilitators and the importance of the activity, choice, satisfaction, etc. (Gray et al. 2006). Finally, the broader view of participation is also seen in a more nuanced discussion of the transactions taking place among the person, task and environment (Mallinson & Hammel 2010).

In a more traditional rehabilitation context, appropriate measurements of participation are often expressed as involvement and engagement in a life similar to that before the injury or assessed through comparisons with non-disabled peers.

⁸ One reason indicators such as employment, education, family status and participation in religious activities are used is that such factors may be explained by common latent traits and empirically correlated (Dijkers 2010: 9).

Various attempts have been made to incorporate the individual's priorities and norms into activity and participation measurements; examples include the COPM (Carswell et al. 2004; Parker & Sykes 2006) and inventories of environmental factors, such as the Craig Handicap Assessment and Reporting Technique (CHART), which measures participation on a scale ranging from 1 to 100 with the non-disabled population as a reference (Whiteneck 2010). Almost regardless of the merits of these instruments, participation is largely interpreted without considering how to study society where participation takes place.

5. FROM CLASSIFICATION TOWARDS A THEORY OF PARTICIPATION?

One of the advantages of treating the ICF primarily as a classification without an explanatory theory is that it may be incorporated and applied to a number of theoretical frameworks, ranging from various types of actor/person-based perspectives on participation that emphasize the ability to involve or distance oneself from roles and actions to ecologic and systems-based theories that focus on understanding the transactions that take place in concrete participation processes (Mallinson & Hammel 2010).

Most health professionals and ICF advocates probably agree on the importance of developing relevant "opportunity qualifiers" to understand external facilitators and barriers to activity and participation.

A major challenge in the concrete operationalization of the ICF is determining what to include in the activity dimension. If activity is limited to the optimal capacity to perform actions regardless of environment, norms and institutions, we could easily end up with a very instrumental understanding of activity. If participation is understood as performance that is guided by norms, values and the culture in which we live, it may be difficult to make a proper distinction between participation and activity. This criticism has been expressed by Gunnar Nordenfeldt (2002, 2006), who suggests that we abolish the distinction between participation and activity and replace it with the concept of action. In addition, Nordenfeldt criticizes the ICF model for not paying enough attention to the actors engaged in the actions and the actors' potential to perform actions despite bodily limitations. This argument is based on a utilitarian view of actors being able to do things rather than a view of disability as a negative outcome of

activity/participation. Despite their differences, both Nordenfeldt and his critics in the field of rehabilitation medicine (Scherer, McAnaney & Sax 2006; McPherson 2006; de Klein-de Vrankrijker 2006) agree that the concepts of activity and participation in the ICF must be further developed in terms of the actors' goals, preferences, will and opportunities. This argument is mainly based on a discussion regarding individuals and their abilities and capacities to control or live the life they want.

An alternative means of developing the ICF into a more theoretically elaborated framework is to go back to its theoretical foundation in biology and adopt a view of participation that goes beyond individual actions taking place in a social environment. This view is consistent with traditional systems theory and reflects the WHO's (2001) original presentation of the ICF model as a holistic bio-psychosocial framework for human functioning. The main question is not whether we accept the claim of a holistic model but whether we should treat each factor in the ICF model as mutually dependent or as having different functions depending on the question asked.

Theory without reference to individuals or people as actors is rare in disability studies.⁹ Few scholars have chosen to omit individual action altogether in their treatment of the ICF. One way to handle the bio-psychosocial systems is to refer to actors in terms of "whole people" taking part in multiple roles. To distinguish people from animals, it is more or less taken for granted in the ICF framework that a person has a will of his or her own and intends to perform different roles and to shape his or her life story (Solli & da Silva 2012: 283).

One major problem with the ICF view that activity and participation may be used interchangeably or the notion that the two concepts should be replaced by a single concept of action (Nordenfeldt 2003, 2006) is that we can easily lose track of the meaning of participation or how it may be understood. One alternative proposed by Solli and Da Silva (2012) is to regard participation primarily as a normative and political concept. In this view,

⁹ Inspired by Niklas Luhmann's system theory, Dimitris Michailakis's (2003) discussion of the concept of disability is an exception to individual- or person-centred models of disability. Michailakis's argument is that the distinction between individual and society, "which constitutes the basis of the well-known scheme of observed differences between impairment, disability and 'handicap', is a distinction based on a naive realism and obscures the problems within disability research" (p. 209). In line with this argument, Michailakis asserts that all categories and concepts are based on distinctions that are relative to the system or model used and to the observer's perspective. The original version of Gary Kielhofner's Model of Human Occupation (MOHO) was also heavily influenced by systems theory from the field of psychology (Kielhofner 1985).

the main norm is the ideal of full participation in all areas of life by people with disabilities. This view also resonates well with human rights and the political struggle to break down social barriers based on discrimination and the social exclusion of certain citizens to the benefit of the majority population (Alves, Fazzi & Griffo 2012; Bickenbach 2014). The problem with the notion of participation proposed by Solli and Da Silva is that it focuses mainly on a narrow understanding of the roles and rights of social citizenship; it is less concerned with community participation or participation in the labour market as consumers, e.g., the bulk of everyday participation in society.

The norms and culture that guide us in our everyday lives and actions are not restricted to human rights; rather, they include part of what we define as people's environment in any society. If we want to incorporate the actors into actions, we must do so in a way that is related to how we as humans see ourselves, how we relate to others, and how we respond to how other people and groups perceive and treat us. These elements constitute the practice of being a participating person. Taking part in activities with others, how we perceive ourselves and how we like to be perceived and socially recognized by others are essential components of participation in any type of social environment. In other words, participation is not only of interest with respect to norms but with respect to all types of social actions and interactions with other people, groups or organizations. One productive way to view this concept of participation is to consider multiple intersections between person, tasks and the environment and focus on participation as "a pattern of life that is personally relevant, acceptable, meaningful, and supported by society" (Mallinson & Hammel 2010: 30).

6. DISCUSSION AND CONCLUSION

In contrast to the many years of revision work on the ICIDH, the ICF was not initially an evidence-based model. Rather, the ICF was a model of disability and health based on a compromise among numerous interest groups, including human rights and disability advocates and experts. The WHO introduced the ICF as a brand new model of disability and health with a strong emphasis on people's abilities as opposed to their disabilities. The ICF was framed within a view of activity and participation as highly contingent and situational, not fixed. The ICF was also introduced with a view of disability as relational, depending on the interaction between the person and the environment, which resembles the view found in

Nordic disability research (Gustavsson, Tøssebro & Traustadottir 2005; Shakespeare 2006; Tøssebro 2010).

Surprisingly few entities have discussed or criticized the theoretical foundation of the ICF model. Contrary to what might be expected, the leading representatives of what has come to be known as the social model of disability have been very quiet or have simply treated the ICF as a continuation of the ICIDH. The researchers and ambassadors of the ICIDH, who lost the battle to have ICIDH established as the WHO's new gold standard, have gained ground mainly in Canada, with a revised model of disability and health resembling the ICF. Although the final Canadian model was also developed in established WHO milieus, it is seldom referenced in international journals or discussions. This lack of attention is even more remarkable because the Canadian competitor, the Disability Creation Process Model (DCP), is more developed with respect to the purposeful engagement of individuals in activity and participation (Levasseur, Desrosiers & St-Cyr 2007). The lack of attention paid to alternative models of relevance for the research questions asked, supports Meyer's idea that an international standard such as the ICF is not merely a classification but also a program that provides experts with scientifically based legitimacy (Meyer 2010). If we want to develop the ICF as a scientific tool, we cannot take it for granted; instead, we must reflect upon its strengths and deficiencies.

As Meyer (2010) suggests, the spread of standards such as the ICF model may serve many functions beyond the obvious ones related to practical applications in clinical work, the bureaucratic manipulation of health costs and priorities, and research. Such models also encourage actors to apply for research funds and bestow prestige and scientific legitimacy upon the people and organizations actively involved in their preparation.

The ICF represents a very ambitious effort by transnational organizations (such as the WHO and the UN) to force nation states and health organizations to unite the concepts of disability and human rights. If the ICF is referenced primarily in the public rhetoric but not followed by nation states, hospitals and health professionals may continue to maintain the status quo.

For the WHO, it is important to build a model based on human rights. The WHO's policy is thus to promote the societal integration of active, participating individuals and to counter discrimination based on sex, religion, ethnicity and socioeconomic status. However, most socioeconomic dimensions remain absent from the ICF framework.

The link between disability and human rights in the ICF project is a good example of how the WHO incorporates a new domain into its definition of disability. On the surface, the ICF resembles a social model of disability, given its emphasis on human rights and social inclusion. However, in reality, the ICF is not a social model but a more liberal framework, wherein the role of the individual is emphasized (Bickenbach et al. 1999; Üstun et al. 2003). In this less-politicised version of disability, it is easier for medical experts, economists, philosophers and social scientists to find common ground than it was in previous models characterized by a sharp distinction between the bio-medical and social models of disability.

Despite potentially conflicting approaches to using and understanding standards such as the ICF, the WHO may actually gain legitimacy, maintain its identity and prove its adaptability to new ideas by allowing a discrepancy between the ICF in theory and the ICF in practice (see also Erikson-Zetterquist 2009: 5). According to the WHO's view that the ICF may be used according to questions of relevance, practitioners are allowed to conduct business as usual as long as they refer to the official script and gold standards (ibid.).

For those engaged in the therapeutic process, the “client's choice, action, and experience” are of crucial importance (Kielhofner, 2008: 4). To develop the ICF as a disability and health model, we must engage in an on-going exploration of commonalities and differences across individuals' worlds of action and meaning.

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PART III

Appendices

Appendices

Appendix 1 – Information letter and consent from the informants to participate in the study

INFORMASJONSSKRIV OG SAMTYKKEERKLÆRING

Studien ”Det kreves to for å danse tango – en kvalitativ studie av integrering, aktivitet og deltakelse i lys av ICF”

Det finnes lite forskning og begrenset kunnskap om ryggmargsskaddes integrering og deltakelse i Norge og i Europa. Som et første ledd i en europeisk studie i ni land, gjennomfører vi høsten 2008 og vinteren 2009 intervjuer av ryggmargsskadd. Fokus ligger her på ulike typer av utfordringer i hverdagen knyttet til aktivitet og deltakelse. I en senere omgang, vil det med utgangspunkt i resultatene fra 2008/9-undersøkelsen, bli laget en omfattende spørreskjemaundersøkelse i landene som inngår.

Vi er i denne omgang spesielt opptatt av konkrete faktorer som bidrar til eller motvirker sosial integrering og deltakelse i hverdagen. Dette er spørsmål som er viktige å vite mer om for helsepersonell som arbeider med rehabilitering, men også for Landsforeningen for ryggmargsskadd (LARS). I tillegg vil prosjektet ha stor verdi i forhold til videreutviklingen av Verdens Helse Organisasjons (WHO) arbeid med å kartlegge og forstå ryggmargsskaddes funksjonsevne og integrering (ICF). Dette er et samarbeidsprosjekt mellom St Olavs hospital, LARS, NTNU, forskere i Nottwil i Sveits, samt den europeiske ryggmargsskadedefederasjonen.

Studien er basert på intervjuer med personer mellom 18-67 år, og som hatt sin ryggmargsskade i minimum 5 år. De norske intervjuene vil bli anonymisert og deretter analysert i lys av norske forhold. Lydbåndopptakene vil bli slettet etter at intervjuene er skrevet ut. De anonymiserte intervjuene vil bare bli gjort tilgjengelige for prosjektleder og forskere som inngår i prosjektet. Samtidig forventer vi oss at resultatene fra andre land skal kunne hjelpe oss å kunne forstå hva som er felles utfordringer, nasjonale fellestrekk eller individuelle tilpasninger. I jakten etter å finne faktorer som bidrar til eller motvirker aktivitet og deltagelse er vi mest opptatt av å forstå integreringen, og i mindre grad personlige forhold som tilhører privatlivet.

Intervjuene vil ta mellom 1 og 1,5 time. Det er frivillig å delta i studien og det finnes mulighet å trekke seg når som helst i forløpet uten å angi grunnen til dette. Det vil selvfølgelig ikke innvirke på din rehabilitering under oppholdet dersom du velge å ikke delta.

Hvis du har spørsmål kring prosjektet ta kontakt med:

Annelie S. Leiulfsrud (prosjektleder):

Tel. jobb 72575027; mobil privat 91525318

Jeg har mottatt skriftlig og muntlig informasjon og er villig til å delta i studien.

Trondheim

Datum

Navn.....

**Appendix 2 –
Interview protocol (European study) and additional questions asked in
Norway**

Bakgrunnsinformasjon i forkant av intervjuet:

Skadeår

Skadeårsak:

Trafikkskade	Annen traumatisk årsak
Sport	Ikke-traumatisk årsak
Overfall	Spinal dysfunksjon
Fall	Annen

Paraplegi/tetraplegia/spina bifida

Paraplegi

Tetraplegi

Spina bifida

Komplett/inkomplett skade

Komplett

Inkomplett

Vet ikke

Sosio-demografi:

Fødseldata

Dag, mån, år

Kjønn:

Antall år i obligatorisk utdanning:

Høyeste nivå av utdanning:

Grunnskole; Videregående skole; Lærling; Høgskole; Universitet

Familie status:

Gift; Samboer, Enke/Enkemann; Skilt; Aldri gift

Bosituasjon:

Hvor mange personer bor i ditt hushold?

Har du barn Ja Nei..... Antall barn:.....

Nåværende yrke:

Har du samme arbeidsgiver som før skaden?

Har du samme arbeidsoppgaver som før skaden?

Hvor stor prosentandel jobber/jobbet du? Før skaden?..... Etter skaden?.....

Lønnet arbeid (privat/offentlig)	Hjemmearbeidende
Selvstendig næringsdrivende	Pensjonist
Ikke betalt jobb	Arbeidsledig (helseårsak)
Student	Arbeidsledig (andre årsaker)
Sykmeldt	Under attføring
Annen	Ukjent

Yrke og type av stilling før skaden/ etter skaden? Beskrivelse av arbeidsoppgaver før og etter.

Er du i arbeid etter skaden? Hvor lang tid etter at du var skadet til du kom i arbeid/alternativt studier?

Det trengs to for å danse tango – med tilleggsspørsmål for den norske studien

INTERVJUSPØRSMÅL

Først noen spørsmål om deltakelse og integrering i samfunnet

A. Når vi snakker om deltagelse i samfunnet for en person med ryggmargsskade. Hva er din forståelse av dette?

B. Når vi snakker om at en person med ryggmargsskade er ”integrert i samfunnet”. Hva er da din forståelse av dette?

-Om informanten ikke oppfatter forskjell mellom dette spørsmålet og det første spørsmålet:

Betyr integrasjon og deltagelse i samfunnet det samme for deg?

C. Føler du at du deltar i samfunnet?

-Gjelder dette alle områder i livet ditt eller bare noen områder?

-Hvilke områder gjelder dette og hvilke områder gjelder det ikke?

-Hvorfor er det slik?

Føler du deg sosialt integrert?

Gjelder dette alle områder i ditt liv eller bare noen?

Intervjuer: Om svaret er ”bare noen” og konkrete områder ikke nevnes:

-Hvilke områder gjelder dette og hvilke områder gjelder det ikke for?

-Hvorfor er det slik, tror du?

D. Når du tenker tilbake på din tid på spinalavdelningen rett etter at du var nyskadd:

-Hva påvirket din senere deltagelse i samfunnet (positivt eller negativt)?

-Var det noen særlige faktorer som bidro til å fremme din senere deltagelse?

-Var det noe eller noen som fikk deg/motiverte deg å ikke gi opp?

-Var det noe som holdt deg tilbake?

(evt Hva med integrering- Var det noen ytterligere faktorer som påvirket integreringen?)

E. Når du tenker tilbake på tiden etter at du var nyskadd: Hva hva det som bidro positivt eller negativt til din deltagelse i samfunnet?

-Var det noen faktorer som bidro til å fremme til senere deltagelse?

- Var det noen faktorer som hindret senere deltagelse?

-Var det noe som holdt deg tilbake?

- Og hva med integrering? Var det noen ytterligere faktorer som påvirket dette?

F. Og til slutt, når du tenker på din nåværende situasjon. Hva påvirker din deltakelse i samfunnet positivt eller negativt?

- Er det noen faktorer som hjelper deg til å delta i samfunnet?
- Er det noen faktorer som hindrer deg til å delta i samfunnet?
- Er det noe du ønsker å forandre i ditt miljø for å fremme din deltakelse?
- Hva med integrering? Er det noen ytterligere faktorer some er viktige for din del?

G. I allmennhet. Kan du tenke deg ytterligere faktorer – positivt eller negativt – som påvirker ryggmargskaddes personers deltakelse?

- Og hva med integrering?
- Er det ytterligere noen viktige faktorer med hensyn til dette?

H. Hva gjør du personlig for å være delaktig i samfunnet? Har du noen spesielle strategier eller en spesiell filosofi når det gjelder din personlige integrering?

I. Kan du nevne på hvilke områder og hvordan du har utviklet disse strategiene?

J. Har disse personlige strategiene forandret seg over tid?

K. Hvilke råd vil du gi andre personer som har en ryggmargsskade for at de skal kunne øke sin deltakelse i samfunnet?

- Hva med integrering? Har du noen ytterligere ideer som berører dette?
- Hvilke råd vil du gi til dine slektninger og venner?

L. Synes du at du i dag tar mer eller mindre del i samfunnet enn du gjorde før din skade?

- Gjelder dette også i forhold til integrering?

Tileggsspørsmål i den norske studien

1. Kan du beskrive en vanlig dag fra morgen til kveld?
Hvordan ser en vanlig dag ut for deg? Hva gjør du? Hvilken hjelp får du av andre?
2. Hva liker du å holde på med på fritiden (for den som er i jobb)/ om dagene (for den som ikke jobber)?
3. Hva likte du å holde på med før du ble skadd?
4. Hvor mange venner har du som du omgås med etter skaden?
Har dette forandret seg fra du var skadet? Hvor ofte treffer du dine venner?

-Hvor ofte treffer du din slekt? Venner? Arbeidskolleger? Foreningsbekjente?
5. Hva betyr mest for deg i hverdagen?

6. Hvor fornøyd er du med din deltagelse i samfunnet? Føler du at andre setter pris på deg? Hvem og hvordan setter andre pris på deg som person?
7. Hvilke er dine største utfordringer som ryggmargsskadd?
8. Hvilke mestringsstrategier/livsfilosofi har du som kan hjelpe andre ryggmargsskadd i tilsvarende situasjon som deg?
9. Hvor fornøyd er du med hvordan du mestrer tilværelsen?
 - Hjemme?
 - På arbeid?
 - Studier
 - På fritiden?
10. Hvilken hjelp får du fra det offentlige?/
11. Hvilken hjelp får du fra familie/venner?
12. Finnes det noen miljømessige begrensninger i området der du bor som hindrer din deltagelse?
13. Hvilken er din største styrke/tilgang? Hvilken er din største begrensning?
14. Hvor viktig er det å være i jobb for deg? Kan du beskrive hvorfor?
15. I hvor stor grad tror du at din skade påvirker hvor aktiv/integrert du er i samfunnet?
16. Hvor høy grad av livskvalitet opplever du at du har? I sin helhet? Med og uten hjelpemidler/støtte fra andre?

Til slutt: kan du fortelle meg hva du syntes om intervju spørsmålene?

- I) Hva likte du spesielt med spørsmålene?
- II) Hva mislikte du?
- III) Har du noen forslag på hvordan spørsmålene kan bli bedre?
- IV) Forsto du forskjellen mellom integrasjon og deltagende?
- V) Er det noen aspekter av integrering som du mener mangler?

Takk for din deltagelse! Om du har noen ytterligere ideer eller kommentarer ta gjerne kontakt med meg.

Appendix 3 – Project approvals from Regional committees for medical and health research ethics (REK)

Region: REK midt	Saksbehandler: Marit Hovdøl Moan	Telefon: 73597504	Vår dato: 03.06.2016	Vår referanse: 2010/3461/REK midt
			Deres dato: 31.05.2016	Deres referanse:

Vår referanse må oppgis ved alle henvendelser

Annelie Leiulforsrud
St Olavs hospital

2010/3461 Det kreves to for å danse tango - en kvalitativ studie av integrering, aktivitet og deltagelse i lys av ICF

Forskningsansvarlig: NTNU Samfunnsforskning AS
Prosjektleder: Annelie Leiulforsrud

Vi viser til søknad om prosjektendring datert 31.05.2016 for ovennevnte forskningsprosjekt. Søknaden om prosjektendring er behandlet på fullmakt av REK midts sekretariat, med hjemmel i helseforskningsloven § 11 og forskrift om behandling av etikk og redelighet i forskning § 10.

Prosjektleder søker om følgende endringer:

1. Ny sluttdato (31.12.2018)
2. Tre nye analyser: a) Nye kategorier knyttet til ICF; b) Mestringsstrategier i hverdagen; c) Kjønnsforskjeller i opplevelse av deltakelse i samfunnet

Vurdering

REK midt har vurdert søknad om prosjektendring datert 31.05.2016.

1. REK midt godkjenner endring av sluttdato til 31.12.2018. Komiteen noterer imidlertid at i henhold til søknad om prosjektendring datert 22.12.2010 ble sluttdato for prosjektet satt til 31.12.2014. Av søknad om prosjektendring datert 31.05.2016 går det frem at prosjektet er aktivt frem til 06.06.2016. Vi kan ikke se å ha mottatt søknad om forlengelse av prosjektet for perioden 31.12.2014 - 06.06.2016. Komiteen minner om at forskningsprosjekter skal ha et behandlingsgrunnlag, jf helseforskningsloven (hfl) § 33. Ettersom prosjektleder ikke har søkt om forlengelse av prosjektet for perioden 31.12.2014 - 06.06.2016 har prosjektet i denne perioden manglet formelt behandlingsgrunnlag, hvilket er i strid med hfl § 33. REK-midt oppfatter imidlertid at man i denne perioden ikke har samlet inn data eller gjort analyser av datamaterialet innsamlet før 31.12.2014. Dette er formildende, og komiteen anser derfor forlengelse av prosjektperioden som forsvarlig.

2. REK midt oppfatter at av de tre nye analysene skissert bygger to av disse på forskningsspørsmål som var inkludert i det opprinnelige prosjektet, men som ikke fikk plass innenfor rammen av doktorgradsavhandlingen. Disse to analysene er derfor dekket av det opprinnelige samtykket og den opprinnelige REK godkjenningen. Den tredje analysen bygger på et forskningsspørsmål som ikke var inkludert i det opprinnelige prosjektet. Komiteen finner likevel at analysen dekkes av det opprinnelige samtykket da forskningsspørsmålet kan sies å utgå naturlig fra prosjektets overordnede tema.

Etter en samlet vurdering finner komiteen at hensynet til deltakernes velferd og integritet er tilstrekkelig ivaretatt. Komiteen godkjenner derfor søknad om prosjektendring, under forutsetning av at vilkårene nedenfor tas til følge.

Besøksadresse:
Det medisinske fakultet
Medisinsk teknisk
forskningsenter 7489
Trondheim

Telefon: 73597511
E-post: rek-midt@medisin.ntnu.no
Web: <http://helseforsking.etikk.uio.no/>

All post og e-post som inngår i saksbehandlingen, bes adressert til REK midt og ikke til enkelte personer

Kindly address all mail and e-mails to the Regional Ethics Committee, REK midt, not to individual staff

Vilkår for godkjenning

1. Godkjenningen er gitt under forutsetning av at prosjektet gjennomføres slik det er beskrevet i søknaden, protokollen og prosjektendringen datert 31.05.2016. Prosjektet må også gjennomføres i henhold til tidligere vedtak i saken og de bestemmelser som følger av helseforskningsloven (hfl.) med forskrifter.
2. Prosjektleder skal sende søknad om prosjektendring til REK midt dersom det skal gjøres vesentlige endringer i forhold til de opplysninger som er gitt i søknaden, jf. hfl. § 11.
3. Prosjektleder skal sende sluttmelding til REK midt på eget skjema senest 6 måneder etter prosjektslutt, jf. hfl. § 12. I sluttmeldingen skal resultatene presenteres på en objektiv og etterrettelig måte, som sikrer at både positive og negative funn fremgår, jf. helseforskningsloven § 12.
4. Forskningsprosjektets data skal oppbevares forsvarlig, se personopplysningsforskriften kapittel 2, og Helsedirektoratets veileder for «Personvern og informasjonssikkerhet i forskningsprosjekter innenfor helse- og omsorgssektoren». Av kontrollhensyn skal prosjektdata oppbevares i 5 år etter sluttmelding er sendt REK. Data skal derfor oppbevares til denne datoen, for deretter å slettes eller anonymiseres, jf. hfl. § 38.

Merknad

Komiteen understreker at dersom det er aktuelt med ytterligere endring/forlengelse av prosjektet forventes det at søknaden sendes inn på forhånd, jf. hfl §§ 11 og 33.

Vedtak

Regional komité for medisinsk og helsefaglig forskningsetikk Midt-Norge godkjenner søknad om prosjektendring med de vilkår som er gitt, med hjemmel i § 11 i helseforskningsloven.

Klageadgang

Du kan klage på komiteens vedtak, jf. forvaltningsloven § 28 flg. Klagen sendes til REK midt. Klagefristen er tre uker fra du mottar dette brevet. Dersom vedtaket opprettholdes av REK midt, sendes klagen videre til Den nasjonale forskningsetiske komité for medisin og helsefag for endelig vurdering.

Med vennlig hilsen

Hilde Eikemo
Sekretariatsleder
REK midt

Marit Hovdal Moan
Seniorrådgiver

Kopi til: berit.berg@samfunn.ntnu.no

Region: REK midt	Saksbehandler: Marit Hovdal Moan	Telefon: 73597504	Vår dato: 03.06.2016 Deres dato: 31.05.2016	Vår referanse: 2009/1708/REK midt Deres referanse:
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Vår referanse må oppgis ved alle henvendelser

Annelie Leiulforsrud
St Olavs hospital

2009/1708 Arbeid og integrering i samfunnet for ryggmargsskade

Forskningsansvarlig: Klinikk for fys med og rehab
Prosjektleder: Annelie Leiulforsrud

Vi viser til søknad om prosjektendring datert 31.05.2016 for ovennevnte forskningsprosjekt. Søknaden om prosjektendring er behandlet på fullmakt av REK midts sekretariat, med hjemmel i helseforskningsloven § 11 og forskrift om behandling av etikk og redelighet i forskning § 10.

Prosjektleder søker om følgende endringer i prosjektet:

1. En oppdatert medarbeiderliste.
2. Ny prosjektslutt.
3. Tre nye analyser (videreføring av tidligere analyser begrenset til Norge).

Vurdering

1. Komiteen har ingen innvendinger mot den oppdaterte medarbeiderlisten.
2. Komiteen minner om at etter søknad om prosjektendring datert 20.03.2012 ble sluttdato for prosjektet satt til 31.12.2020. Komiteen ser derfor bort fra den omsøkte endringen av sluttdato da denne er satt til 31.12.2018.
3. Komiteen finner at de omsøkte nye analysene er dekket av det reviderte informasjonsskrivet datert 20.03.2012, og har derfor ingen innvendinger til denne endringen.

Komiteen har ingen forskningsetiske innvendinger mot endringen av prosjektet. Under forutsetning av at vilkårene nedenfor tas til følge, er hensynet til deltakernes velferd og integritet fremdeles godt ivarett.

Vilkår for godkjenning

1. Godkjenningen er gitt under forutsetning av at prosjektet gjennomføres slik det er beskrevet i søknaden, protokollen og prosjektendringen datert 31.05.2016. Prosjektet må også gjennomføres i henhold til tidligere vedtak i saken og de bestemmelser som følger av helseforskningsloven (hfl.) med forskrifter.
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Med vennlig hilsen

Hilde Eikemo
Sekretariatsleder
REK midt

Marit Hovdal Moan
Seniorrådgiver

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