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# Participation in older adults – in the context of receiving home-based services

Thesis for the degree of Philosophiae Doctor

Trondheim, May 2013

Norwegian University of Science and Technology  
Faculty of Social Sciences and Technology Management  
Department of Social Work and Health Science



**NTNU – Trondheim**  
Norwegian University of  
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## **Preface**

This thesis is part of the project “Participation and agency when aging in place.” The project has focused on older adults’ participation in everyday life when living in place and receiving home-based services. The topic has been explored from different perspectives including service providers’ and older adults’ experiences of both facilitators and barriers for participation. In the thesis I have had two main foci including i) exploring how service providers understand and describe participation in older adults, and ii) how older adults understand and describe participation in everyday life and in interaction with the service providers and the service system.

I want to express my gratitude to everyone who has participated in the study; the older adults who participated in the survey and in the qualitative interviews and the professionals in home-based services, all of you willingly sharing your time and experiences in interviews or group discussions. As researchers, we depend upon your will and time to contribute, which by no means is a matter of course. Thank you for all of the valuable information!

The project was initiated and lead by Professor Arne Henning Eide and associate professor Kjersti Vik. The latter has also accomplished post-doctoral work within the same project, focusing mainly on the service providers’ professional perspective on participation among older adults. Vik and Eide have additionally been my supervisors, main supervisor and co-supervisor, respectively. I want to thank them both for giving me the opportunity to work on this project and for including me in the manifold which the research area “Participation” at Sør-Trøndelag University College represents. A special thanks to Kjersti, for your presence, inputs, support, discussions and generosity during almost four years of intense work and cooperation. I have also highly appreciated the supervision of Professor Borgunn Ytterhus, my second co-supervisor. To all three of you; thank you for responding wisely and constructively to all my applications/request. Without you, no thesis!

I am the first author of and have also written all parts of the articles included in this thesis. The supervisors are co-authors, Eide and Vik in the first and second articles, while Vik and Ytterhus are co-authors in the third and fourth articles (see list of papers for specification of the order of second and third authors).

Many persons deserve to be thanked for helpful contributions in my PhD process:  
Kyrre Svarva at the SVT faculty at NTNU, for technical aid and statistical support with the questionnaire, the employers from the municipality of Trondheim who assisted me in the process with the survey and Eva Magnus for constructive and critical comments on my work at the time of the thesis seminar.

I have also had a great time together with the other PhD students at Sør-Trøndelag University College, Faculty of Health and Social Work, including helpful discussions and social participation. A special thanks to Lisbeth! Finally, I want to thank my two sons Ola and Lars, for always being the greatest joy and much more important than any PhD work, and my family and friends for showing interest in my research. Some of you deserve a very special thanks for being supportive at the end of my project; Hanne and Trine, my parents Liv and Ole, Hege, Gry and Ruth Kristin.

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Aud Elisabeth Witsø

## **List of publications**

**I:** Witsø, A.E., Eide, A.H., & Vik, K. (2011). Professional carers' perspectives on participation for older adults living in place. *Disability and Rehabilitation*, 33: 557-68.

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**IV:** Witsø, A.E., Ytterhus, B., Vik, K. (2012). Taking home based services into everyday life – Older adults' participation with service providers in the context of receiving home based services. Submitted in *International Journal of Older People Nursing*



## Summary in Norwegian

Deltakelse for samfunnets borgere, pasientdeltakelse og deltakelse som rettighet vektlegges i politiske dokumenter, profesjonelle retningslinjer og i lovgivning. Den overordnede målsettingen for denne avhandlingen er å utforske begrepet deltakelse, erfaringer med og forutsetninger for deltakelse blant eldre folk som mottar hjemmetjenester. Dette temaet utforskes fra perspektivene til både tjenesteytere i og eldre tjenestemottakere av hjemmebaserte tjenester. Avhandlingen har til hensikt å oppdage likheter og forskjeller i deres perspektiver, samt å se nærmere på hvordan tjenesteyterne støtter tjenestemottakernes mulighet for deltakelse i hverdagslivet.

Datamaterialet består av fokusgruppediskusjoner med til sammen 30 tjenesteytere i ulike deler av hjemmebaserte tjenester, rekruttert fra en stor og en liten kommune i Norge. Videre er en spørreundersøkelse og kvalitative dybdeintervjuer blant henholdsvis 155 og 10 eldre personer som mottar hjemmetjenester gjennomført. Deltakerne i disse studiene ble rekruttert fra samme kommune.

Funn fra **studie I** viser at tjenesteyterne i hovedsak hadde et oppgaveorientert syn på eldre tjenestemottakeres deltakelse. Deltakelse ble forstått som å ta del i eget liv, inkludert å utføre små oppgaver i hverdagslivet, hjemme og ute. Å opprettholde og gjenvinne ferdigheter ble også vektlagt. Tjenesteyterne vektla sin egen rolle i eldre folks sosiale liv og for deres muligheter til å ta del i beslutninger. En felles oppfatning var også at tjenestene i seg selv bidro til at eldre tjenestemottakere ble hjelpeløse og passive. Funn fra **studie II** støtter ikke at tjenesteyterne er svært viktige i de eldre tjenestemottakernes sosiale liv. Funn fra denne studien indikerer at deltakelse foregår i kontekstene hjemme og ute, og at tjenestemottakernes tilfredshet med deltakelse har sammenheng med deres egen oppfatning av aktivitetsutførelse, helse generelt og følelsesmessig velvære. **Studie III** viser at eldre tjenestemottakere oppfatter deltakelse som en verdibasert prosess for å klare seg selv og for å opprettholde stolthet og verdighet. Å være herre i eget liv og å tilpasse seg endret funksjon og kapasitet for å opprettholde likeverd, gjensidighet, kontroll og sosiale relasjoner ble viktig. Informantene vektla familie, venner og naboer, og fellesskap og tilhørighet ble tilstrebet gjennom å delta i varierte aktiviteter og sosial deltakelse. **Studie IV** viser at tjenesteyterne ble integrert i de eldre tjenestemottakernes hverdagsliv, men at sosial deltakelse med tjenesteyterne ble opplevd som underordnet praktisk og personlig støtte til å gjennomføre hverdagslivets aktiviteter. Tjenesteyterne representerte imidlertid en tilknytning til samfunnet for øvrig og en opplevelse

av sikkerhet. Hverdagspraten var sentral i eldre folks deltakelse med hjemmetjenesten. Deltakelse ble også erfart som å balansere sin egen myndighet i møte med tjenesteyterne og som å forvente at adekvate tjenester er et felles ansvar. Forsinkelser og manglende profesjonelle ferdigheter ble oppfattet som barrierer for deltakelse.

En hovedforskjell i funnene viser at tjenesteutøverne opplever at tjenestemottakerne er og blir passive av å vente på at hjemmetjenesten skal komme, mens tjenestemottakerne opplever at de deltar aktivt i hverdagslivet. En annen hovedforskjell viser at tjenestemottakerne og tjenesteyterne vektla sosial deltakelse ulikt, men begge parter verdsatte hverdagspraten når tjenester ble utført. En tredje hovedforskjell tyder på at eldre folk erfarer deltakelse i hverdagslivet generelt som en prosess, mens tjenesteyterne har en mer oppgaveorientert forståelse av deltakelse. Tjenestemottakerne satte imidlertid pris på og forventet avgrenset og oppgaveorientert deltakelse med tjenesteutøverne. Tjenesteutøvernes forståelse av deltakelse synes å være i tråd med politiske føringer som å legge til rette for brukermedvirkning og medbestemmelse i beslutninger, mens tjenestemottakerne var mer opptatt av å være myndig aktør eller «herre i eget liv».

Denne avhandlingen bidrar med ny kunnskap om begrepet deltakelse, ved å foreslå at deltakelse for eldre folk som mottar hjemmetjenester kan forstås som praktiske, emosjonelle og intellektuelle dimensjoner, og som en verdibasert prosess for å klare seg selv og opprettholde stolthet og verdighet. Avhandlingen foreslår at for å støtte deltakelse for eldre folk som mottar hjemmetjenester, bør både politisk og praktisk tjenestenivå gjenkjenne og støtte tjenestemottakernes egne prioriteringer og strategier for å klare seg selv.



## Summary in English

The citizens' participation, patient participation and the right to participate is central in policy documents, clinical guidelines and in legislation. The overall aim of this thesis is to explore the concept of participation, the experiences with and conditions for participation among older adults who receive home-based services. The topic is studied from both service providers' and older adults' perspectives. The thesis works to discover similarities and differences between their perspectives, and how service providers contribute to support older adults' participation.

The data consists of focus group discussions with 30 professional service providers, from different parts of the organization of home based services, recruited from two different municipalities in Norway. Further, a survey of 155 older adults and qualitative interviews with 10 older adults were accomplished. The participants in these two studies were recruited from the same municipality.

Findings in **study I** show that service providers mostly had a task oriented perspective on older adults' participation. Participation was understood as taking part in life, including carrying out tasks in the contexts of inside and outside. Keeping up and regaining functions was considered an important task. Service providers emphasized their own role in the older adults' social life and as influential to older adults' opportunities to participate in decision-making. A common view was that service delivery itself contributed to helplessness and passivity in the older adults. Findings in **study II** support a distinction between participation in domestic/private and outwards activities, but did not support that service providers are critical for older adults' social life. The findings supported, however, that older adults' satisfaction with participation is associated with self-reported activity performance, overall health and emotional well-being. In **study III** the findings revealed that older adults perceived participation as a value based process of fending for themselves and keeping up dignity and pride. Being an agent and adaption in order to maintain equality, reciprocity, control and social relations became important. Family, friends and neighbors were emphasized, and community and belonging were sought through a variety of activities and social participation. **Study IV** revealed that social participation with the service providers was experienced as subordinate to practical and personal support in everyday life activities. However, the service providers represented a link to society and a sense of security. Participation was experienced

by the older adults as balancing agency and expecting joint responsibility for appropriate service delivery. Delays and lack of skills were experienced as barriers to participation.

A main difference in perspectives when comparing findings, is that service providers experienced older adults as passive recipients of services, while the older adults experienced themselves as actively participating in everyday life. A second main difference, is that service providers and the older adults emphasized social participation differently. However, both parties valued the small-talk dimension in service delivery. A third main variation, when comparing findings is that the older adults experienced participation as a value-based process in everyday life, while the service providers had a task oriented perspective on participation. The older adults did, however, appreciate and expect that services were accomplished accurately and on time, being more in line with a task-oriented perspective on participation. Another main difference in perspectives was that service providers emphasized participation as decision-making and self-determination, being in line with aspects of participation in policy documents, legislation and in the organization of welfare services. The older adults' participation, however, was more characterized by balancing agency in their everyday encounters with the service providers.

This thesis contributes with new knowledge to the concept of participation, by suggesting that older adults' participation can be understood in practical, emotional and intellectual dimensions and as a value based process of fending for themselves. Further, the thesis suggests that in order to support older adults' dignity and pride, both policy and practice of home based services must recognize and support the older adults' priorities and strategies of agency in order to fend for themselves.

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## 1. Introduction

The topic of this thesis is older adults' participation in everyday life when living in their own homes and receiving home-based services. The majority of older adults age and manage daily life without any special services, and the older population in Norway is healthier than ever (<http://www.folkehelseinstituttet.no>). However, the aging population continues to increase, and so will the number of older people aging in place with chronic conditions and the rates of older adults needing home-based services in order to live in place (WHO, 2004; St.meld. 25, 2005-2006). Thus, the attention to this demographic change and the goal of supporting and facilitating older adults' ability to live in their own homes and to participate in daily life and society as long as possible has become more prominent worldwide (WHO, 2004, 2008a). Health and social policy frameworks both internationally (WHO, 1999, 2002, 2004; EC, 2011) and nationally (St.meld. 25, 2005-2006; NOU, 2011:11; Prop.90L, 2010-2011; St.meld. 47, 2008-2009) aim at healthy and active aging, and they hold participation as one of the core goals in the health services.

The health and welfare organizations' focus on the aging population's participation in development and delivery of services is based upon some key principles. Among these are the human rights and democratic perspectives that stem from the disability movements and user organizations, insisting on the rights of all citizens to be active agents in their local matters, cultures and circumstances (St.meld. 40, 2002-2003; UN, 1991; 2002; 2007).

Early intervention is another key perspective. One goal of early intervention is to help the health and welfare organizations to focus on proactive intervention (being preemptive rather than reacting to problems after they arise). Other goals are to shift focus from illness to prevention of illness, from treatment to early tracking and outreach activities, from compensation to rehabilitation, from care to prevention and from information to motivation in order to promote better health, function and well-being among all members of the population (NOU, 2011:11; Prop.90L, 2010-2011; St.meld.

47, 2008-2009). Participation can thus be considered a tool for and an outcome of early intervention (Desrosiers, 2005; Vik, 2011).

Participation is important because it relates to the well-being of older people (Bergland & Kirkevold, 2001; Dinham, 2005; WHO, 2001; Walker, 2009), is considered an indicator of successful aging (Law, 2002) and has a positive influence on mental and physical health (Everard et al., 2000) and cognitive function (Glei et al., 2005; Rovner et al., 2009; Ronán et al., 2010). The citizens' participation also represents an expectation of the welfare state. However, participation restriction is common in older adults (Wilkie et al., 2006). Consequently, participation is claimed to be a professional objective in the practice of the health and social work professions in the sense of promoting health, encouraging patient participation, inviting user involvement and bolstering autonomy in the daily lives of the service recipients. In order to help citizens to live actively, independently and responsibly, the health and welfare organizations emphasize participation as co-determination and for influencing successful service delivery (St.meld. 25, 2005-2006; NOU, 2011,11; St.meld. 40, 2002-2003; Prop.90L, 2010-2011; St.meld. 47, 2008-2009).

Despite political and professional emphasis on the necessity of participation by older adults, there is little knowledge of how older adults themselves experience and how service providers support their participation in the context of receiving home-based services. Furthermore, beyond being central in policy documents, clinical guidelines and legislation, there is no consensus thus far on how to understand participation conceptually or theoretically. Health concepts and frameworks are continually expanding, but consensus and clarity on how to work with participation as a central principle in professional practice and service delivery is lacking. Although participation is an increasingly prominent concept, current services are often designed to cure and prevent diseases rather than to promote recipients' participation and activity (NOU; 2011, 11). The interface between service providers and recipients may present opportunities and tools for participation. Consequently, the understanding of participation in service delivery must be studied extensively. In response to this need, the present thesis will explore and discuss the concept of, the experiences with and

conditions for participation among older adults who receive home-based services, a group of people at risk of participation restrictions. Their views are essential to any workable public policy and professional practice that relates to older peoples' lives.

### *Research objectives*

<sup>1</sup>This thesis is an exploratory study of the concept of participation with primary aims to enhance knowledge of how service providers and older adults experience and perceive older adults' participation in everyday life as well as to discover which factors contribute to participation in older adults, and especially professional service providers' contributions to this participation. This is anticipated to be key knowledge for pursuing participation as a central ingredient in home-based services. The thesis will study the concept of participation from both service providers' and older adults' perspectives. Empirical studies of both older adults' and service providers' experiences with participation may reveal possible variations between their perspectives on the topic. Therefore, this thesis works to discover and discuss the similarities and differences between the service providers and the older adults' experiences and understanding of participation in older adults. Based upon and in comparison with previous empirical studies, this thesis also aims to contribute to substantial theory on the concept of participation in older adults.

The specific research questions are:

- i) How do professional service providers understand and describe older adults' participation in everyday life in cases where the latter are living in place and receiving home-based services?
- ii) What factors influence older adults' satisfaction with participation?

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<sup>1</sup> The thesis is part of the project titled "Participation and agency when aging in place." The overall aim of the project is *to enhance knowledge of how older adults who receive long-term, home-based services participate in daily life and how service providers work to support their participation.*

- iii) How do older adults understand and experience participation in everyday life?
- iv) How do older adults understand and experience participation in the context of receiving home-based services in particular?

### *Thesis outline*

The thesis is organized into seven chapters. The introduction chapter clarifies the topic of the thesis and establishes the starting point and context of this study. Chapter II then presents the background, including the perspectives, policy and frameworks that form the foundation and backdrop behind the current understanding and future possibilities of participation at an individual level. This chapter also includes perspectives on aging and disability, the concept of aging in place and the active aging framework. Finally, this chapter provides a short presentation of previous studies that have examined home-based services for older adults and describes the study context including organization of home-based services in Norway.

In Chapter III, the concept of participation is presented in relation to older adults and research on participation in older adults, followed by three sub-sections. The first explores participation in relation to service delivery. Next, participation in relation to the ICF is presented, followed by a sub-section on the experience perspective in relation to participation. Together with the equal rights perspective (which can be found in the background section), the experience perspective of participation in everyday life and in service delivery make the basis for using the concept of participation in this thesis.

The methodological approach – including the design, epistemological positioning, methods, research process, ethical issues and methodological considerations – is presented in Chapter IV.

Chapter V presents the findings. In relation to the everyday life participation of older adults receiving home-based services, the four articles that are based upon the empirical



data from the study illuminate the following topics: i) service providers' perspectives on older adults' participation when living in place and receiving home-based services, ii) satisfaction with participation in daily life activities in older adults receiving home-based services, iii) experiences of participation in everyday life in older adults' living in place and receiving home-based services and iv) older adults' experiences of participation in home-based service delivery.

The articles numbered 1-4 follow Chapter V.

Chapter VI discusses the findings in relation to the process of participation in everyday life, experiences of participation in service delivery and participation as an equal right for members of society. Based on the discussion and comparison of primary findings across studies I-IV (in Chapter IV) the findings will be further raised to a substantial conceptual level in the "Findings in relation to the concept of participation" in this chapter. Hence, both Chapters V and VI make the substantial theoretical contribution in this thesis. Reflections about practical implications are presented in Chapter VII, followed by the references and appendixes.

## **2. Background**

### **Central concepts**

Although this thesis focuses on the perspectives of older adults and service providers on participation in everyday life, it is essential to be aware of the social, political and organizational aspects that influence the possibilities for participation at an individual level. This chapter will therefore describe some of the central international and national perspectives related to aging in general and organizational aspects related to home-based services, in order to present a backdrop of the social context in which the subjects of this study participate on a daily basis.

### *Perspectives on aging*

The terms used to describe older people vary in the literature and in policy documents. In a European survey, older respondents found the terms “the old,” “elderly” and “aged” unacceptable, whereas they preferred the terms “older” and “senior” (Walker, 1993). According to Falconer and O’Neill (2007), the first three terms often invoke a pejorative and reductionist terminology that helps to obscure the positive aspects of aging and the great variability between individuals. The Human Rights Commission of the United Nations has clearly outlined that the descriptor “older” should be used (UN, 1995). The numerous positive aspects of aging, such as experience, wisdom, enhanced creativity, maturity and strategic skills are often overlooked in an ageist society. However, the term “elderly” is often conflated with frailty, which certainly does not apply to all older people (Falconer & O’Neill, 2007). Furthermore, frailty in older adults is not necessarily a constant phenomenon. In this thesis, the terms “older people” or “older adults” will be applied in the text.

The term “aging” refers to a process that can be viewed from different perspectives. The most common view is perhaps the one covered by biological aging, which looks at the physical changes within the body throughout the lifespan. The biomedical model has also been dominant in gerontology. The biomedical model is reductionist in the sense that it focuses almost entirely on the physical body. Practitioners using the biomedical model prefer biophysical answers, and the model has contributed extensively to the contemporary fragmented view of the body (Longino & Powell, 2009; Råheim, 2001). The biomedical perspective is claimed to have a dominant force in Western culture by representing a “savior” of biological aging via the biotechnological advancements that reconstruct the body to prevent, halt or hide the aging process (Powell & Wahidin, 2007).

There is growing agreement that there is no single fundamental cause of healthy and active aging. Multiple factors work together to facilitate optimal functioning and participation in later life. My own understanding of aging and functioning coincides with such a perspective. Accordingly, older adults should be viewed as individuals and when in need of services these should be adjusted to their individual needs for

participation. Many of the factors limiting the engagement and participation of older people in society are linked to age-related discrimination and ageism. Ageist assumptions and attitudes can often be unconscious and may limit older adults' opportunities to participate in society (Shannon, 2012). The picture of older people seems to waver between a depressing view of "the elderly" who are plagued by disease, loneliness and neediness and an optimistic view of seniors who are active and resourceful (Gjertsen, 2008). Stereotyped perspectives on older adults' needs and participation should be discovered and met with counterarguments. By exploring service providers' and older adults' experiences of older adults' participation in everyday life and when receiving services, the ambition of this thesis is to contribute to widen the picture and show the heterogeneity and complexity surrounding older adults receiving home-based services.

#### *Perspectives on aging and disability*

One may draw parallels between the changing perspectives of aging and the changing perspectives of disability that emerged throughout the past century. The medical model represented the dominant understanding of disability until the 1970s. This model considered disability to be a problem related to the individual, and strongly emphasizing diagnosis and individual characteristics. In comparison, aging has traditionally been strongly related to processes of functional decline and to the representation of frailty, poor health and neediness in the individual.

The disability rights movements' and organizations' fight against discrimination throughout the 1970s and '80s was a prominent reason for the emergence of the social model of disability. The social model believed that physical and social barriers within the organization of social structures, not individual characteristics, determined disability (Oliver, 1991; Tøssebro, 2010; WHO, 2001). This model has later been criticized for having a one-sided focus on the discriminating structures in society at the expense of an alternate understanding of disability (Shakespeare & Watson, 2002; Söder, 2000). My own understanding of disability resembles the relational model most closely, which centers on the relationship and interplay between the individual and the environment.

This understanding represents a shift from focusing on individual factors to focusing on cultural, social and environmental barriers to participation. This model characterizes the contemporary understanding of disability among Nordic social scientists, and several public service documents in Norway have lauded this model (NOU, 2001:22; St.meld. 40, 2002-2003; NOU, 2005:8). However, researchers have also criticized this model's understanding of disability concentrating largely on conditions that are mostly related to the individual level (Knøsen & Krokan, 2003).

A clarification following the Norwegian Official Report nr.22 (2001) included a change in the terms used in relation to disability in Norway, because the phenomenon itself is considered too complex to fall under one term. It was considered necessary to differentiate the individual aspects and the environmental aspects in order to avoid the monopoly of individual thinking. Thus, it was suggested to use the term impairment when discussing individual aspects of disability. The term disability is thus reserved for relational aspects (Tøssebro, 2010). The perspective of a relational understanding of disability implies that people with impairments can be disabled in some situations and not in others. Therefore, such a view may not regard a given person as disabled, but it may recognize the ways in which society is disabling certain members. In this perspective, it is, for instance highly relevant to study and discuss the role of home-based services as an environmental factor in relation to older adults receiving home-based services.

A lack of consistency in my use of terms appears some places in the articles. However, I have tried to use the terminology as presented above. While reviewing the articles, I have also used the terms "functional decline" and "changing capacity," which relate to the individual aspects of disability in older adults. I have also used the term "barriers to participation" to characterize the disabling factors in society.

The changes in understanding of disability have influenced the development of The International Classification of Functioning, Disability and Health (ICF) (WHO, 2001), which has replaced the previous International Classification of Impairments, Disability and Handicap (ICIDH) (WHO, 1980). The ICF is primarily a classification of health, functioning and disability, but also represents an important milestone in the conceptual

development of disability, as a multidimensional perspective of disability wherein the term disability represents a characterization of a process that includes limitations and restrictions related to the body, activity and participation. ICF replaced the ICIDH's term "handicap" with the term "participation." Another important development is the inclusion of environmental factors, and the reciprocal relationship between environment, functioning and disability. Thus, ICF attempts to include disabling processes in an integrated, multidimensional perspective (WHO, 2001; Tøssebro, 2010). With the ICF, WHO has attempted to adopt a bio-psychosocial model (Imrie, 2004), incorporating and accommodating what is useful from both the medical and the social models of disability (WHO, 2001).

The ICF model represents a frame of reference for all articles included in this thesis, especially participation in every-day life, home-based services and environmental factors in the older adults' lives. The definition of participation within the ICF model will be further presented in Chapter III under the section "Participation in relation to the ICF."

An overall political consensus in Norway is that people with impairments should have full rights to inclusion and participation in society on an equal basis with others (St.meld. 40, 2002-2003; NOU, 2010:5). Norway is expected to ratify the Convention on the Rights of Persons with Disabilities in order to promote, protect and ensure the full and equal enjoyment of all human rights and fundamental freedoms by all persons with disabilities and to promote respect for their inherent dignity. The right to participate in political, public and cultural life, recreation, leisure and sport, equal rights and accessibility are among the convention's central principles (UN, 2006).

Accordingly, Norway's policy concerning people with impairments has shifted from a care and welfare perspective to a human rights perspective, including stronger emphasis on public adaption, societal participation and legal rights. This emphasis is considered to be of great importance for the individual as well as for society (Ot.prop. 44, 2007-2008). However, on an international level, older people are considered to represent a human rights challenge, and a need for a convention on older people's rights is supported by the UN (UN, 2012) Applying the rights-based approach to the

implementation of change in ageing policy, similar to that taken in the disability sector, could contribute to the removal of exclusionary barriers for participation, whether they are physical, financial, social or psychological, by the introduction of laws and policies (Shannon, 2012).

In Norwegian health and social policy documents, legislation and services, the term “care” is widely used in relation to older adults (St.meld. 25, 2005-2006; Shdir, 2004; St.meld. 28, 1999-2000). In St.meld. 25 (2005-2006), which also is termed “The Care Plan,” care services were chosen as a collective term for home-based services, home nursing, support persons, day activities, relief/assistance, care housing, homes for older people and nursing homes. The term “care” also appears in public statistics and municipal account directions (NOU, 2011:11). Care can be understood as a natural part of interpersonal relations and as a basic need of all human beings. Although the term “care” has several dimensions, its use in relation to public services and policy may have problematic connotations. First, it underlines the imbalance in the power relationship between service providers and service users, including in this also the balance of power. Furthermore, clients may interpret this term as an invitation to take a passive and recipient role in encounters with the service system (NOU, 2011:11). Studies have indeed found that practitioners tend to provide home-based services as passive help to older adults (Vik & Eide, 2011a; Vik & Eide, 2011b; Vik, 2011) and that the clients may interpret their encounters with staff and the service system as barriers to control and self-determination in everyday life (Ellefsen, 2001; Vik et al., 2007; Haak et al., 2007; Johannesen, Petersen, & Avlund, 2004; McGarry, 2009; Lyttle, 2008).

In my research, I have decided to undertake the participation perspective in order to explore the conditions for participation in older adults receiving home-based services. I have avoided the term “care,” using terms such as “home-based services” instead of “home care services” and “health services” instead of “health care services,” due to my increasing attention to the content of the term. As this has been a process during the work with this research, I have however, not managed to be consistent with this terminology in all of the articles.

### *Aging in place*

Place is primarily understood as the older adults' homes but may also include their neighborhood or any surroundings that are meaningful to them. The concept of aging in place represents a combination of ideology, social policy, demographics, economics and the preference of the majority of older adults to remain in their homes and communities as long as possible (NOU, 2010:5; Vasunilashorn et al., 2012; Janes, 2008). The Nordic countries have undergone a deinstitutionalization of long-term care over the past 30 years, including a process of reforming health and social policy and services within a variety of sectors. Being able to live at home as long as possible is a political goal. It is also regarded as a right (St.meld. 45, 2002-2003; St.meld. 25, 2005-2006; SHdir, 2004).

The literature on aging in place has changed over time. The early seminal work of Lawton and Nahemow (Lawton, 1973) examined dynamic interactions between housing environments and the physical capabilities of older persons. They recognized the need for a variety of living environments that could address a range of functioning from independence to dependence upon institutional care. During the past 30 years, the concept of aging in place has evolved to emphasize services and technology.

Furthermore, aging in place-relevant areas and trends in the research during the past ten years have included homes and neighborhood characteristics (Michael, Green & Farquhar, 2006; Gardner, 2011) and communities (Gitlin, 2003; Oswald et al., 2007). Other studies have focused on home modifications (Johansson, Borell & Lilja, 2009), community and social services (Marek & Rantz, 2000; Mitty, 2004; Vik, 2011; Vik & Eide, 2011a+b), assistive devices/technology (Mahmood et al., 2008; Brittain et al., 2010) and health and functioning (Marek et al., 2005; Shank & Cutchin, 2011). Another focus of research has been on social capital (Tang & Lee, 2011; Bookman, 2008) and on the relationships between formal and informal care and to what extent they complement each other for older homecare recipients (Dale et al., 2008, Daatland & Lowenstein, 2005). In short, all of the aforementioned areas influence the capability of older adults to age in place (Vasunilashorn et al., 2012). Research on aging in place related to the context of home-based services and service delivery will be presented in later sections of this chapter.

Aging in place has also been explored through different theoretical lenses. Rowles (1983; 2000) took a phenomenological perspective on the topic, and then Rowles and Ravdal (2002) investigated the aspects of people's connections to place that have been taken for granted, such as "sense of place," "place attachment," "place identity" and "habituation in place." Place has also been examined from the transactional perspective (Cutchin, 2007; Cutchin, Owen & Chang, 2003; Shank & Cutchin, 2011), and this thesis follows that line of thought. The transactional perspective builds on Dewey's Pragmatist philosophy and was proposed as a way to move from an individualized towards a more contextualized view. This perspective views person and place transactionally (as a part of the other) as opposed to a dualistic perspective (Dickie, Cutchin & Humphrey, 2006). According to Rowles (1983), places are part of the significant physical, social and personal world in which we construct our lives. Thus, the home becomes the dynamic center of the life world (Rowles, 1987), and the psychosocial link between person and the home (place) comprises a primary source of meaning (Rubinstein, 1989). This meaning depends upon many factors, reflecting the complexity of relationships between place and person, past and present as well as experiences and objects, all of which change over time. In a transactional perspective meaning is constantly negotiated or re-created due to the continual re-coordination of place and person (Shank & Cutchin, 2011).

Although aging in place is mostly cast in positive terms, it also represents challenges on both micro and macro levels. The economic incitement for a policy of aging in place are obvious, as aging in place represents decreased costs compared to institutional care. However, living in place becomes challenging when availability and organization of services and criteria for eligibility mismatch the needs of older adults. Aging in place may also be susceptible to problems such as caregiver burden, hidden abuse, isolation and loneliness (Mallet, 2004). Physical barriers for participation and housing conditions may also place strain on older adults who wish to age in place (Cumming et al., 2001; Johansson, 2008).

Home-based services, which are a primary environmental factor in this thesis, intervene with older adults' lives in the context of place. One could assume that such services



have a potential for supporting and facilitating participation in older adults' everyday life. However, there is also a risk that home-based services may intrude upon older adults' preferences and values relating to participation in place, and they may thus represent a barrier (Vik & Eide, 2011a+b; Vik, 2011; McGarry, 2009). In order to avoid conflicting understanding and counterproductive efforts, it is therefore of great importance to understand the perspectives on participation of both service providers and older adults, and how they experience services that support older adults' participation.

#### *Active aging – international and national perspectives*

The term “active aging” has partly emerged from and overlaps the concepts of “productive aging” and “successful aging” (Walker, 2006, 2002). The productive aging concept is grounded on a life course perspective that presumes communities, workplaces and older people themselves will benefit immensely whenever older people are active beyond the usual retirement age. The emergence of this concept coincided with policymakers' growing concern for the implications of an aging population on the expenditures of pensions. The productivity perspective, including a strong focus on the delay of retirement age, is emphasized by the Organization for Economic Cooperation and Development (OECD) (Walker, 2008).

Successful aging is largely associated with the conceptual model developed by Rowe and Kahn and is believed to depend upon carrying over the activity patterns and values typically associated with middle age into old age (Bowling, 2007). While the productive aging concept has been criticized for being too narrow, the successful aging concept has been criticized for being too idealistic and discriminating. Both concepts have been criticized for homogenizing older people, generalizing about the aging process and providing limited account for confounds such as disability, illness, frailty, obesity, drug or alcohol addiction and a lifetime of inactivity (Hutchison, Morrison & Mikhailovich, 2006).

The World Health Organization adopted the concept of active aging in the late 1990s to advance a broader approach to aging. According to WHO, active aging is “the process

of optimizing opportunities for health, participation and security in order to enhance quality of life as people age” (WHO, 2002, p. 12). WHO bases this concept on the United Nations’ principles of independence, participation, dignity, care and self-fulfillment, implying a human rights approach to aging. Equality of opportunity and treatment in all aspects of life as people grow older is one of WHO’s key goals. Active aging includes focusing on life-long learning, working longer, retiring later and more gradually, being active after retirement and engaging in capacity-enhancing and health-sustaining activities. Interdependence and intergenerational solidarity are important tenets of active aging (WHO, 1999; 2002; EC, 2007). It is stated that by staying active and participating, individuals can improve their quality of life by being engaged in life as fully as possible at all life stages. This requires individuals to be physically active, cognitively and socially engaged, occupationally or vocationally involved and emotionally and spiritually healthy (Bowling, 2007; WHO, 2002). The WHO model for active aging refers to determinants of active ageing, whether economic, social, physical, behavioural or personal in nature. However, several studies have found that expectations around active aging are typically defined by policy makers and service planners and that these expectations may diverge from the modes of older people themselves (Stenner et al., 2011; Clarke & Warren, 2007). A few studies have explored ordinary older peoples’ meanings of active aging (Clarke & Warren, 2007; Bowling, 2008; Stenner et al., 2011). These studies have all found that active aging is complex and understood by older people beyond determinants such as physical functioning and structural factors, and may thus according to Stenner et al. (2011) serve as correctives to a deterministic presupposition that dominate the field. However, little is known about how frail older adults experience participation in everyday life and how their experiences coincide with the aims of the active aging framework.

Policy makers and stakeholders all over Europe are encouraged to set personal goals for active aging and to take action. During the last decade, the health policy in Norway has aspired to include all groups of people in a general service model. The country’s health policy has a strong focus on efficiency, quality of services and strengthening patients’ rights (Helgøy, 2005). The ideal of equal treatment of all patient groups is central, which means that Norway does not provide special services reserved for older adults

except for people with dementia (Helse- og omsorgsdepartementet, Demensplan, 2015). The active aging concept does not exist as a publicly expressed goal in Norwegian health care policy, but the concept does seem implicit in the health care reforms of recent years. A strong focus has been on the redirection of housing policy for older people and a trend towards living at home as long as possible while receiving individually adapted services.

In the White Paper 25 (2005-2006), “active aging” is replaced with the term “active care” and there is a strong focus on social and cultural activities, community participation and user-participation or involvement in the meaning of having options and influence on services. However, the Official Norwegian Report nr. 11 (2011) has identified the active aging framework, which obviously is a much broader concept than “active care” and “user-involvement,” as central to the development and innovation of future services related to care. The report argues that the term “care” relates more to health than it does to social aspects and that it invokes paternalism. In order to encourage older adults to expect to take more control over their own health, it is argued that practitioners need to include multiple terms to cover the rights and the variety of needs in older people, because care is just one of them. Other relevant terms are practical support, assistance, service, treatment or even more precisely, descriptions of the actual action required. In the instructions of “Quality in nursing and care,” (SHDir, 2004) aspects such as independence, self-care and social needs, like community and activity are emphasized. However, these instructions relate to younger people with impairments and rely upon the ideology behind the personal assistance tradition.

Aspects of enabling and facilitating participation and active aging in older adults are also covered by the proposal to the Storting (Prop.90L, 2010-2011), which supports active participation at both individual and organizational levels to promote good health and to prevent disease and poor health. Furthermore, the Official Norwegian Report nr. 5 (2010) focuses on the development of a system for technical aid and security for accessibility and adaption of technical aid to promote active participation, equality and inclusion in work, education and in daily life for people with impairments. Finally, the Official Norwegian Report nr.11 (2011) gives considerable attention to the area of

technology support. Rapid technological change and developments within the welfare service area are expected to improve the possibilities for participation in older adults in the future. The area of technology support is important, but will not be given further attention in this thesis.

The active aging approach seeks to shift strategic planning away from a 'needs-based' approach to a 'rights-based' approach, as this approach moves away from the assumption that older adults are passive targets. Therefore, this approach supports the goal of prolonging the number of healthy years in peoples' lives and prolonging older peoples' responsibility to continue exercising participation in both political and community life. In order to participate in society, older adults are expected to actively participate in their own care, such as attending to their health. At the same time, health services are becoming increasingly patient-centered and individualized (EC, 2007; St.meld. 25, 2005-2006; see also the sub-section "Organization of home based services"). Accordingly, the aspects of human rights, societal costs, technology developments, individual needs and responsibility perspectives coexist in public policy, documents and guidelines. These aspects may represent a clash of interests that would call for awareness of the usefulness and consequences of a given concept. However, one may argue that the possible clash of interests depends upon the degree of reflection on and communication between the perspectives (Hvinden & Johansen, 2007). It is necessary to ask questions about what participation means for those who are involved, because participation is more than an attempt to reduce economic costs.

Critical perspectives in gerontology suggest that the roles society encourages older adults to fulfill are merely socially constructed and thus shaped by cultural norms and values as well as by political and economic reasons (Rožanova, 2010). WHO's active aging concept takes on a broader approach than the concepts of productive and successful aging. However, governments may simplify the concept and favor active aging as a rationale for reducing spending and for individualizing the responsibility for retaining independence in later life. Frailer and vulnerable older people may be at risk of losing quality lives under this rationale. Consequently, a model of an active aging approach should embrace both frail and fit older people (Walker, 2002, 2008). This

thesis is interested in discovering what participation means to frail older adults receiving home-based services, factors influencing their satisfaction with participation, and in which contexts and how their participation is influenced by the service delivery. The insight gained into their viewpoints will serve as an empirical base to provide knowledge and future policy on helping frail older people to participate and age actively and overcoming barriers to participation in their everyday life.

### **Organization of home-based services**

In this sub-section a short presentation of the study context will be presented.

In Norway, 4.5% of the population were 80 years of age or older, and 15% of the population were 65 years of age or older in 2011 ([www.Folkehelseinstituttet.no](http://www.Folkehelseinstituttet.no), 2012). About 108,300 people aged 67 and over were receiving home-based services while approximately 40,000 people lived in nursing homes. When taking age into consideration, there was an increase of 5 % from 2009-2011 in the number of recipients of home-based services below 67 years of age, a small decrease in recipients from 67 to 89 years of age and an increase of 13% among those older than 90 years ([www.StatisticsNorway.no](http://www.StatisticsNorway.no), 2011). The number of adults aged 67 and older is projected to double by 2050, and the number of people aged 80 and older is estimated to increase from approximately 220,000 in 2007 to approximately 500,000 in 2050 (St.meld. 25, 2005-2006). It is assumed that larger numbers of older adults will be in need of home-based services in the future due to their larger overall numbers.

Home-based services aim at providing appropriate and high-quality services in order to meet people's health and social needs. These services are understood, practiced and funded differently across European nations (WHO, 2008), because the policy challenges vary within each country according to the contingencies of history and context. Formal, home-based services are not fully developed in several southern European countries, whereas the Nordic countries have comparatively less developed voluntary sectors.

In the Nordic countries, municipal authorities are responsible for the home-based services. Home-based services are statutory in Norway (Helse og

omsorgsdepartementet/Ministry of Health and Social Affairs, LOV-2011-06-24-30) and are comprised of a variety of services, such as home nursing, help with personal hygiene, practical help in daily activities (cleaning, laundry, snow-shoveling), preparing meals and running errands, home help, aid call alarm (security alarm), and meals on wheels. The local health and welfare organization assesses and approves individuals' eligibility for home-based services. The Individual Based Care Register (IPLOS) was established in 2006 and provides a national mandatory system for mapping, registering, planning and reporting health and social services in the municipalities (Helsedirektoratet/Norwegian Health Directorate, 2009).

All documented needs for home-based services in Norway are registered in the IPLOS register (St.meld. 25, 2005-2006). At the individual level, the register is the basis for allocation of services. At the municipal level, the executive officers/case officers approve of the extent of services. The services are described by a set of 17 variables concerning assistance needs. The requirements are described in a standardized manner and include those who apply for or are receiving services from the municipalities. The variables measure different aspects of the clients' needs, such as practical assistance with everyday living, home nursing and long-term stays in nursing homes. Each of the "needs of assistance" variables are registered in scores from 1-5 or 9 if the information is considered irrelevant (Helsedirektoratet/Norwegian Health Directorate, 2009). For the purpose of national statistics, IPLOS includes a special measure to simplify one's level of need into one of three categories: "some/limited," "average to great" and "extensive." For further description of IPLOS scores, see the methods section of article II.

### **Research on home-based services**

In the Nordic countries, a body of research has focused on organizational trends and implications for work environments (e.g., Trydegård, 2005) and for service delivery from the perspective of professionals (Szebehely, 2005, 2007). Several studies have discussed the welfare state model, organizational change and trends in the welfare sector, such as NPM (New Public Management), that impose top down regulation, standardization, and purchaser-provider models of service assignment and delivery, and the implications for service delivery and care (e.g. Dale, 2008; Vabø, 2009, 2011abc,

2012; Szebehely, 2003; Vabø & Szebehely, 2012). Vabø (2007) found for example that the purchaser-provider model strengthened organizations' administrative level, and revealed that professionals noted that service delivery was divided into strictly time-limited tasks, making it difficult to respect the varying and changing needs among older service recipients. A confrontation between those who supported a strictly defined approval of services and the service providers themselves, who felt unable to meet the needs of the individuals within the limitations, appeared (Vabø, 2007). Other studies in the context of home-based services have focused on unmet social needs and loneliness among older adults (Wreder, 2008; Dale, 2010). A perception among service providers that older adults are lonely, yielding a wish among them to reduce this loneliness, is found in several studies (Vik & Eide, 2011b; Wreder, 2008; Dale et al., 2010).

Across a Nordic research context, there seems to be an agreement on prerequisites for well-functioning home-based services. Researchers hold that three conditions are necessary for service providers to meet the varying needs of different recipients of services: continuity, time and flexibility. However, researchers have found that recent organizational changes and trends have been threatening these conditions for good service delivery (Eliasson-Lappalainen et al., 2005; Vabø, 2008). Home-based services in Norway have been criticized for increasingly emphasizing a medical orientation and for giving priority to medical treatment, medical follow-up and caring at the cost of services related to social participation and activity (NOU, 2011:11; Brevik, 2010). Interestingly, recent statistics based on the IPLOS register have presented a decrease in coverage for home-based services in all groups of older adults and an increase in coverage for people from birth to 66 years of age. Previously, researchers explained these changes by citing the better overall health of the population and the older population's decreasing need for services (Abrahamsen, 2006; Otnes, 2007). However, new literature and IPLOS statistics point to the need for broader causal connections (Brevik, 2010; Strand, 2012). It is argued that changes in one's health cannot be isolated from the effects of a variety of other factors, such as changes in municipal priorities, restructuring of services, national health reforms and the economy of older people. Brevik (2010) questions whether Norwegian health care is leaving the preventive strategy with early intervention and is turning toward the people with the greatest needs.

To summarize the backdrop of contemporary home-based services in Norway, the population of older adults is increasing and a growing number of older people will age in their own homes. The home, or place, represents a key context for active aging, and participation is central within this concept. However, the content and meaning of aging in place and active aging might change with generational shifts. Thus, policies and understanding of active aging in the context of place will probably also dominate the future politics of services for older adults. As shown, a number of studies on home-based service have been conducted, but few have focused on participation. Given the expansion of services for the growing number of older people, and the medically orientation of services, older people are provided a narrow spectrum of services, yielding limited flexibility and services directed at health needs as opposed to needs for living an active life and participating in society. Thus, researchers must develop their understanding of participation and its relationship to service delivery so that policy, organization and development of services can appropriately reflect older adults' needs to participate in everyday life and in society.

### **3. The concept of participation**

There are three primary areas of research on the concept of participation: i) participation among different stakeholders, ii) participation in service delivery and iii) participation within the ICF framework.

The concept of participation is widely discussed, and research studies define participation in a variety of ways. Thus, a consistent terminology of the concept does not yet exist.

In the literature, numerous studies have compounded a variety of terms with participation to elucidate what they mean exactly by participation. Examples of compositions are social participation (Bukov, Maas & Lampert, 2002; Noreau et al., 2004), social involvement (Larsson Lund et al., 2005), community participation (Keysor et al., 2006), participation in occupations or occupational participation (Hemmingsson



& Jonsson, 2005; Desrosiers, 2005; Vik et al., 2008; Law, 2002), participation in society (Cardol et al., 2002b), societal participation (Cardol et al., 2002a) participation in physical activities (Trost et al., 2002) and participation in leisure activities (Paillard-Borg et al., 2009). Other relevant terms are user participation or user involvement (Kujala, 2003; Kemshall & Littlechild, 2000) and patient participation (Sahlsten et al., 2008).

In order to gain an understanding of what participation for older adults may imply, the following sub-section presents and reviews participation by giving special focus on why participation is considered important and activities in which older adults are found to engage, in everyday life. The next sub-section will provide a presentation of perspectives in relation to participation in service delivery followed by a perspective on participation within the ICF. Finally, a literature review in relation to the experience perspective on participation will be presented.

Overall, the bases for using the concept of participation in this thesis are: i) the experience of participation in everyday life, ii) participation in service delivery, and iii) participation as the equal right to participate in society. The latter has been described in the background section and will not be further explained in this section.

### **Participation in relationship to older adults**

Participation in older adults is important for longevity (Lennartsson & Silverstein, 2001) and for preventing functional decline (Avlund et al., 2004). Participation is also important for reducing the risk of dementia (Verghese et al., 2003) and yielding better quality of life (Silverstein & Parker, 2002). Some aging theories underline the necessity of participation in order for older adults to age successfully. The early theory of activity held that maintenance of social roles and activities that are meaningful to people enhance their feeling of well-being when aging (Havinghurst & Albrecht, 1953). In contrast, the theory of disengagement, developed by Cumming & Henry (1961) proposes that gradual withdrawal from activities and social interactions is an inevitable accompaniment of old age aiming at easing the transition to death and minimizing the disruption to society. Researchers discredited the activity theory for advocating a single,

idealized lifestyle when they discovered empirical data demonstrating the heterogeneity of older people's lives (Bowling, 2007). Another aging theory is the continuity theory (Atchley, 1989), arguing that successful aging depends upon carrying forward one's values, lifestyles and relationships from middle to later life. Successful aging, as forwarded by Rowe and Kahn (1997), includes low risk of disease and disease-related impairments, high mental and physical functioning and active engagement with life. This understanding of successful aging has been criticized for ignoring the multiple meanings of loss for successful aging (Scheidt et al., 1999; Rozanova, 2010). However, there has also been a shift of emphasis away from the importance of the volume of activities undertaken for well-being in later life to a model that researchers consider more realistic, stressing adaption and adjustment to the challenges of aging via redistributing and substituting activities.

A (meta) theory that reflects successful aging as a process of adaption as well as lifespan theory is selective optimization with compensation (SOC), which Baltes and Baltes (1990) initially established. Later, Freund and Baltes (2000), Krampe and Baltes (2003) and Riediger, Li and Lindenberger (2006) developed SOC into its current version. The theory of SOC holds that adults *select* fewer and more meaningful goals and activities, *optimize* their existing abilities through practice and tools (such as new technologies) and *compensate* for the losses of some abilities by finding other ways to accomplish tasks. The SOC process is regarded as a means of managing available resources (Freund & Baltes, 2008).

Researchers have heavily criticized the activity, disengagement and continuity theories. These theories have been criticized for being and giving normative connotations, for claiming being universal, for ignoring the dynamics and variety of aging and the restrictions of the individual in order to conceal the patterns of inequalities in society and social differentials.

The review above touches upon some reasons why participation is considered important. However, older adults' participation takes place in a context. In order to enable participation in older adults receiving home-based services, it is necessary to understand what kind of activities older adults participate in and in which types of contexts, which will follow in the next sub-section.

### ***Research on participation in older adults***

Reviewing empirical research on participation in older adults shows that studies fall into i) participation in treatment and prevention, such as participation in exercise in combination with medical treatment of cancer (Payne et al., 2008), and participation in relation to prevention of falls (Nyman & Victor, 2011, 2012; Smith et al., 2012), ii) participation in service delivery, such as participation in medication-related decision making (Neeraj & McHorney, 2000; Belcher et al., 2006) and iii); the concept of participation, such as participation experienced at very old age in the context of home (Haak et al., 2008a; Haak et al., 2008b) or in rehabilitation (Vik et al., 2008). Other studies have focused on participation in daily life, such as daily activities (Parisi, 2010) and in connection with a particular diagnosis such as stroke (Ekstam et al., 2007). Other areas of research on participation in older adults cover social participation (Levasseur, Desrosiers & Noreau, 2004; Noreau et al., 2004), civic participation (Martinson & Minkler, 2006) and participation as being productive (Fernández-Ballesteros et al., 2011).

One area of research with relevance for this thesis focuses on the activities in which older adults participate in their everyday life. Previous studies have reported that older people have an engaged lifestyle (Verbrugge et al., 1996) and are involved in a variety of activities (Kolanowki et al., 2006). Parisi (2010) found that older adults continue to engage in daily activities, including watching television, reading, socializing, shopping and several other home and community engagements. However, several studies have found that the nature of the activities may change over time (Parisi, 2010; Paillard-Borg et al., 2009; Verbrugge et al., 1996). Iso-Ahola (1994) and Parisi (2010) found that individuals tend to reduce their participation in exercise and outdoor activities while increasing their participation in hobbies (i.e., volunteer work, gardening, handicrafts) and home-based activities. For example, Larsson et al. (2009) found that for the oldest participants, everyday life was about following the habits and routines related to household chores such as doing dishes, watering the plants, cooking, vacuuming, etc.

Leisure participation is found to lie at the core of life and is particularly important in the lives of seniors. Finseraas et al. (2009) found that retired seniors continued to travel abroad on holidays and visit their cottage or summer house, but some seniors prioritized going abroad more than spending time in their cottage or summer house. Furthermore, Finseraas and colleagues found that retirement had no influence on participation in cultural activities such as going to the cinema, concerts or art exhibitions. In Norway and the US, older adults tend to value outdoor walking as an activity (Crombie et al., 2004; Helsedirektoratet/Norwegian Directorate of Health, 2009b). An Australian study by McKenna et al. (2007) found that older people's occupations and roles are diverse and that increasing age appears not to reduce occupational or role engagement. This study also found that the value of roles is not always reflected in the amount of time devoted to them. Furthermore, mentally restorative activities are those that wholly absorb and interest a person, and older adults' participation in such activities have been found to be significantly correlated to daily functioning, depressive symptoms and variety (Jansen, 2008).

The findings in the studies mentioned above may indicate what participation in everyday life implies for older adults. Research has shown that what is experienced as meaningful participation in activities does not change for older adults even if they become ill (Legarath & Avlund, 2005). Home-based service delivery is part of everyday life in some older adults. However, there is little knowledge of how frail older adults experience participation in activities when they depend upon services at home, and the role of service delivery for facilitating preferred participation.

### **Participation in relation to service delivery**

Following the shift from a care and welfare perspective to a human and democratic rights perspective, a strong focus upon the citizen's voice within the organization and delivery of services emerged. Participation in service delivery is founded on principles of human and democratic rights involving autonomy and the right to take part in planning services. Community-based theories related to empowerment, self-

determination and decision-making has been a common framework for policy makers to apply when informing the field of participation in general (Malone & Hartung, 2012). The right to participate in service delivery is mirrored in policy documents in a variety of ways. The right of autonomy is emphasized in health services and is based upon the Helsinki Declaration ([www.regjeringen.no/nb/dep/hod/dok/nouer/2001/nou-2001-19/7/2/1.html?id=364564](http://www.regjeringen.no/nb/dep/hod/dok/nouer/2001/nou-2001-19/7/2/1.html?id=364564)). The concept of autonomy represents one tradition of user-involvement, and the ideology of health and social work practice and education stresses autonomy and user involvement as necessary for collaboration between professionals and clients. Being autonomous includes allowing clients the right to self-determination in and co-determination of the treatment they are given. Several studies have documented that having autonomy implies having control over everyday life (Baltes & Carstensen, 1996; Vik et al., 2008). Thus, one can say that autonomy is an important prerequisite for participation in service delivery (Cardol et al., 2002b; Clapton & Kendall, 2002).

The term user-involvement is related to involving individuals in the decision-making processes concerning their life situations (individual level) or involving representatives of user-organizations in shaping or framing services (organizational or political level). User involvement is considered to be both a democratic right and a working method based on the knowledge and experiences of the service-users as well as a strategy for reaching the goals of an inclusive society (NOU, 2001: 22; [www.regjeringen.no/.../Forskrift-om-individuellplan.html?id=415905](http://www.regjeringen.no/.../Forskrift-om-individuellplan.html?id=415905); [www.regjeringen.no/.../verktoykasse/brukermedvirkning/brukermedvirkning.html?id=582859](http://www.regjeringen.no/.../verktoykasse/brukermedvirkning/brukermedvirkning.html?id=582859)). The Norwegian Government states that the interface between users of services and the service providers represents a test of the value basis of the municipal services. Furthermore, experts assume that the degree of involvement varies depending upon where the service recipient is in her/his process within the service system. According to Adams (2008), there are different degrees of involvement in service delivery, such as information, consultation, partnership, delegation and citizen control.

The nursing literature takes a particular view of participation in care (Sahlsten et al., 2009). In general, it recognizes the term patient-participation as the patient's right to influence and direct his/her care and to take part in the decision making concerning care (Eldh et al., 2006, 2010; Sahlsten et al., 2008) and different types of medical treatment (e.g., Bottorff et al., 2000). Older adults' capacity to participate in decision-making is another focused area within the nursing and medical literature (Moye & Marson, 2007; Finucane et al., 2005). A recent study by Eldh et al. (2010) found that patients describe participation as sharing knowledge and respect, and as an activity that is more complex than involvement in decision-making. Sahlsten et al. (2008) found that nurses experience patient participation as something they give to the patient and something they activate. In contrast, previous research has indicated that older adults receiving home-based services feel that service delivery actually reduces their function and provides less opportunities for participation and decision-making (McGarry, 2008; Vik et al., 2007; Vik & Eide, 2011a+b).

There are rising expectations around aspects such as consumer choice and citizen voices within organizations and their delivery of services. A discourse of entitlement or user rights has germinated from the value of customized and individualized service delivery. This entitlement has emphasized the importance of user choice, self-determination and control in the funding and provision of services (WHO, 2008b). However, studies have found that older adults may not have the same experiences or assumptions compared to younger persons, even those with impairments, while making choices or decisions related to services (Kane, 2001). Nevertheless, studies have shown that older adults receiving home-based services are satisfied with their opportunities for decision-making but less satisfied with their opportunities for participation in everyday life (Huseby & Paulsen, 2009; Næss, 2003).

Home-based services and service delivery are founded on the principles of autonomy and user involvement. Contrasting the experiences of services of service providers and receivers is, however, still necessary to reveal the mechanisms involved yielding the wanted result. The anticipated diversity in perspectives may form a key in

understanding why service providers' intentions do not always lead to autonomy and user involvement, and why the result sometimes is the opposite.

### **Participation in relation to the ICF**

Participation has become a broad value and objective for health and welfare services. During the past ten years, the ICF has become an important point of reference for the discourse on participation in general, and has contributed strongly to the perceived relevance of participation for professionals working in health and welfare service systems. The ICF defines participation as *involvement in a life situation*, and relates participation to perspectives of functioning and health (WHO, 2001). *Involvement* includes taking part, being accepted, belonging, being included or engaged in an area of life or having access to needed resources (WHO, 2001). This definition has been criticized for being vague and excluding the subjective dimension and experiences (Hemmingsson & Jonsson, 2005; Perenboom & Chorus, 2003; Ueda & Okawa, 2003; Wade & Halligan, 2003). Ever since the development of ICF, a body of research on the subjective dimensions of participation has emerged. This body of research has focused on the individual interpretation of participation (i.e., the qualitative aspects of participation and the experiences of individuals who receive and provide different types of services; Hammel et al., 2008; Vik et al., 2008; Vik & Eide, 2011a+b; Lund et al., 2007). A further presentation of this research appears in the section "The experience perspective in relation with participation."

ICF conceptualizes functioning and disability as a dynamic interaction between a person's health condition, contextual or environmental factors, and individual factors. The latter is however not fully developed. In line with the ICF perspective, WHO (2001) proposes that a person's functioning and disability, including her/his participation, arises from the interactions between health conditions, contextual or environmental factors. ICF claims to build upon a biopsychosocial perspective by integrating the medical and social models of disability with the intent to represent and contribute to an integrative understanding of health (Brown, 2000). Thus, the ICF

framework may contribute to illuminating participation in older adults from both an individual and a wider social perspective.

In the ICF manual, the component of participation (together with the activity component) is related to the following nine domains of functioning: learning and applying knowledge, general tasks and demands, communication, mobility, self-care, domestic life, interpersonal interactions and relationships, major life areas and life itself, specifically its community, social and civic dimensions (WHO, 2001). Despite the agreement on the influence of environmental factors on participation, Hammel et al. (2008) claim that the tendency to fail at capturing the interplay between person and environment during practice is a problematic aspect of universal models such as the ICF. The significance of developing participation measures that capture the experiences of people with impairments has been highlighted by people with impairments themselves (Gray et al., 2006). It is proposed that key aspects to generating knowledge about participation and how to influence participation are i) the subjective meaning and ii) the influence of the environment on choices, control, opportunity and satisfaction (Hammel et al., 2008).

Using the ICF framework, several studies have developed measures on participation and the mechanisms that facilitate or restrict participation (Gray et al., 2006, 2008; Van Brakel et al., 2006; Brown et al., 2004; Gandek et al., 2006; Osir et al., 2006; Pallant et al., 2006; Sandström & Lundin-Olsson, 2007; Wilkie et al., 2005). Furthermore, the Facilitators and Barriers Survey (FABS/M) by Gray et al. (2008), the Measure of the Quality of the Environment (MQE) by Fougeyrollas et al. (1999) and the Craig Hospital Inventory of Environmental Factors (CHIEF) by Whiteneck et al. (2004) are measurements that professionals can use to assess which environmental features are important for understanding participation. The different measures vary in content and in how they operationalize participation.

In my research, the ICF has represented a framework for study II. The definition of participation within the ICF has also represented a frame of reference for studies I and III, and motivated this thesis' focus on participation experience. While ICF has focused on participation in relation to environmental factors and functioning, there is still little



knowledge of how participation is experienced. As we shall see in the findings, ICF is a frame of reference that can unite the individual and societal perspective, but it fails to capture the experiences of older adults.

### **The experience perspective in relation to participation**

The following overview reveals that many studies in the past decade that explore the experience of participation have covered different contexts among different groups of people. Most of these studies included adult people with different types of impairments or illnesses. Only a few studies were concerned with older adults or included older adults. An oft-cited study of people with impairments in general found that there was neither a gold standard of participation nor one defined set or frequency of activities that accounts for “full” participation. Rather, this study conceptualized participation as a cluster of values including active and meaningful engagement/being a part of society, choice and control, access and opportunity/enfranchisement, personal and societal responsibilities, having an impact and supporting others, social connection, social inclusion and membership (Hammel et al., 2008).

Other studies have taken place within the contexts of vocational rehabilitation (Kvam et al., 2012), wheelchair users (Hjelle & Vik, 2011), individuals living with chronic pain (Borell et al., 2006) or living with physical disabilities (Asbjørnslett & Hemmingsson, 2008), women on long-term sick leave (Johansson & Isacsson, 2011), people with mental illness and everyday occupations (Sakiyama, Josephsson & Asaba, 2010), persons with a spinal cord injury in life situations (Larsson Lund et al., 2005) and patients in the midst of their transition period from hospital to home (Van de Velde et al., 2010). Furthermore, Häggström & Lund (2008) have studied perceived participation among persons with acquired brain injuries and Van't Leven & Jonsson (2002) studied perceived occupational performance in severely disabled nursing home patients. Finally, a study by Magasi et al. (2009) aimed at capturing the subjective perspectives of participation in multiple rehabilitation stakeholders.

When it comes to studies that research the participation of older adults living in place, they have primarily covered the contexts of participation in occupation during home-based rehabilitation (Vik, 2007) and participation in relation to independence in very old age, including aspects of home and neighborhood environments (Haak, 2006). A small quantitative basis of research on factors influencing older adults' participation in community living has also emerged, which explores personal and environmental factors' explanations of participation in daily activities and social roles (Anaby et al., 2009) and the contribution of participation in explaining well-being among older adults living with chronic conditions (Anaby et al., 2010). Levasseur et al. (2004) studied relationships between subjective quality of life and social participation of older adults with physical impairments. They attempted to discover whether participation differs according to level of activity among older adults living in communities (Levasseur et al., 2008). These studies showed that participation accomplishment depends upon personal factors related to the older adults' physical and mental abilities (Anaby et al., 2009) and that participation had a unique contribution to older adults' well-being where satisfaction with participation rather than the accomplishment of activities was of importance (Anaby et al., 2011). Levasseur et al. (2004) found that interpersonal relationships, responsibilities, fitness and recreation were categories of social participation most strongly associated with quality of life. Another study found that older adults' participation level and obstacles in the physical environment differed according to level of activity, whereas satisfaction with participation differed only when the activity level was sufficiently disrupted (Levasseur, 2008).

The qualitative studies illuminate that the experiences of participation across different groups depend upon contextual and personal factors. Participation is not experienced as an objective way of performing activities within a societal context or as frequencies of activities performed (e.g. Van de Velde et al., 2010; Borell et al., 2006; Hammel et al., 2008). Participation is not experienced as static – it is a process of and influenced by adaption to changes, environmental opportunities, changing capacity, values and the dynamics of living everyday life. Accordingly, a few studies have focused on how strategies are adopted to enhance experiences of participation related to changing capacity (e.g., Häggström & Lund, 2008; Johansson & Isaksson, 2011).

Across all studies in the field, the subjects commonly experienced participation as engagement, yet this engagement varied due to personal factors such as age, life situation and functioning or disability. Engagement is, in all studies, related to actions and doings, and some studies include feeling and being. People can experience these latter two alone or with others (e.g., Borell et al., 2006; Van de Velde et al., 2010; Van't Leven et al., 2002). Furthermore, participation as engagement is found to be related to personal meaning, habits, routines (e.g., Johansson & Isacsson, 2011) and personal self-fulfillment as well as fulfillment of roles and identity (e.g., Van de Velde et al., 2010).

Experiences of social participation have a variety of aspects, the most common being social connection and belonging in a meaningful context. The aspects of social participation upon which people with impairments strongly focused in the studies were equality, inclusion and membership (e.g., Hammel et al., 2008; Van den Velde et al., 2010; Hjelle & Vik, 2011; Asbjørnslett & Hemmingson, 2008). Other common aspects related to social participation were doing something and being someone for others or contributing to society (e.g., Borell et al., 2006; Hammel et al., 2008; Johansson & Isacsson, 2011; Magasi et al., 2009). A few studies connect the experience of participation to agency (Borell et al., 2006; Vik et al., 2007) and to agency-relevant terms such as having or trying to preserve choice and control (e.g., Kvam et al., 2012; Vik & Eide, 2011; Hammel et al., 2008), decision-making and exerting power. All of these terms can be understood as components of agency (e.g., Hjelle & Vik, 2011; Häggström & Lund, 2008).

To my knowledge, only a few qualitative studies of the experiences of participation among older adults have been undertaken. Vik et al. (2008) completed an extensive study of older adults' experiences of participation in occupation during home-based rehabilitation. They found that the participants viewed their wishes to be in control as a will to exert power. Thus, the study understood agency as an important feature of participation. Vik et al. also found that participation included dynamic engagement ranging from individual agency (decision-making, choice, acting in daily life) to letting life itself be the agent.

Another study among very old adults (+85) in the context of home (Haak et al., 2008) found that these adults experienced participation as performance-oriented, including engaging in the performance of activities for others, that is, doing or meaning something for others and performing with personal satisfaction. Participation was also experienced as being togetherness-oriented, including sharing experiences, being among others and linking to the outside world. The participants experienced participation as being part of a larger context and committed or devoted to something. Home was found to be the origin for participation, where participation as acting/doing and being took place.

Van't Leven & Jonsson (2002) studied perceived occupational performance in severely disabled nursing home patients and found that continuity of some familiar occupations of personal interest was important. Furthermore, the patients experienced self-determination and control in daily activities as well as social contact with people as important. The study showed that some persons need to continue performing such an occupation themselves, whereas others may be able to fulfill their need for doing by being present in the atmosphere of the doing.

The preconditions for participation in the studies mentioned here can possibly differ in relation to underlying explanatory models of disability. However, the expectations of participation as a right and a responsibility seemed to differ between different groups of people in the reviewed studies. Thus, one's ability to understand personal rights and responsibilities seems to differ among the groups of people featured in the studies mentioned here. While some of the studies among adults with disabilities focused rigorously on rights and fighting for rights (e.g., Hammel et al., 2008; Hjelle & Vik, 2011; Magasi et al., 2009), other studies among other groups, such as the study among persons with acquired brain injury, focused rather on the subjects' wish for and value of acceptance and inclusion or of taking part (e.g., Asbjørnslett & Hemmingsson, 2008; Häggström & Lund, 2008). In addition, equal rights did not receive a strong focus in the studies of older adults' participation (Vik, 2007; Haak, 2006).

Studies that have taken the experience perspective on participation have found that participation is contextual and is much more than performance. It is not always connected to activity, occupation, doing or socializing, and it can also be experienced as a sense of being and belonging or as feelings. These experiences are closely related to one's values (Hammel et al., 2008) and can also be intertwined, as described by Van den Velde et al. (2010). Hence, participation is a nuanced, multidimensional and complex phenomenon that can be experienced and played out uniquely in each instance on individual, social, community and societal levels (Hammel et al., 2008).

Knowledge of the experiences of older adults' participation is scarce in general, and older adults' participation in everyday life and in the context of receiving home-based services has, to my knowledge, not yet been explored in detail. Besides the aspects illuminated here, and in order to answer the research objectives, I considered it relevant to do both an in-depth examination of a population of older adults receiving home-based services and of their service providers and a survey of older adults' satisfaction with participation in the context of receiving home-based services, for the sake of increasing the knowledge of participation in this group of people. This knowledge is important to gain insight into how their participation is facilitated and supported by the service providers and to provide possible implications for practice, including further development of home-based services.

## **4. Methods**

### **Research Aims**

The specific research objectives in this thesis were:

- Study I            To generate knowledge about service providers' understanding and descriptions of older adults' participation in everyday life, when living in place and receiving home-based services; and how service providers'

understanding influences participation for older adults receiving services in their own home.

- Study II To explore satisfaction with participation among older adults receiving home-based services:
- Is satisfaction with participation in daily life activities among older adults that receive home-based services related to activity performance, health, and environmental factors such as physical/structural barriers and frequency of home-based services?
  - To what extent can older adults' self-reported activity performance, health, and environmental factors such as physical/structural barriers and frequency of home-based services explain their satisfaction with participation?
- Study III To generate knowledge about older adults' understandings and experiences of participation in everyday life in general; to explore and illuminate older adults' experiences of and conditions influencing participation in everyday life when living in place and receiving home-based services.
- Study IV To illuminate and understand how older adults experience participation with service providers in their everyday life.

### **Study design**

Different designs were chosen in order to answer the research questions, to develop knowledge about and contribute to substantial theory-building on older adults' participation in everyday life and in the context of receiving home-based services. Table nr.1 provides an overview of research approaches and methods used.

Study I was designed as a qualitative and grounded theory study. Focus group discussions were chosen as they provide an opportunity for all parties' active involvement and examination of individual and shared group perspectives (Ivanoff & Hultberg, 2006; Krueger & Casey, 2000), in this case, the agreements and disagreements of people working within home-based services. Discussions in groups produce insights that would be less accessible without the interaction in the group setting. A group effect could be that by listening to others' experiences, participants' ideas, memories and experiences are stimulated (Krueger & Casey, 2000). The service providers' experiences and perspectives were assumed to represent a key to understanding some of the conditions for older adults to stay active and participate. Therefore, service providers' perspectives were chosen to represent a first entrance to understanding older adults' participation in every-day life.

Study II was designed as a cross-sectional study and to combine both descriptive, explorative and analytic aspects and testing of relationships between variables. Service providers' experiences and descriptions of older adults' participation and barriers to older adults' everyday participation in study I formed a basis for study II, together with components in the ICF model. Based upon findings in study I and the ICF framework a survey including the health, activity, participation, environmental and personal components was designed. In order to study older adults' own evaluation of participation in everyday life, we chose the variable satisfaction with participation and studied relationships with frequency of home-based services, self-reported activity and health variables.

Study III and IV were designed as qualitative and grounded theory studies applying individual interviews in order to explore and illuminate how older adults describe and experience participation and conditions influencing participation in everyday life and in the context of receiving home-based services. Based upon findings in both studies I and II, it became apparent that it was necessary to explore and capture a broader picture of aspects affecting older adults' experiences of participation and to reach older adults with greater variety in needs of home-based services, social situation and support. Accordingly, studies III and IV were designed to provide richer and more elaborative

data concerning participation and how participation was experienced in a sample of older adults with greater variety in functioning and needs of services than in the sample in paper II.

Taken together, all studies elaborate and contribute valuable data to illuminate older adults' participation in everyday life while they receive home-based services and factors that facilitate and represent barriers to their participation. The grounded theory design includes being constant comparative and moving between levels of descriptions and conceptualizing, and it aims to construct substantial or formal theory. According to Charmaz (2006) and Urquhart (2009), substantial theory addresses delimited problems in specific substantive areas. The design in this thesis is predominantly exploratory and aims at contributing to substantial theory on the concept of participation within the specific area of older adults' participation in everyday life and in the context of receiving home-based services. From a broad perspective, each exploration within a new substantive area could help to refine a formal theory. According to both Glaser (2007) and Strauss and Corbin (1998), generating formal grounded theory includes a constant comparison of many substantive grounded theories and across different areas. Thus, a formal grounded theory has broader general implications than substantive theories. The studies in this thesis and other empirical studies with which they are compared are not only within the same substantive area. However, the ambition of theory development is primarily on the substantial level and to be used as a springboard towards formal theory in future research.

In the "Discussion" section, I compare and discuss findings (studies I-IV) and core categories (studies I, III, IV) and in relation to other studies and theories. The final subsection "Findings in relation to the concept of participation" aims at summing up this thesis' contribution to substantial theory building.



	<b>Study I (incl. paper I)</b>	<b>Study II (incl. paper II)</b>	<b>Studies III + IV (incl. papers III + IV)</b>
<b>Design/research approach</b>	Focus group discussions Explorative	Quantitative Explorative and analytic	Individual qualitative interviews Explorative
<b>Participants</b>	Professionals in home-based services N=30	Older home-based service recipients N=155	Older home-based service recipients N=10
<b>Methods of data collection</b>	Focus group discussions & semi-structured, open-ended interview guide	Structured questionnaire/ Survey	Semi-structured, open-ended interviews
<b>Data analysis methods</b>	Constructivist grounded theory, constant comparative	Descriptive statistics, Correlation, Principal component analysis, & Multiple linear regression	Constructivist grounded theory, constant comparative

Table I. Thesis overview

### **Triangulation**

The methodological approach in this thesis was inspired by triangulation of both qualitative and quantitative methods. Traditionally, qualitative and quantitative methods have been presented as opposite poles representing two incompatible paradigms, the naturalistic versus the positivist paradigm, which are bound in different ontological groundings. However, this perspective has met strong counter-arguments in recent decades, and it has been argued that the divide between qualitative and quantitative is becoming an increasingly “outdated” dichotomy (Brannen, 2005). Qualitative and quantitative methods may rather supplement each other and with different focus they may contribute to broaden our understanding of a phenomenon (Yoshikawa, et al., 2008).

The current project was inspired by a sequential exploratory design (Creswell, 2003). I gathered qualitative data first, then quantitative data and finally qualitative data once more. I chose this design for its appropriateness to the research questions for which little prior knowledge exists. Thus, triangulation represented possibilities that one single method could not offer, because different methods capture different aspects of the studied phenomenon.

There are several arguments for the benefits of combining methods. Findings in qualitative and quantitative data can combine for a broader perspective. Combining methods may produce outcomes such as corroboration, elaboration, complementarity and contradiction and may thus enhance concurrent validity and robust knowledge. Among the advantages of quantitative data, the most important to this study are knowledge of numbers, distribution, structures of and relationships between variables, while the qualitative data provide rich information about the processes concerning participation in the older adults’ everyday lives. With a comprehensive backdrop, I could analyze and interpret findings in the other data as well as findings that are apparently contradictory (Brannen, 2005; Johnsen & Onwuegbuzie, 2004). Examples from this project were: i) the service providers believed that the older adults were

passively waiting for them to come and put emphasis on their own role in the older adults' social lives and minimal attention to the role of family and friends in older adults' lives (paper I); ii) no correlation between satisfaction with participation in the older adults and frequency of home-based services, and we found that a majority of participants were satisfied or very satisfied with their participation (papers II and III); and iii) even though the older adults were mostly content with the service providers, they also noticed that the providers could represent barriers to their participation in everyday life (paper IV). These findings could be nuanced and discussed in relation with each other. However, they could also be a result of methodological differences. For example, respondents have a tendency to believe they are more satisfied when answering questions of satisfaction in surveys compared to respondents partaking in qualitative interviews where they can talk more freely (Sandbæk, 2001). Nevertheless, contradictory findings should draw attention to different aspects of the topic of the research. The findings in the qualitative interviews with the older adults (papers III and IV) could thus contribute to reveal the nuances, moderate and specify findings in papers I and II and to revealing contradictions between them.

### **Literature search**

I commenced this project with a systematic literature search in order to gather an overview of empirical and theoretical knowledge on participation in older adults. Throughout the project, I regularly searched for literature in different sources and databases, such as Academic Search Elite, Article First, OT Seeker, Google Scholar and PubMed. At the end of the project and in order to ensure the quality of the literature search I repeated the process together with a librarian. References in relevant articles and books have also provided important sources of knowledge and provided me an overview of the topic. Furthermore, I have received literature recommendations from supervisors and colleagues during the project.

My searches featured several combinations of the following terms: participation, everyday life, daily life, daily life activities, older adults, older people, aged, ICF, aging in place, active aging, and theory.

I also searched some relevant scientific journals directly, including *Disability and Rehabilitation*, *Scandinavian Journal of Caring Sciences* and several journals on aging. I focused on articles dating from 2000-2012, but I did include some older articles and books of relevance.

### **Epistemological aspects**

This thesis combines moderate constructivist and realist aspects in order to cast the research questions in different perspectives. In my opinion, one can understand old age and the functional decline in an older adult or actual participation in an observable activity, such as a material component, which would, in effect, be a realist understanding of the phenomenon. However, older adults' perceptions of aging, impairment, participation or participation restrictions while receiving home-based services can also be a product of cultural aspects. Thus, social interaction, interpretation and construction are central to the analyses in this thesis.

However, social constructivism and realism are often presented as two opposing scientific perspectives. The early work of Peter Berger and Thomas Luckmann (1966), entitled *The Social Construction of Reality*, is central to constructivism. A core belief of constructivism is that knowledge of the social reality continuously also produces this reality. A constructivist perspective focuses on the flexibility and variety of ideas of reality. This scientific perspective is central to most areas of social science. Related to this thesis, one could for example, accept and expect that service providers, older adults and researcher(s) have both similar and different ideas on the same topic; older adults' participation in everyday life. In contrast, a realist perspective assumes that the world exists without our realization of it. By building upon long traditions of the natural sciences, this perspective seeks the truth (Nordtvedt & Grimen, 2004). Realists believe

that reality exists independently of the researchers', the service providers' or the older adults' ideas and descriptions of it. Nevertheless, both perspectives embrace several modified variants or directions. In this thesis I follow the argument that scientific perspectives can coexist and complement each other. This argument supports that a realist does not necessarily have to believe that all phenomena are independent of our ideas or descriptions of them. He can accept that social constructs exist, although he would not assume that all phenomena are constructs (Nordtvedt & Grimen, 2004). Furthermore, the moderate constructivist direction as opposed to radical constructivism acknowledges that scientific theories and observations are constrained by the real, material world, but not completely so. Cultural values and social variables play a shaping role, too (Hess, 1997; Alvesson & Sköldbberg, 2005; Wenneberg, 2000).

#### *Constructive grounded theory approach*

Papers I, III and IV build upon a constructivist approach to the grounded theory method. Grounded theory is an inductive methodological approach that intends to enhance knowledge about notable phenomena that influence the everyday lives of people. Grounded theory builds inductive analysis from the data. I have analyzed the data closely and 'ground' my conclusions in the data by following the guidelines recommended by Charmaz (2006) (see the "Data collection methods" and "Methods of analyses" sections). A constructivist grounded theory approach is particularly important for the topic in this thesis, as empirical understandings of how older adults who receive home-based services perceive participation in everyday life while receiving home-based services are scarce in the literature. Participation theories are also scarce, so I chose a grounded theory approach. It provided me with a means to describe experiences and a means to imbue understanding with the ability to explore a phenomenon through substantive theorizing (Charmaz, 2006, 2008; Bryant & Charmaz, 2007).

Glaser and Strauss developed grounded theory in the 1960s. They aimed at fighting the dominance of positivistic quantitative research. However, critics have claimed that Glaser and Strauss gave a positivist and objectivist direction to knowledge production

and to grounded theory method and that they offered a method that could claim equivalent status to quantitative work. The epistemological orientation assumed that reality could be discovered, explored and understood, representing a perspective that holds up a reality that is unitary and knowable. Given this perspective, an objectivist grounded theorist represents an authoritative expert bringing an objective view to research, claiming a value free neutrality and remaining separate and distant from the participants in research and their realities. Glaser and Strauss aimed to provide a clear basis for systematic qualitative research (Glaser & Strauss, 1967). Although their positivist and objectivist epistemological orientation is widely criticized, a key strength of their method is that it offers a foundation for rendering procedures and processes of qualitative research visible, comprehensive and replicable (Bryant, 2007; Charmaz, 2006).

During the past years, grounded theory has moved from its positivist origin to a constructivist point of view (Charmaz, 2006, 2008). Constructivist grounded theory contrasts the objectivist grounded theory approach in several ways. A constructivist grounded theory approach represents flexible guidelines, not rigid prescriptions, for data collection and analysis. According to Charmaz (2006), a constructivist approach aims at showing the complexities of particular worlds, views and actions. The approach considers a value free and neutral researcher impossible and not even preferable, as neither researcher nor participants are untouched by the world. They make assumptions about what is real. Both possess stocks of knowledge, occupy social statuses, and pursue purposes that influence their actions and views in the presence of each other. A constructivist grounded theory takes a reflexive and constructivist stand in relation to the production and presentation of knowledge. The research (papers I, III and IV) in this thesis is deliberately inspired by a constructivist grounded theory approach. This will be further described in the “Methods of analysis” section.

## **Selection of participants**

### ***Study I***

For the focus group discussions a purposive sampling strategy was conducted to achieve a specific variation (Charmaz, 2006). In total, the sample comprised 30 professionals, all working in municipal health and welfare services in two municipalities in Mid-Norway, who exhibited variety in age, gender, length of working experience and profession or education. The participants were recruited and provided written information and invited to participate by the leader of their working unit.

Initially, the intention was to include service providers from the home-based services in a large municipality only. However, it became apparent after the first focus group discussion and initial analysis that professionals from different areas of the service system should be included in order to capture a broader picture of service delivery among older adults living at home. Thus, participants in five of the groups were included from the home based services, municipal rehabilitation team, occupational therapists, health and welfare office and home nurses, respectively. The focus group discussion with nurses in the largest municipality could indicate that home-based services were organized differently and possibly provided nurses other conditions for facilitating participation in older adults in a smaller municipality than in a larger municipality. Therefore, it became apparent that a focus group discussion with nurses in a smaller municipality was necessary.

### ***Study II***

The inclusion criteria were **a)** being within the age range of 67-100, **b)** living in place, **c)** receiving municipal home based services (practical support/help with daily-life activities and home-nursing), **d)** an ADL score  $\geq 1.53^2$  on the IPLOS scale for needs

for assistance, **e)** competent to give informed consent and **f)** having the ability to communicate with others in an individual or a group-interview setting.

The sample included 155 older adults living in place and receiving long-term municipal home-based services, and comprised older adults across the relevant age span, including both men and women. In order to accomplish a principal component analysis on the data, the suitability of the sample size was assessed by inspecting the correlation matrix and by using the Kaiser-Meyer-Olkin measure of sampling adequacy (KMO). Results from these inspections indicated that a sample size of 150 would be adequate for accomplishing principal component analysis (Field, 2009). The sample size was also considered sufficient because the primary focus in the study was to analyze the relationships between the different components in the ICF model rather than achieving representativeness (see “*Study II*” in the “Methods of analysis” section, and the “Material and Methods” section in paper II).

Collaboration with the municipality was necessary to enable drawing a sample from the IPLOS database (see the “Organization of home-based services” section). The municipality’s Department of Service and Internal Control was able to draw this sample.

For both practical and ethical reasons, only individuals with moderate to low levels of service needs were included. In this way, we reached a sample size of 155 while excluding older adults with dementia or other cognitive illnesses from the sample. Excluding participants within these groups was necessary to ensure the participants’ lawful consent to participate in the study. Similarly, older adults with high levels of care needs were not included to fulfill consent requirements. Every third person from a sample of 800 elderly people with a score of  $\geq 1.53$  (which totaled 800 people) was drawn. This score indicated individuals with low to moderate service needs. This score

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<sup>2</sup> For further explanation, see the sub-section “Organisation of home based services” in the background section or the methods section in article II titled “Older homecare recipients’ satisfaction with participation in everyday life activities” in this thesis.



also included “tip-scores,” which means that out of 17 different variables, three of them could have a score of 3, some a score of 2 and the rest could have a score of 1. After identifying participants by means of the IPLOS database,<sup>3</sup> three persons from the staff department in the municipality facilitated the information to the sampled individuals and requested their consent to participate and give interviews.

For description of the sample’s drop-outs, see the “Sample” section in paper II.

### ***Studies III and IV***

For studies III and IV, a purposive sampling strategy was conducted to achieve a range of specific variations (Charmaz, 2006). The following criteria were used for inclusion: competence in informed consent and having the ability to communicate verbally with others in an individual situation. The sample comprised 10 older adults, all living in place and receiving long-term, municipal, home-based services in different parts of a city in Mid-Norway with variety in age, gender, housing, living alone or with spouse/family, levels of service needs and frequency of home-based services (see Table nr. II in papers III and IV). The participants were recruited by staff working in the home-based services.

In grounded theory studies selection of participants is closely related to data collection and analysis of data, and is part of the constant comparative process. The “methods of analysis” section presents further information about the constant comparative process in this thesis.

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<sup>3</sup> [www.Helsedirektoratet/iplos.no](http://www.Helsedirektoratet/iplos.no)

## **Data collection methods**

### ***Focus group discussions (study I)***

The first paper in this thesis is based upon data from focus group discussions. The purpose of the focus group discussions was to explore a certain topic from different angles by encouraging discussions among the participants. The topic for discussion was older adults' participation in everyday life or while receiving home based services. It was not intended to arrive at an agreement or consensus within the group about the topic but to encourage the participants to share their experiences with each other and to develop their reasoning. Thus, focus group discussions are suitable for exploring participants' views and experiences by discussing them with others in the same target group (Dahlin Ivanoff & Hultberg, 2006; Krueger & Casey, 2000) and therefore considered in this thesis to be a useful approach to gathering data from service providers working within different organizational and geographical units within the same community.

The groups in this study comprised participants aged 25-60 years with a maximum of six participants in each group. This group size is small enough to enable the participants to participate more freely in the discussions (Krueger & Casey, 2000; Kitzinger, 1994; Dahlin Ivanhoff & Hultberg, 2006). Each group was interviewed once. The discussions were focused on what the participants had in common (Krueger & Casey, 2000). All participants had worked with older people, although at different municipal levels. Some of them provided direct service delivery and others worked at an administration level. They focused on discussing their perspectives on participation in general as well as discussing older adults' participation in their daily life, needs, ambitions, individual factors and environmental factors, including the role of professional caregivers.

The moderator applied a semi-structured interview guide with open-ended questions and prepared an interview guide for each interview, making it possible to follow up on topics and themes from previous interviews (see appendix).

Each focus group lasted about two hours, including refreshments, presentations, information and small talk to “break the ice.” An assisting moderator from the project group at the Participation-network of Sør-Trøndelag University College took notes and made summaries during all interviews. The interviews were tape-recorded and transcribed verbatim. The first five focus group discussions were moderated by the third author, while the first author assisted with the fifth focus group and then moderated the sixth.

### ***Interview-based survey (study II)***

The second paper in this thesis is based upon data from the interview-based survey (see appendix). The survey was conceptually influenced by the latter five components of the ICF model: body functions and structures, health conditions, activities and participation, environmental factors and personal factors (WHO, 2001). These components represent theoretical constructs. In the ICF, participation is viewed as a persons’ involvement in a life situation and is related to what a person performs in his current environment, while activity is viewed as the execution of a task or action by a person and is related to what this person is able to execute. The environmental component relates to the physical, social and attitudinal environment in which a person lives and conducts his life, while the personal component relates to features of the person that are not part of a health condition, that is, gender, race, age, lifestyle, coping styles, social background, habits and so forth. Together with the body functions and structures component, these components serve to understand and study all aspects of human health in a relational way (WHO, 2001).

As this thesis is a part of a larger research project, only a limited part of the survey data has been included: satisfaction with participation in daily life activities, individual factors (psychosocial indicators), execution of daily life activities, health status and environmental factors including the individual’s relationship with service providers and service system.

Measures of the impact of frequency of home based services, self-reported performance of activity, health and physical/structural barriers to the older adults' satisfaction with participation were chosen in order to provide complementary information to the professionals' point of view on older adults' participation (paper I).

#### *Instrumentation*

The interview-based survey was accomplished with face-to-face interviews in the older adults' homes. The data collection was confined within a municipality in Mid-Norway. A group of three researchers including the first author, from Sør-Trøndelag University College and within the priority area of *Participation*, and three persons from the staff department in the municipality conducted the interviews. The research group developed the research instrument together, and both researchers and staff from the municipality had shared training sessions on its' use to strengthen the reliability. Each interview lasted from 1-2 hours.

The questionnaire was designed from pre-existing and validated questionnaires and comprised the following components.

*Participation*: Satisfaction with participation in life activities from the Participation of People with Mobility Limitations Survey (PARTS/M; Gray et al., 2006)

*Personal factors*: Sociodemographic background variables of age, gender and family situation (IPLOS, the municipality of Trondheim)

*Health condition*: Assessment of overall health and emotional problems from the COOP/WONCA Functional Assessment Charts (World Organizations of Family Doctors; Bentsen et al., 1999)

*Activity*: Execution of daily life activities and ADL items from Sunnaas ADL (Vardeberg et al., 1991)

*Environmental factors:* Assessment of service delivery including service level and frequency of service (Matthias & Benjamin, 2008); Craig Hospitals Inventory of Environmental Factors (Whiteneck, 1992)

For further information regarding the instruments, see the “Measures” section in paper II.

***Qualitative individual interviews (studies III and IV)***

Papers III and IV in this thesis are based upon data from individual interviews. The intention of the individual interviews was to collect data on older service recipients’ perspectives on participation in daily life and in situations of receiving home based services by discovering their needs, ambitions, individual factors and environmental factors, including the role of the professional service providers.

According to Kvale (2007) and Kvale and Brinkmann’s (2009) recommendations, the qualitative interviews were planned as interactions between two equal partners and the content was developed during the interview. A semi-structured guide with open-ended questions was thus applied in order to stimulate the participants to talk about their daily lives as freely as possible (Kvale, 2007; Patton, 2002) (see appendix). An interview guide for each interview was also prepared so that I could follow up on topics and themes from previous interviews. The participants were interviewed in their own homes at times and in places that were convenient to them. Each interview lasted between 1 ½ and 2 ½ hours. Altogether, the interviews produced about 300 pages of written text.

The main objective in study III was to explore how older adults experienced participation in their daily life in general, and in study IV we explored how they experienced participation with home-based services.

## **Methods of analyses**

### ***Studies I, III and IV***

In papers I, III and IV, a constant comparative approach, inspired by a constructivist grounded theory methodology to analysis, was applied (Charmaz, 2006). The analysis began once the interview began, and when transcribing the interviews verbatim. The data analysis in this approach was an ongoing process that authors carried out as a constant comparative analysis consisting of several analytic turns that began with line-by-line analysis and then progressed to a focused coding of the data. The three authors, separately at first and then together, proceeded from separating the data to bringing the data back together and making sense of them (Strauss & Corbin, 1998; Charmaz, 2006). The initial coding process included coding with words reflecting actions in the data rather than applying pre-existing categories to the data. The focused coding required decisions about which initial codes made the most analytic sense so that the authors could categorize the data incisively. Thus, the focused coding process was more directed, selective and conceptual than the line-by-line coding. Furthermore, writing memos about the focused codes was another analytic turn in the process. We constructed analytic notes to explicate and fill out codes and to prompt analysis of the data and codes early in the process. Hence, the purpose of the process of initial and focused coding and memo writing was to ground the analysis in the data.

Examples of focused codes in paper I were “attending to minor matters inside the house” and “carrying out tasks outside the house.” In paper III, the codes were “following the regularities of everyday life,” “trying and striving to fend for oneself” and “making one’s practical arrangements for daily life.” In paper IV, examples of focused codes were “expecting joint responsibility for appropriate service delivery,” “being understanding and indulgent” and “making one’s mark.” The codes that were related to each other were grouped in categories such as “carrying out tasks in everyday life” (paper I), “getting oneself going” (paper III) and “balancing agency – a process of giving, taking and letting go” (paper IV). The relationships between the categories in each study were discussed among the co-authors thoroughly. We ultimately decided

upon core categories that embrace the analytic content across the categories. In paper I, the core category “taking part in one’s own life” shed light on the professionals’ experiences of older adults’ participation. In paper III, “keeping up dignity and pride” emerged as the core category that embraced the older adults’ experiences with participation in everyday life in a veracious way. Finally, “taking home-based services into everyday life” emerged as a category that embraced the older adults’ process of responding to changing capacity in everyday life.

The basis for this thesis is primarily the empirical data and understanding of participation in everyday life in older adults receiving home-based services in relation to what they tell about it, which goes beyond simply understanding the data in light of a specific theory. In the analysis, I have tried to stay close to data in the sense of trying to let interpretations of the participants’ sayings stay close to their own descriptions. In this way, I have tried to let the empirical data lead the way to my categorizations during the process of analysis. The categorizations have contributed to the choice of frameworks and theoretical perspectives that are used to explain and discuss the empirical data. However, and in line with a constructivist grounded theory approach, it is not considered possible to be free from theoretical or contextual influence. A part of the constant comparative approach included comparing findings with findings in the other studies in the project, and with other studies within the same area of research. In order to recognize new findings in my own research, it was also necessary to have an overview and to understand the current theoretical and empirical conversation relevant to participation in older adults. However, I have tried to reflect consciously on which bias and ideas that have influenced me during the data gathering and process of analysis, in order to minimize negative influence such as forcing them (see the “Methodological considerations” section).

#### *The process of refining categories*

In grounded theory studies, data analysis is closely related to data collection and selection of participants. According to Charmaz (2006), theoretical sampling, saturating and sorting is the grounded theory’s strategy for obtaining further selective data to

refine and complete major categories (Charmaz, 2006). Hence, based upon findings from studies I and II (see the “Study design” section and the “methods of analyses” section, too) and the ongoing analysis of data, and in order to refine categories, participants with greater levels of service needs were selected and recruited during the data collection period. To exemplify; the professionals in study I described the older service recipients as being partly lonely and in need of social contact with the service providers. The providers of study I also experienced themselves and the organization of services to represent barriers to older adults’ participation in everyday life. In contrast, we found no relationship between frequency of home-based services and satisfaction with participation in study II. Based on these findings and after the first five interviews in study III, it thus became apparent that it was necessary to reach older adults with little informal social support and older adults feeling lonely in order to capture a broader picture of aspects affecting older adults’ experiences of participation. The participants had thus far described a general contentedness, including participation with the home-based services, and they did not place great emphasis on the social aspects of participation with the service providers. Thus, a necessity of exploring further preliminary theoretical categories at that stage became apparent, including older adults’ balancing agency, the content of their values and their interaction and socializing with the service providers. Based on these findings and considerations, we asked the home nurses to recruit participants they believed were living in a situation of loneliness.

### ***Study II***

Paper II aimed at investigating relationships between satisfaction with participation in daily life activities and activity performance, health, and environmental factors such as physical/structural barriers and frequency of home based services. To what extent the above-mentioned factors could explain older adults’ satisfaction with participation in everyday life activities was also explored.

The primary basis for the overall design was keeping closeness to the empirical data and trying understanding the older adults’ answers in a relational way; more than



understanding them in the light of a certain theoretical perspective related to each of the components in the ICF model. Satisfaction with participation is described as an evaluative and thus subjective component of participation, and the essence of this phenomenon is argued to correspond with a person's attitude to his or her participation in various domains (Gray et al., 2006). This variable could be an indicator of actual participation and the quality of that participation, so in this thesis it was chosen as an outcome variable in order to explore this element of the concept of participation in older adults receiving home-based services. The PARTS/M which our instrumentation builds upon was developed by Gray et al. (2006). Based upon empirical research, satisfaction with participation was found to be an important evaluative and a subjective component of participation and hence included as a variable in the PARTS/M (Gray et al., 2006). Later Haak et al. (2007) found that satisfaction with participation might represent older adults' adaptation and selection of activities that are most important to them (Haak et al., 2007). Satisfaction with participation is also found to be closely related to personal goals and priorities and might better reflect an individual's perception of his/her optimal participation level (Levasseur, Desrosiers & Tribble, 2008).

Data from the survey could contribute to knowledge of the distributions, numbers and frequencies of the older adults' satisfaction with participation in different daily life activities, as well as relationship between such activities and other variables.

Strategies for the analyses were as follows:

- i. Exploring and analyzing statistical properties of scales and variables included
- ii. Univariate analyses (frequencies) of variables in the model/data material
- iii. Bivariate analyses of the associations between variables and satisfaction with participation
- iv. Analyses of a model of satisfaction with participation as outcome (dependent variable)

A principal component analysis was carried out as part of examining the construct validity of the PARTS/M satisfaction with participation scale and to explore underlying structures (Field, 2009; Pett et al., 2003). The principal component analysis resulted in

two variables which were included as outcome variables for further investigation of the topic. Linear multiple regression analyses were performed to estimate to what extent satisfaction with participation in i) outwards and ii) domestic and private activities could be explained by the predictors of activity limitations, overall health, overall emotional well-being and physical/structural barriers. SPSS 17 was applied for the analyses (Field, 2009). For further description of the variables and the methods for analysis, see “Methods of analysis” section in paper II.

### **Ethical issues**

The studies were carried out in accordance with ethical research guidelines and with approval from the Norwegian Social Science Data Services ([www.nsd.no](http://www.nsd.no); studies I, II, III, IV).

The project was carried out in cooperation with a municipality in Mid-Norway but offered no economic advantages for any of the cooperating parties. Information was provided to all involved parties both verbally and written. Informed consent was also openly discussed and obtained. At the start of study I, all information about the project and data collection was given by the leader of the working units in the two municipalities.

In relation to the qualitative interviews with the older adults (papers III and IV), information about the project was at first provided by contact-persons in the home-based services who knew the older adults and was later repeated by the interviewer/researcher after consents were obtained. In some of the interviews, the older adults had prepared questions they wanted to discuss and clarify before agreeing to start the interview. A couple of the older adults started the interview situation by stating that they were very confident with the home-based services and that they had nothing about to complain. This could, of course be true, but could also indicate a fear of possible sanctions. In such situations an open dialogue about the project and the intentions of data gathering was of specific importance.

In relation to the survey (paper II), all information about the project and data collection was at first sent the sample by post and after a week, the older adults were contacted by telephone by the group of persons in the staff department in the municipality. This group verified whether the sample had received the posted inquiry and answered questions about the project. They also made appointments for time and place of the interviews for those older adults who wanted to participate in the study. Signed informed consents were obtained by the interviewers at the start of the interviews, and all information about the project was repeated by the interviewer/researcher at the start of each interview.

The survey included a variety of older adults, and therefore a variety of different homes to visit. Ethical questions in relation to accomplishing interviews in other peoples' homes were regularly discussed within the group of interviewers in order to sharpen our ethical consciousness. We tried to prepare ourselves and discussed how to meet possible challenging situations in respectful ways before and after interviews. How our personal reactions to illness and impairments, how people live and behave, and reactions to factors in the homely atmosphere, that is the smell of cigarette smoke or hygienic conditions, could influence the interview situation was discussed. In some interview situations it turned out that the older adults' motivation to participate in the survey was low, or that they most of all wanted to talk about other things in their lives. In the group we discussed to what degree, in what ways and at which point we could lead the conversation back to the questionnaire or how to end an interview without insulting the older adult.

A dilemma associated with studies carried out in the homes of frail or vulnerable older people is that conditions that are injurious to health or are potential dangerous may be discovered by the researcher. During the time of the completion of the survey, a serious fire hazard in one of the homes was revealed. However, the concern was not shared by the older adult. In this case, the group discussed and decided to make an anonymous call of concern to the local authority in charge of the services for this older adult. Another dilemma is that participants may have a wish for further contact with the interviewer. In

one case, this resulted in polite rejections of further contact after offering several follow-up phone calls to a local authority and a volunteer bureau.

The questionnaire was comprehensive and each interview was estimated to last approximately 1 1/2 – 2 hours. In the group we discussed how this could influence both researcher and older adults and what to be aware of. It could, for example, result in the researcher hurrying the interview in order to be finished or make the older adult weary. By reflecting on the topic the interviewers could avoid situations of unethical behavior. The interviewers had previous experience from working with older adults in a variety of settings: therapy or activity groups, individual consultation and/or in nursing homes. This may have contributed to a greater sensitivity to the older adults' non-verbal signals during the interviews. In all interview situations, elements in the environment that could make the situation relaxed were taken into consideration, such as regulating tempo of speech, light and sound, temperature, and time and length of the interview to the participants' needs (Robson, 2002). In some of the interviews, the participants had questions about the organization of services and the researcher initiated follow-ups by the relevant authority at the participants' request.

In the focus group discussions, refreshments were served to make the situation more comfortable and relaxed (Krueger & Casey, 2000). In the qualitative interviews with the older adults, time was spent on accepting coffee and refreshments and small-talk when initiated by the older adults.

According to ethical guidelines for research, it was in all encounters emphasized that the participants could withdraw from the study at any time.

### **Methodological considerations**

Different designs and methodological approaches have been taken in order to answer the research questions. Although each of the methodological approaches has both strengths and weaknesses, the weaknesses of taking one single approach could thus be reduced. Triangulation of both qualitative and quantitative methods and the inclusion of

both service providers' and older adults' perspectives illuminate several aspects of and conditions for older adults' participation in everyday life. In the following some methodological challenges in relation to qualitative and quantitative data will be discussed, respectively.

### ***Cautions related to production and interpretation of the qualitative data***

In qualitative research, reliability is closely connected to the trustworthiness of the produced knowledge. It also depends upon the researchers' knowledge and competence on the topic in order to analyze the data in a valid and trustworthy way. One way to strengthen trustworthiness is to aim at transparency in presentation of the methodological approach (Kvale, 2002). The constructivist grounded theory approach represents in and of itself a systematic approach with flexible guidelines, which may facilitate transparency. I have, in this chapter and in the papers, described the processes and procedures leading to the findings, while I made visible the coherence in the findings and core categories across studies in the articles and also in the general discussion (chapter 6).

The beliefs that people assign meaning to the world, that their experiences are situated within a historical and social context and that there are multiple realities are central to qualitative studies. A constructivist grounded theory approach considers a reflexive stand in relation to the production and presentation of necessary knowledge (Charmaz, 2006). During the interviews with the older adults I discovered for example that my own ideas of their participation at first were influenced by the experiences of the service providers in study I and also by the media. Firstly, I had expected the older adults to be more critical to service providers and delivery. Secondly, I was impressed by the older adults' engagement and the variety of strategies used to maintain participation in everyday life despite illness and impairments. How my expectations and experiences could influence interview situations and possibly force the data analysis was continually discussed and reflected on with co-authors.

The aim of qualitative studies is an analytical generalization, indicating a reflective judgment about the extent to which findings in one study can be used as a guide to what might occur in similar situations or contexts (Kvale, 1998). Illumination, understanding and transferability are central aspects (Golafshani, 2003). Consequently, the findings in papers I, III and IV suggest a possible understanding of how participation, personal and contextual factors could be understood in similar samples and conditions to these studies (Patton, 2002).

The transferability of the findings could be understood in relation to the study participants' or relevant others' recognition or identification of the descriptions in the text. People with special knowledge on the topic and their identification of theoretical interpretations may also represent a test on the transferability. In my case, I have discussed this type of transferability and confirmed it in communications with my supervisors and colleagues and during PhD courses, seminars and presentations at conferences.

The research in this thesis may contribute to challenge possible stereotypes and ideas of older adults as lonely, fragile and passive recipients of support, much of which comes through the media. From such a perspective, one should probably not expect the findings to create immediate recognition among people in general or among staff in the home care services. However, one could expect the findings to create interest and curiosity at organizational levels of services for older adults, at educational levels and also among people in general, because aging in place concerns everyone.

#### *Inclusion of participants*

The participants in papers III and IV were recruited by nurses in the home-based services. They were initially contacted by phone by the first author and were provided thorough information about the project. The nurses were at first asked to recruit older adults with variations in age, gender, living accommodations, illnesses and functional reduction. The necessity of informing potential participants in a simple but sufficient

way and the necessity of informed consent was emphasized and discussed. How to give simple but complete information about the research project was also emphasized in the dialogue with the nurses. However, some of the nurses who were asked to recruit participants expressed having a large workload. They felt that recruitment could be difficult and take much of their time. Furthermore, the project concerns older adults' participation in general as well as their participation with the service providers in particular. Taken together, these aspects may have persuaded the nurses to avoid asking older adults that were obviously critical to home-based services at that time to participate. They may have chosen those having the best socio economic conditions or the most content with services and service providers and easiest ones to ask. Nevertheless, the nurses recruited participants whom they considered capable and felt would benefit from taking part in and accomplishing an interview about the topic. Even though the aspects mentioned above may have influenced the sample and the data, other studies confirm that Norwegian older adults are mostly content with services (Huseby & Paulsen, 2009) and that a majority of Norwegian older adults experience good socio-economic conditions (<http://www.ssb.no/inntind/main.html>; 09.08.2012)

Another question of legitimacy is whether the sample sizes in studies I, III and IV are adequate for transferable data. However, sample size is determined by informational considerations (Patton, 2002; Robson, 2002). Selection depends upon the point of redundancy, and information must be gathered until one reaches diminishing returns (Strauss & Corbin, 1998). We found that after the sixth focus group discussion with service providers (study I) and the tenth interview among older adults (studies III and IV), no information emerged that provided new theoretical insight into the properties of the categories in the studies. Thus, our data collection ended at this point. One could argue that the legitimacy of the research also depends upon to what extent the findings are supported or confirmed in other studies or future research. Thus, one way to follow up on potential problems with sample size is to collect new cases and build future research on the existing data material (Charmaz, 2006). However, as described in the previous sections in this chapter "Study design" and "Selection of participants related to data collection and analysis – implications across studies," findings from the different

studies in this thesis have contributed to elaborate, corroborate and complement each other. This will be further discussed below.

***Cautions in relation to production and analysis of the quantitative data***

One can assume that being an older adult and in need of home-based services can be experienced in a variety of ways due to age, functional reductions, illness and a variety of personal and environmental factors. Thus, in study II, it would have been interesting to include older adults with low, moderate and high levels of service needs in the sample, as older adults with high levels of service needs were not included in this study. Hence, the homogeneity of the sample places restrictions on the generalizability of the findings to other groups of older adults. Furthermore, ages ranging from 67-100 represent more than one generation of older adults. One may therefore question whether including a more homogenous sample in terms of age could have produced different findings. Caution should thus be taken when transferring the findings to other socio-cultural, organizational and time situations. However, this sample with minor service needs is an important group to study, because they will reach frailer states and over time are in need of higher levels of home based services. In order to delay or transform a transition to frailer states in this group of older adults, knowledge of their situation and their needs is necessary. Building upon findings in studies I and II, and in order to gather complementary data, we also included older adults with major needs for home-based services in study III. Interestingly, and thus strengthening the trustworthiness, findings from both studies II and III indicate that one should look beyond service needs, activity performance and capacity when considering participation and satisfaction with participation. Taken together, our findings are in accordance with studies by Levasseur et al. (2008) and Cardol et al. (2002).

Study II was conducted in one Norwegian municipality, and the findings could thus reflect characteristics of living in this particular context and the home-based services offered in this specific municipality. This limitation emphasizes the need for research on participation and satisfaction with participation in different cultural and organizational



contexts. Our findings could thus be useful for comparisons with findings in other contexts.

In study II, a questionnaire not validated for the study group was used, and some of the instruments were translated from English to Norwegian. An extensive translation process was initiated, including both language and content, in order to accommodate the cultural context. This process of preparing the questionnaire was accomplished in collaboration with co-researchers and technical support from the Norwegian University of Science and Technology (NTNU). Trial interviews were also accomplished with two older adults in order to assure the quality of the questionnaire.

An important aspect in relation to validity is whether the question asked really measures what it intends to measure. The validity of the satisfaction with participation variable in the questionnaire was considered to be good according to discussions and judgments in the group of researchers. The adjustments of the questionnaire in relation to the translation process was also discussed with and confirmed by the instruments' originator, David Gray, and his colleagues at Washington University, St. Louis.

However, in paper II, the principal component analysis that was undertaken on the satisfaction with participation variable showed that several factors loaded above .4 on both factors. Nevertheless, two variables were maintained based upon the theoretical relevance and high reliability scores and made the outcome variables in the study. For further details about the methodological considerations in relation to the analyses undertaken, see "Study limitations" in paper II.

The interview-based survey was carried out face-to-face in the older adults' homes in order to clarify questions and concepts with the respondents. To strengthen reliability, the first author carried out twice as many of the interviews compared to the colleagues and had regular meetings with the other colleagues in order to discuss challenges related to the questionnaire and interview situations and to ensure that interviews were carried out in a similar manner.

One should bear in mind that a survey with data collection at one point in time provides weak evidence for causality between surveyed constructs, compared with longitudinal designs and of course controlled experiments. One may argue that the focus group discussions, the qualitative interviews and the survey represented mere snapshots of behavior and attitudes at one time and place, and that this is a general weakness with the empirical data for this thesis. However, the participants' presentations are valid for them in the variety of situations they described (Kvale, 1998). Accordingly, I believe that their stories have validity for other older adults living in similar life situations.

## 5. Findings

**Study I:** Witsø, A.E., Eide, A.H., & Vik, K. (2011). Professional carers' perspectives on participation for older adults living in place. *Disability and Rehabilitation*, 33: 557-68.

This qualitative study focused on the concept of participation from the perspectives of professional service providers and their experiences and descriptions of older adults' participation in everyday life when living in place and receiving home-based service delivery. The main finding was that the professionals understood the older adults' participation as taking part in their own life, which included carrying out tasks in everyday life in two different contexts: inside the house and outside the house.

According to the service providers, the older adults spent most of their time inside the house carrying out and doing small tasks and daily matters as well as hobbies such as watching TV, doing crossword puzzles or listening to the radio.

Participation as carrying out tasks outside the house was perceived as limited to a nearby radius and exemplified as going grocery shopping and to the hairdresser.

Nevertheless, the professionals perceived that the older adults participated in society

and happenings by engaging in news and input from media in their own homes and that the older adults thus could feel that they were participating in society even while they were taking part indirectly.

The professionals also related participation as carrying out tasks to attending organized social activities such as municipal day centers which were widely offered, including making use of organized transport in order to get to the day centers. Other social activities that were mentioned were attending meetings in organizations like the Lodge and making use of shared communal areas close to home.

Participation was also understood as interaction with the service providers and was perceived as being included and taking part in decision-making, which represents a universal need for being in control. The staff considered the older adults to be in great need of social participation and they put emphasis on their own role in the older adults' social life. Participation as interacting in service delivery was thus referred to as being both at an intellectual and interactional level.

Furthermore, participation as keeping up and regaining functions was considered an important task. Thus, the professionals experienced the older adults' choices not to participate or handing decisions over to the service providers as dilemmas for workers in the service delivery. They also shared an understanding of the older adults giving up doing small tasks, wanting the staff to do the tasks for them and spending increasing time waiting for the service providers to come. They considered their own role as influential and critical to the older adults' opportunities to participate in decision-making, such as lack of time and motivation. The most common view was that service delivery itself contributed to passivity and helplessness in the older adults.

**Study II:** Witsø, A.E, Eide, A.H., Vik, K. (2012). Older homecare recipients' satisfaction with participation in daily life activities. *Physical and Occupational Therapy in Geriatrics*, published online, April 2012.

This quantitative study examined relationships between the satisfaction felt by older adults receiving home based services (N=155) with participation in “domestic and private” and “outward” everyday activities and self-reported activity performance, health (feelings and overall health scores), physical/structural barriers and frequency of homecare services. The participants in the study (mean age 82.99, SD 6.03) were interviewed based upon a questionnaire that included questions on “satisfaction with participation” from the Participation of People with Mobility Limitations Survey (PARTS/M; Gray et al., 2006). The distinction between “outwards” and “domestic and private” activities was made in light of a principal component analysis. This finding supports the distinction between different contexts for participation as found in study I.

A main finding was that no significant correlations between the outcome variables and frequency of home based services were found. This finding is somewhat contradictory to the professionals’ perception of their own professional role in older adults’ lives as pointed in study I, which indicated that professionals believe that older recipients of services are in need of more social participation with the service providers than the service providers can provide due to organizational barriers.

The findings support, however, the assumptions that older adults’ satisfaction with participation in both “domestic and private” and “outwards” activities is associated with self-reported activity performance, overall health and emotional well-being. The main findings from a standard multiple regression were that the feelings and activity performance scores were the strongest predictors of “domestic and private” participation satisfaction, while the overall health score and physical/structural barriers were the strongest predictors of “outward” participation satisfaction.

The study supports the importance of looking beyond activity performance when considering participation and participation satisfaction. The role of professional home based services, the impact of self-perceived health and activity performance in older adults’ daily lives all point to a need to explore further their participation with home based services as experienced by older adults themselves.

**Study III:** Witsø, A.E., Vik, K., & Ytterhus, B. (2012). Participation in older homecare recipients: A value-based process. In press: *Activities, Adaptation and Aging*.

This qualitative study illuminates the experiences of participation in everyday life in general among 10 older adults living in place and receiving home-based care. (Their experiences during their participation with the service providers are reported in study IV.)

The main finding was participation identified as “keeping up dignity and pride,” representing a value-based process of fending for oneself. This was defined as concentrating on being an agent, including a process of accepting and acting upon changing capacity and barriers. Participation included practical, emotional and intellectual dimensions and strategies for behaving flexibly and in accordance with change in both individual and external conditions. It turned out that participation took place in three contexts: at home, in the neighborhood and in activities and relationships beyond home and neighborhood.

Keeping up dignity and pride concerned a process of getting oneself going in everyday life and of keeping one’s place at home, in the neighborhood and within the family. Participation was related not only to following routines and doing regular daily life activities as usual but also strategies of trying and striving to fend for oneself. Participation was further experienced as doing and engaging in meaningful leisure activities alone or together with others in meaningful places such as home or in the neighborhood. Changing capacity claimed time that the older adults could have spent on performing activities important to them, so they emphasized finding the right balance for participation in activities. Hence, participation was related to personal attitude and values.

The roles of family, friends and neighbors were emphasized and continuity, community and belonging were sought through a variety of activities and social participation. Adaption in order to maintain equality, reciprocity, control and autonomy in social relations became important.

The role of the physical environment (such as an accommodation that provides an individual access to regular social participation), a feeling of security and choice of a variety of common activities was emphasized. For those who did not have access to neighbors, daily visits from service providers became important.

The study shows that it is critical to understand the function of older adults' practical, emotional and intellectual strategies as well as to understand their efforts and strivings, what types of personal and environmental resources they have and how they utilize them in order to fend for themselves in everyday life.

**Study IV:** Witsø, A.E., Ytterhus, B., Vik, K. (2012). Taking home based services into everyday life – Older adults' participation with service providers in the context of receiving home based services. Submitted in *International Journal of Older People Nursing*

This qualitative study illuminates older adults' experiences during their participation with service providers and with the home-based service system. Participation was identified as taking home based services into everyday life, representing a process of responding to changing capacity, and was characterized by emotional and intellectual aspects of participation. The experience of participation was identified as balancing agency and expecting joint responsibility for appropriate service delivery. The older adults were mostly content with the service providers but experienced organizational obstacles in the service system, such as delays and the providers' lack of skills. The older adults felt that these were barriers to their participation in everyday life.

Participation was also identified as social participation with the service providers, which was experienced as subordinate to practical and personal support in everyday life activities. However, the older adults appreciated the small talk dimension of socializing with the service providers. This dimension relates to basic human needs and social roles such as enjoying the feeling of and exchange of kindness, civilities, sense of humor and being confirmed and recognized as a human being. Furthermore, social interaction with the staff represented a way of linking to society, because the staff members differed in gender, cultural backgrounds and ages. Participation with the home-based service system also represented a sense of security and belonging.

# Paper I

Is not included due to copyright





# Paper II

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# Paper III



## **Participation in older homecare recipients: a value-based process**

**Witsø, A.E., Vik, K., Ytterhus, B.**

**Activities, Adaptation and Ageing (In press, Dec.2012)**

### **Abstract**

This article aims to increase the understanding of participation when aging in place. The qualitative interviews of 10 cognitively healthy Norwegian homecare recipients (72–89 years) illuminate how they describe participation in everyday life. The core category identified was “keeping up dignity and pride,” representing a value-based process of fending for oneself, including accepting and acting on changing capacity, and concentrating on being an agent in everyday life. Additionally, the two categories “getting oneself going” and “keeping one’s place: at home, in the neighborhood and in family” included the older adults’ descriptions and understanding of participation in their everyday lives. In order to promote participation, the professionals in homecare services must recognize and give attention to the older adults’ variety of participatory strategies in everyday life.

### **Introduction**

The number of older adults aging in place with functional limitations and chronic conditions is increasing, and represents a challenge for societies with regard to recognizing their resources and their place-specific experiences and needs (Eurostat, 2010). The majority of older people wish to live as long as possible in a familiar environment, with “place” including homes, neighborhoods (Gardner, 2011), and communities (Gitlin, 2003; Oswald et al., 2007). The World Health Organization’s policy ideal is to enable older adults’ participation (WHO, 2002). Participation in meaningful activities is known to promote both physical and mental health (WHO, 2002), to prevent loneliness (Newall et al., 2009; Thorsen & Claussen, 2008), and illness (WHO, 2004). Participation is an important factor to understand older adults’ dignity (Van’t Leven & Jonsson, 2002), healthy aging (Andrews, Cutchin, McCracken, Phillips, & Wiles, 2007; HAR Network, 2011), and well-being (Adams, 2011; Law, 2002; WHO, 1999), and hence is important for enabling successful aging in place.

Studies on participation in older adults mostly concern participation in very old age (80+); others consider participation in physical activity, in different kinds of treatment, in rehabilitation, in the context of home, and in civic engagement. There is limited knowledge concerning older adults’ experiences of participation when living in place and receiving

home-based care, and how perceived participation influences the process of aging in place (Witsø, Eide, & Vik, 2010). Therefore, by highlighting older peoples' voices we can make it easier to understand their experiences of participation in everyday life and contribute to the discussion of effective home-based services.

The concept of participation is widely discussed and may have diverse meanings. The International Classification of Functioning (ICF) framework has contributed to the development of research on participation in several contexts during the last 10 years (Cerniauskaite et al., 2011). Within the ICF, participation is defined as "involvement in a life situation" (WHO, 2001). However, recent empirical research has contributed to further conceptualize the construct from the insider perspectives of different groups. Hammel et al. (2007) found that participation was understood as a cluster of values. Haak et al. (2008) found that for very old adults, home is the locus and origin for participation, and that participation was experienced by means of engaging in the performance of activities, and as a feeling of togetherness with others. Vik, Nygård, Borell and Josephsson (2008) studied home-based rehabilitation and found that older adults experienced participation as engagement in daily life activities. The older adults were motivated by strong needs for control and ambitions to make their own decisions about daily life in their encounters with healthcare workers.

Several studies show that participation is closely connected to environment (Law, 2002; Shippee, 2011; Vik, Nygård, & Lilja, 2007). Studies of older adults who receive home-based care have found fewer opportunities for participation and maintaining an active life (Brown, McWilliam, & Ward-Griffin, 2006; McGarry, 2009; Vik, 2011a; Vik & Eide, 2011b; Vik et al., 2007; Witsø et al., 2010). Depending on homecare services is an important environmental factor in the present study. A possible discrepancy in perspectives of older adults' participation in everyday life, between professionals in homecare services and the older adults, may in itself represent a barrier to older adults' participation and to the organization of effective home-based services. Clearly, it is of importance to generate knowledge about older adults' understandings and experiences of participation in everyday life in general and in the context of receiving home-based care in particular.

The purpose of this article is to illuminate and understand older adults' experiences of participation in everyday life when living in place and depending on home-based care. Their perspectives on participation with the home carers will be reported elsewhere.



## **Methods**

The article is based on qualitative in-depth interviews (one to two hours) of 10 older Norwegian adults (eight women and two men, aged 72-89 years) with age-related and physical impairments and illness. A grounded theory approach was utilized to explore the meanings, experiences of, and conditions influencing participation. The interviews took place at the older adults' homes and were situated in a Norwegian city of 170,000 inhabitants during autumn and early winter 2011. The study was legally and ethically approved by the Norwegian Social Science Data Services ([www.nsd.no](http://www.nsd.no), 2010) and the regional ethical committee ([www.sprek.no](http://www.sprek.no), 2010), respectively.

The participants were recruited by purposeful sampling as described by Charmaz (2006), comprising variation in gender, age, living accommodation, social situation, level of care, and health problems. Practically, recruitment was completed by professional caregivers in the homecare services. All of the informants lived alone, with the exception of one woman who lived with her husband in a single-family house. Housing, major health problems, and level of care are described in Table I.

Particip.	Age	Impairments	Habitation	Walking aid/device	Homecare services	Care intens.*
1 Anne (F)	79	Hip operated, stiffness	Single-unit dwelling, alone	Rollator inside/outside, wheelchair for transportation outside	Bathing/shower, on/off with support/medical stockings, getting rid of garbage, fetching post/mail, cleaning, safety alarm	middle
2 Peter (M)	86	Chronic pain in neck and shoulders, stiffness	Single flat in assisted-living block, alone	Rollator when shopping	Home nursing care (×1), cleaning, safety alarm	low
3 Christine (F)	76	Dizziness, frequent faller	Single flat in senior housing block, alone	Rollator inside/wheel chair outside	Home nursing care (×4), personal care, inspection call, cleaning, safety alarm	high
4 Tor (M)	72	Neurological disease	Single flat in senior housing block, alone	Rollator outside	Home nursing care (×2), inspection call, cleaning, safety alarm	middle
5 Mary (F)	82	Hip-operated, knee-operated, pain	Single flat in assisted living block, alone	Rollator inside/outside	Switch on/off the stove, private cleaning, safety alarm	low
6 Elisabeth (F)	84	Hip-fracture operated, visually impaired	Single flat in block, alone	Rollator inside/outside	On/off with support/medical stockings, private cleaning, safety alarm	low
7 Carla (F)	85	Brittle bones	Single unit dwelling, alone	Rollator inside, wheelchair outside	Home nursing care (×4), personal care, fetching post/mail, meals on wheels, cleaning, safety alarm	high
8 Marianne (F)	72	Visually impaired, reduced walking ability	Single unit dwelling, with husband	Rollator inside/outside	Personal care (×2), physiotherapy (×4 per week), private cleaning, safety alarm	middle
9 Ingrid (F)	89	Dizziness, fatigue	Single flat in joint senior ownership, alone	Rollator on hold	Home nursing care (×1), safety alarm	low
10 Lisa (F)	87	Neurological disease, frequent faller	Single unit dwelling, alone	Rollator inside/outside	Personal care (×2), cleaning, meals on wheels, preparing breakfast/lunch, physiotherapy (×2 per week), safety alarm	middle

**Table I: Participant characteristics**

\*Based on IPLOS (Individual Needs of Nursing or Care Services Statistics, Norway), estimating an arithmetic mean of a group of five variables: social functioning, attendance of health, housekeeping, personal care, and

cognitive functions. Giving the scores: some/restricted (low), medium/great (middle), comprehensive (high) need of assistance.

The interviews were performed by the first author, and were recorded and transcribed verbatim. The names of all informants are altered in the text. All authors have contributed to both analysis and writing of the article.

### *Analysis*

The analysis was based on a constructivist grounded theory methodology as described by Charmaz (2006), representing flexible yet systematic guidelines for collecting and analyzing qualitative data. A key feature in grounded theory is that data collection and data analysis are kept concurrent by initial and focused coding and by writing memos. A constant comparison during each stage of the analysis (Strauss & Corbin, 1998; Bryant & Charmaz, 2007) of data with data, codes with codes, and categories with data and codes was accomplished.

Thus, the codes from the initial coding process and the codes from each interview were constantly compared, e.g., “following a rhythm in everyday life,” “needing security in daily life,” “emphasizing one’s personal values,” “receiving carers from the public homecare services,” “socializing with neighbors and friends,” “having family visitors,” “doing leisure activities,” and “using technology aid.” The focused codes developed through a refining process of further comparison of data to data and data to codes. The authors discussed the content of each focused code and the relation between them before deciding where they could and finally should belong.

The core category was finally identified as describing older adults’ participation as “keeping up dignity and pride.” The category consists of two main categories: first, “getting oneself going,” and second, “keeping one’s place.” “Getting oneself going” includes the participants’ understanding and definition of participation in their ongoing everyday life, mainly in the context of home, but also to some extent outside the home (see Table II). “Keeping one’s place” covers different dimensions of social participation. Both categories include practical, emotional, and intellectual aspects of participation (see Table II).

<b>Keeping up dignity and pride</b>	
<b>Getting oneself going</b> <ul style="list-style-type: none"> <li>○ Following the regularities of everyday life</li> <li>○ Trying and striving to fend for oneself</li> <li>○ Making one's practical arrangements for daily life</li> </ul>	<b>Keeping one's place: at home, in the neighborhood and in the family</b> <ul style="list-style-type: none"> <li>○ Making home a meaningful place – continuity and belonging</li> <li>○ Linking to the external world</li> <li>○ Being a family member</li> </ul>

**Table II: Core category, categories, and sub-categories**

## **Findings**

### ***Keeping up dignity and pride***

Fending for oneself, in the sense of keeping up dignity and pride, as long as possible – in place – emerged as the most outstanding value and the main project in the older adults' lives. The two main subcategories, "getting oneself going" and "keeping one's place," represented processes concerning concentrating on being an agent in day-to-day life, including accepting and, at the same time, acting on instable capacity and changes in everyday life, in order to keep up a meaningful day-to-day life. A dimension of participation as agency relating to both main categories was "holding on to one's values." When energy and capacity decreased, the older adults acted upon their daily and regular activities and social interaction – on the basis of their values. Priorities were given in correspondence to participation giving personal meaning. Being able to live everyday life based on personal values represented connection to and continuity in time, place, and self. Values gave directions to how the informants participated on their own and together with others. Holding on to values made it possible to maintain a sense of control and continuity.

Participation seemed to take place in three contexts: (i) at home, (ii) in the neighborhood, and (iii) in activities and relationships beyond home and neighborhood. Participation was described in three dimensions: practical, intellectual, and emotional. Practical dimensions refer to the older adults' ways of organizing and arranging practically in everyday life.

Emotional dimensions of participation refer to the feelings participation evoked, like satisfaction, anger, or frustration. Finally, intellectual dimensions refer to how the older adults handled the feelings evoked by participation in different contexts in everyday life, i.e., their ways of staying rational, planning, and reflecting on their participation in old age and with changing capacity.

### ***Getting oneself going – structuring and organizing everyday life***

The main category “getting oneself going” represented a process concerning the older adults’ ways of following, structuring, and organizing ordinary everyday life activities – contributing to the overall project in the older adults’ life; fending for oneself in the sense of keeping up dignity and pride. “Getting oneself going” was about “following the regularities of everyday life,” “trying and striving to fend for oneself,” and “making one’s practical arrangements for everyday life.” The three subcategories included different ways of experiencing and expressing participation as “getting oneself going.” All subcategories expand on the process of acting upon changing capacity and concentrating on being an agent. To get oneself going also included practical, emotional, and intellectual dimensions and contributed to keeping up dignity and pride on a regular daily basis.

### *Following the regularities of everyday life*

Means of getting oneself going in everyday life were following personal routines and preferences and habits that made an obvious, meaningful, and continuous structure in the older adults’ lives and, thus, on the basis of and in accordance with their personal values. The regularity comprised doing the same daily activities from day to day, at approximately the same time. The calls and visits of the home carers seemed to enter into the routines and were also considered a natural part of daily life.

*[...] I get up in the morning and go to the bathroom on my own [...] I stand by the washbasin and wash myself. Then I make myself some breakfast, either oatmeal porridge or two slices of bread and tea. Then one of the home carers arrives just after breakfast and helps me with my stockings. I get up early, you see, usually at seven or seven thirty. I like getting up early, because when I get tired I just walk in there and sit down in the armchair, and then I can watch the telly, take a nap and watch the telly again. (Elisabeth, 84)*

Other regular activities were watching the television news and weather reports, having the radio on and reading the newspaper every day, having regular days for attending day-care centers, going shopping, and eating dinner with relatives or friends. Illness and impairment made them feel more weary and tired. Hence, resting became a natural and regular part of daily life. Generally, the informants wanted to continue their regular activities. In order to do so, they adopted new ways and strategies of creating variation within the regularities, thus representing practical aspects of participation:

*I go for short walks every day now, several times. It depends on my legs. In between the walks, I have to go inside and lie down and rest. (Mary, 82)*

Following the regularities of everyday life and keeping up a continuous day-to-day structure represented practical and structural dimensions of getting oneself going in the older adults' everyday lives. However, being marked by reduced and instable capacity also challenged the older adults emotionally and intellectually. Thus, keeping up dignity and pride was associated with a certain extent of strain and struggle. The next subcategory embraces participation understood as the older adults' value-based strategies to act on emotionally, practically, and intellectually demanding parts of "getting oneself going" in everyday life.

#### *Trying and striving to fend for oneself*

The value of *fending for oneself* was something that everyone, regardless of assistance needs, was concerned with. The aspect of fending for oneself was not necessarily a question of being without assistance, but was related more to agency in the meaning of preserving one's own pride and dignity. One way of acting as an agent could, for example, be to consciously attempt or try (not giving up). To try, even if one did not always succeed, was seen as extremely important to the respondents. Carla (85) was among the least mobile and in the most need of assistance, but said:

*It's important for me to have it neat [laughs], but I cannot do that. But I try, you know. It's important to try, but I quit fast, though. Yes. Because when I lift my hands, I feel it [...], but if one is just to sit and feel sorry for oneself, it will just go down the drain [laughs], and I don't want that to happen.*

The values gave direction to how the participants tried to live up to the project of fending for oneself, which could be seen as an ongoing task. Changed and varied capacity could add some strain to getting what one wanted, which again created frustration – and the participants said that they could be both angry and sad when they perceived that their participation was limited. They still had strategies, e.g., taking their anger out on the rollator, feeling sorry for themselves for a short time, pulling themselves together and moving on, praying, or using their sense of humor. Acting on the feelings it evoked represented emotional aspects of participation. For Tor (72), it worked to have a reckless attitude, instructing himself, using commonsense, talking to himself:

*Things get so much easier if one can get a bit reckless [... T]he use of swearwords ... gives you a bit of extra adrenaline ... a bit of a kick, yes, so I mobilize my temperament... I think I'm pretty good at that. I think I have learned that, because it is getting easier getting up in the morning than it used to be.*

Humor was a much used strategy for facing altered capacity. Mood became important, both when being alone and in managing to get oneself going. Interestingly, experiences of having been worse off in relation to previous impairments and experiencing levels of participation going up again seemed to help them to be open to the possibility of resuming participation in activities that were important to them.

The participants expressed being happy with their own participation when they succeeded in whatever goal they set for themselves or in what they thought was important to succeed or participate in. If they had to fight a bit, they would, in addition, experience it as a victory when they succeeded.

A common strategy among the older adults was that, despite their pain and trouble with illness, they experienced their situation as good and they basically felt well. This seemed, among other things, to be related to the understanding that it could have been worse. This understanding seemed to be affected by the way media portrays older people's situation. Mary (82) put it like this: *"But you know... you read a lot of strange things, the headlines of the papers... but, of course, there are some having a hard time too. But I feel very privileged."* Gathering confirmation from the outside world to confirm one's health not being as bad as it

could be was another strategy to keep belief in one's ability to fend for oneself and thus a strategy to getting oneself going: "*Yes, in relation to how it could have been, so... I have a GP that I see... he thinks it looks good, yes.*"

Another aspect of getting oneself going was about *finding the right balance for participating in activities and taking one day at a time*. To balance the quantity of activities could, e.g., be a question of deciding to hand away simple tasks; this could be either tasks that were not experienced as important to do anymore, or tasks that were too demanding. In this sense, balancing represented both intellectual and emotional aspects of participation in order to fend for oneself and keep up dignity and pride. Handing over the responsibility for finances to a son or a daughter could, e.g., be related to a feeling of relief ("*I think it's so nice; I have more than enough with the problems I have... I think it's good that she is responsible for it*" – Elisabeth, 84), or to ambivalence ("*in one way it's a bit sad, but on the other hand it's nice too, not having to do it*" – Christine, 76).

Finally, a value-based way of thinking about consequences of old age and changing health was to not take the future for granted. The older adults did not plan far ahead, but rather lived according to the motto "one day at a time," and thus also represented an intellectual aspect of participation.

#### *Making one's practical arrangements for daily life*

Prevention and compensation for further decrease in function was about *making the best out of physical environments*. Many of the participants had made changes to their housing situations. Four of them had moved away from houses that were unmanageable to assisted or senior housing. To adapt practically in everyday life was also a question of "better safe than sorry." Most of the older adults had, for example, removed typical obstacles and fall-traps such as thresholds and carpets. Further, to avoid incidents because of the pain in his arms, Peter (86) said that he shopped only a little at a time, and often. He could not, for example, open the lids on bottles and jars, and handled that in the following way"

*I try to avoid buying those beetroots and jars that are really tight, and the same with those jam jars, and, if I do, I get the people at the store to open them for me, loosen the lid and put it back again, and put plastic around so it doesn't get all messy.*



Further, to avoid situations of helplessness the participants planned and asked for restricted help in restricted situations. Thus, planning and arranging creatively in these ways represented participation at both an intellectual and practical level.

In summary, “getting oneself going” embraced participation understood as the process of acting on changing capacity in ordinary daily life activities, in order to continue to fend for oneself at home. This process included following, structuring, and organizing regular daily life and developing and adjusting strategies in order to overcome challenges related to changing capacity and illness and thus to keep up dignity and pride.

### ***Keeping one’s place: at home, in the neighborhood, and in family***

In order to keep up continuity, in the sense of dignity and pride, the older adults acted on the implications of changing capacity to their social roles and recreational and social lives. They had strategies to keep and fill their places instead of passively receiving or giving up their places in recreational and social life. As for the previous category, home and neighborhood were the most important contexts for participation. However, the present category additionally embraces the context of family life and includes the dimension of belonging.

The first subcategory illustrates the process of acting on changing capacity and the home environment in order to make home a meaningful place in relation to activities and memories – linking present and past. The second subcategory highlights dimensions and functions of social participation, as connecting and belonging in the neighborhood in particular and to society in general. The third subcategory embraces participation as the older adults’ strategies to belong and keep up agency in family.

### ***Making home a meaningful place – continuity and belonging***

The recreational activities were characterized by less routine and more stated pleasure compared to following the everyday life regularities; however, both were characterized as taking place at home and representing continuity in everyday life. The older adults kept up their favorite activities at home, but took breaks more often than in the past and waited for, for instance, the pain or rigidity to go away. The valued activities kept up participation and made home still a meaningful place to be.

Tor (72) had deliberately chosen to fill his small senior apartment with what consumed him the most, which was the building of mechanics and clocks. He said:

*I have my hobby standing around here, so whichever corner I end up in I have clocks standing or hanging [... T]hat is a detail I remember, when my parents got that clock over there [...] when I was eight, 10 years and sat behind the clock and just looked at what was inside, just watched it. I was so fascinated by it.*

Not surprisingly, the home represented a personally significant environment that seemed to be able to stimulate participation and feelings of belonging and attachment. Interestingly, both attachment and belonging were also experienced in the present place by the older adults who had moved from a home where they had lived for years to senior accommodation.

Moving to something smaller and more functional had admittedly meant a reduction of items, rooms, and furniture with sentimental value. For Mary (82), however, the move, which was based on her choice and wish, had made it easier for her to realize fending for herself.

Memories were alive inside her mind, and she could reminisce about funny things from long ago during lonely nights:

*It can be when I go to bed at night and have turned off the light and I can remember a trip or another. We did a lot of traveling, my husband and I. So there are many fun trips I have thought a lot about, because then I experience it all over again.*

As we have seen, participation in valued recreational activities in their own company at home was central to creating continuity, belonging, and meaning for the older adults. However, we will see how continuity and belonging was additionally maintained by actively engaging in different types of social and outward-oriented participation.

#### *Linking to the external world*

The neighborhood was an important arena for social participation for all participants. Living in senior accommodation gave physical connection to common areas like the hallway, common rooms, and meeting places by the mailboxes, as well as access to organized activities facilitating social contact like arranged activities such as common lunches, bingo, and exercise, etc. The proximity and variation in supply of activities were brought forward as something positive for participation and something that allowed for continuously being an agent of social life. Reported drawbacks of senior accommodation included a tendency to talk a lot about illness, and Tor (72) brought forward the importance of having a conscious relationship to one's neighbors. Important to him was: "[...] *to establish a good relationship*

*with neighbors and kind of select the ones you might not want to have a lot to do with, and those who are good to have a connection with.”* In this way, he participated in terms of both keeping and taking a place in the neighborhood.

For all informants, participating in the neighborhood had many functions, such as sharing interests in the local arenas and physically belonging somewhere, hence representing both intellectual and emotional aspects of participation. Important functions that participation by taking one's place in the neighborhood could bring were recognition and affirmation through sharing stories, activities, and values, giving mutual help, and the fact that people could feel connection by being of the same generation/time. Ingrid (89) said:

*Me and a neighbor of mine, we talk each day, because we have decided to look out for each other. So if we are free on Saturdays, if one of us isn't going away, we ask each other over and we sit from half past seven, eight, to around ten and then it's over. Yes. We are so similar it's almost scary. I sort of, I guess we are brought up in the society we had in the old days. It was called a civil society.*

The participants placed great value on the community, but at the same time they stressed autonomy and did not want to bother their neighbors. Regular social contact and the possibility to chat face-to-face every day became important. For the participants living without access to neighbors, daily visits from home carers contributed to fill the small-talk needs, even though the carers historically had grown up in different eras.

When mobility decreased, outings in the neighborhood became important, and this gave the older adults the feeling of being a part of the local world. An outing could be a walk to the neighborhood store or the city center or a taxi ride to the shops to watch the bustling life there, representing both practical and emotional aspects of participation. Mary (82), with limited mobility, said:

*I take a taxi over there, so I get to see some people, and I get to see what it looks like in town, sit down a bit, and do some shopping. Then I must lie down the rest of the day when I get home, because it's such a strain. But it is worth it, oh yes! You get some inputs impulses and you get to see what it's like in town.*

Another dimension related to “linking to the external world” was *having close friends*. In contrast to neighborhood contact, which was more superficial, the respondents talked of their deeper friendships. These friendships, which preferably had a long history, also included relationships to siblings. They seemed to be very important to the older adults, and offered an opportunity for closeness, togetherness, and belonging – all elements of keeping one’s place. In contrast, the loss of old and close friends or siblings could deprive the participants of a good conversation partner and community, but also social activities related to participation with the person who passed away.

For those informants who could not meet their friends physically, the phone became important:

*I have a friend [...] and the other day we talked for a whole hour on the telephone [laughs]. Oh yes, it's the whole life, you know. [...] We're in contact as often as we can [...] and we have written to each other and sent gifts for birthdays and Christmas, every year, this must have been since we were in grade four. I can call her and say anything.” (Anne, 79)*

A third dimension is *taking part in social fellowships and leisure activities outside home or neighborhood*. The older adults also participated in activities such as volunteer work, club meetings (work or sewing), cinema, concerts, visits to day centers, and rehabilitation activities led by professionals. Some of the participants compensated for the loss of personal capacity of participation in outward-oriented activities by inviting the “world” to their own homes, representing both practical and emotional, but also intellectual, aspects of participation. One had friends from church on regular visits. Another received visits from the library – so that loans, returns, and discussions on books could be carried out in her home:

*So I'm in contact with the library, to say the least! [...] A young woman comes here every three weeks, I think, and brings with her a big bag of books, interviews me first so that she kind of knows what to select, and she brings with her what I haven't read, and I get new ones. It is fantastic! [...] Very fun to follow new Norwegian authors, I think. So basically I get tips from the librarian. I find it very fun to follow the young writers. (Mary, 82)*

We can see from her story that not only did she keep her place by connecting to the world outside and by having the librarian visit her at home, but also through following the development of new Norwegian authors. *Being a family member*

One dimension in the subcategory “being a family member” is *maintaining independence – a joint project*. Interestingly, the older adults told about how their closest family cooperated in the “fending for oneself as long as possible project.” A common trait was that all participants received both practical and social support to some degree from their children or another close family member. Practical assistance could be providing a ride to and company at the health center or the shop instead of completing the whole task for the older adult, or assisting with parts of the cleaning or snow clearing from time to time. For some, cooperation toward independence was directly connected to the division of duties. Peter (86) said, for example: *I go to the neighboring community to buy deer meat. And then my daughter cooks the meat for me, because I’m not that good at that. So I keep it in the freezer to bring out.* Tor (72) said that his ex-wife shopped for gifts for their grandchildren and he paid for them. He thought it was a good division of duties since it was a lot harder for him to do the shopping than it was for her, and at the same time he participated by paying.

Keeping up social roles in family traditions was another way to keep one’s place, in order to keep up dignity and pride. However, changing capacity challenged the older adults in doing so. The respondents emphasized their own roles and made necessary adjustments in order to achieve or maintain reciprocity and equality in social participation with family. One way of making necessary adjustments was to replace a fatiguing activity with a less fatiguing one, while still keeping one’s place as filling a valued social role in family:

*I always hosted the Christmas dinner, but this year I will drop that. I get so tired, that’s the way it is. [...] So I have to stop that (hosting Christmas dinner). Rather a coffee table. I have decided that.* (Ingrid, 89)

Another strategy to maintain a certain equality was evident when the respondents took responsibility to adjust the shape and nature of social meetings and family activities, making it more attractive, for example, for the grandchildren to visit. Examples of this in the data were efforts to serve food that they knew appealed to children and to have games prepared for them.

A final dimension of being a family member was *joining family activities*. Central to the concept of being a family member was being in regular contact with family. The nature of the contact varied, but it was mostly carried out in the home of the older person or at the

children's home. Furthermore, they were well oriented to the lives of their children and grandchildren: where they were, what they were doing, their education and family life. In one way, this engagement could be seen in relation to "linking to the external world," but also as a prolongation of their own life and self. Further, the participants seemed to be engaged in the choices of younger family members, and had suggestions on those choices and priorities linked to, for instance, education, work, or ways of living in relation to their own values and morals.

In summary, the four dimensions of being a family member – "receiving practical and social support," "division of duties," "maintaining equality," and "joining family activities" contributed to keep up the older adults' pride and dignity as family members. Thus, feeling a sense of belonging to one's family was associated with keeping one's place in the sense of continuing to be an active member with influence on relationships and activities, and not being a passive recipient of family support.

## **Discussion**

The purpose of this article was to illuminate older homecare recipients' descriptions of participation in everyday life.

The overall experience of participation was seen as concentrating on being an agent in order to "fend for oneself, as long as possible, in place." Altogether, this process concerned keeping up one's pride and dignity. Our study identifies several barriers to participation, but the participants had a variety of strategies for acting on changing capacity and barriers in daily life. These strategies were both flexible and creative, and represented intellectual, emotional, and practical aspects of participation.

The theory of selective optimization with compensation (SOC), highlights how individual and collective processes of SOC allow older adults to engage in life tasks that are important to them despite reduction in energy and capacity (Baltes, 1997; Baltes & Baltes, 1990; Baltes & Carstensen, 1999). Hence, the findings in the present study are highly relevant to illuminate processes of SOC. According to Baltes & Baltes (1990), people show adaptiveness in choosing goals that converge with societal demands and structures, individual capacities, and personal motives. The older adults' selection processes in the present study comprised reductions or readjustments of participation in activities important to them in both regular daily life activities and recreational and social activities. In a proactive sense of selection

(Baltes & Carstensen, 1996), the findings illuminate how the older adults made a variety of environmental changes, e.g., planned for and moved to a smaller and more functional apartment or made practical arrangements inside their home, in order to prevent possible future barriers to participation like falls and further health problems and to maintain participation in personally valued and meaningful recreational activities at home. Another example of proactive selection was moving to an age-friendly neighborhood, facilitating a continuity of meaningful social activities and a sense of belonging together with other older adults. Furthermore, social participation with family was subject to selection processes of adjustments and readjustments of social roles and activities in order to maintain equivalence in family relations, thus keeping up dignity and pride.

The processes of compensation differed from selection in that the original goal of fending for oneself was maintained, but new means were enlisted to compensate for loss of capacity in order to maintain or optimize prior functioning in the older adults' lives (Baltes & Carstensen, 1996). Although the decision to apply for and accept being in need of homecare services had been forced by abrupt losses or illness or gradually reduced functions, one could say that accepting being in need of homecare services altogether facilitated the older adults' most important goal – fending for oneself at home. Other empirical studies have found that older adults struggle to their utmost in order to manage and govern daily life without support, thus representing a basis for spontaneity and freedom (Dunér & Nordström, 2005; Haak et al., 2007; Vik et al., 2008). Interestingly, in the present study the acceptance of being in need of both home-based care and family support implied in itself that independence was not understood as living without support. The participants actively negotiated a personally acceptable level of support needed with public service providers and family members. With active involvement in their own lives, the older adults seemed to come to terms with their loss of functioning in a manner that was acceptable for themselves. This finding could possibly imply that the older adults had passed turning points of being decisive in their strategies and intentions (Dunér & Nordström, 2005). Furthermore, turning points like loss in functioning and coming to need homecare services or support from family could be seen as response shifts, referring to transition periods in which expectations are redefined or reset (Rochette et al., 2006; Rapkin & Schwartz, 2004).

The analysis showed how the older adults acted on their feelings and frustrations related to reduced functioning with anger, humor, and personal instructions to themselves, all in order to get themselves going in daily life. Moreover, we found that succeeding with domestic

activities in place after struggling with them made the older adults happy with their participation. This finding, in addition, adds knowledge to the findings of recent empirical studies that participation can be understood as values (Hammel et al., 2007) and that satisfaction with participation is closely related to personal goals and priorities (Levasseur, Desrosiers, & Tribble, 2008; Witsø, Eide, & Vik, 2012) and to emotional well-being (Witsø et al., 2010; Witsø et al., 2012), and might reflect an individual's optimal participation (Rochette, Korner-Bitensky, & Levasseur, 2006).

Furthermore, the older adults applied more passive but intentional new ways of compensation for reduced functioning, like handing selected tasks over to, for instance, home carers, family, neighbors, or the grocery store staff. In addition, the ways of keeping one's place in family in the sense of sharing the completion of tasks with family members could illustrate collective compensation strategies to keep up equivalence in relations, dignity, and pride.

According to Baltes & Carstensen (1996), the process of optimization includes the enrichment, refinement, and maintenance of resources and reserves and the enhancement of adaptive fitness in selected life domains, thus involving investment in developmental tasks of old age. In one sense, one could claim that the project of fending for oneself in the sense of keeping up dignity and pride as a whole could be seen as a developmental task of old age in itself, thus representing optimization. Taken together, the older adults' practical, emotional, and intellectual strategies of getting oneself going and keeping one's place represented investment of time, energy, and persistence, thus additionally representing instances of optimization of participation as fending for oneself. Furthermore, the value of fending for oneself could represent new or refined value-based ways of thinking about participation in old age, in the sense of "accepting changing capacity," "not taking the future for granted," "finding the right balance for participation," "better safe than sorry," "making comparisons," and "taking one day at a time," thus representing ways of optimization of participation as keeping up dignity and pride.

A recent study by Witsø et al. (2010) found that professionals in homecare services did not emphasize social contact with family and neighbors as important for older adults' participation, and that the older adults more than anything were in need of social contact with the home carers. Other studies have found that homecare services often are accomplished as passive help (Vik, 2011; Vik & Eide, 2011; Witsø et al., 2010). The present study may illuminate that homecare services could have insufficient knowledge of the older adults' and



their families' "insiders' perspective" of participation and factors contributing to participation. Older adults often live in a world of underdemand rather than overdemand (Baltes & Carstensen, 1996). Hence, the older adults' strategies of selection and compensation as presented in this study might be difficult to understand from the perspective of professionals in homecare services. Efforts to fend for oneself could possibly be understood by the professionals as barriers to the older adults' quality of life.

This study has shown that it is critical to understand the function of older adults' efforts and strivings to fend for themselves in everyday life. In order to organize effective services facilitating participation, professionals need to pay attention to older adults' priorities and explore the values and goals their priorities are based on. Understanding older adults' priorities and variety of means of compensation and optimization is critical in order to support their resources and continuation of participation. In addition, one may argue that professionals should assist the older adults in the process of exploring transition periods or turning points and contribute to closing up a possible gap between reality and expectations in order to minimize barriers and dissatisfaction and maximize preferred participation.

### **Methodological considerations**

The findings in this study were based on a limited number of interviews with older homecare recipients, aged 72–89, living in Norway. The experiences of the participants cannot be generalized to other populations, but one can assume that certain aspects such as values, daily routines, habits, changing capacity, and the need for social support appear among elderly people across different societies. They may, however, be most comparable among older people living in a society with similar homecare services. Further, it is important to note that our data does not say anything about family members' opinions and experiences. Family members' stories about their parents' aging in place would have given more complete information about the older adults' participation. Furthermore, we may assume that following the participants over time could have given richer and more nuanced information about changing strategies in connection with changing capacity.

## **Conclusions**

Taken together, this empirical study adds knowledge to the concept of participation when aging in place (WHO, 1999, 2002). Theoretically, the study highlights the theory of selective optimization with compensation (Baltes & Baltes, 1990; Baltes & Carstensen, 1999). Our findings illustrate that participation among people in old age is based on their values. Participation included emotional, intellectual, and practical aspects and strategies for behaving flexibly and in accordance with change in both individual and external conditions. Thus, in order to obtain insight into older adults' experiences of participation, it is important to explore the individual and collective processes of selection, compensation, and optimization including adjustments, readjustments, and transformation of domains and tasks (Baltes & Baltes, 1997). In order to support older adults' dignity and pride, both policy and practice of homecare services must recognize the older adults' priorities and strategies of agency in order to fend for themselves.

## **Acknowledgments**

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# Paper IV





**Taking home based services into everyday life; older adults' participation with service providers in the context of receiving home based services**

**Witsø, A.E., Ytterhus, B., Vik, K. (2012)**

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**Abstract**

The aim of this study was to explore the experiences of older adults' participation with home based services when living in place. Ten Norwegian older adults with a variety of age-related physical impairments and frequency of home based services were interviewed. The data was collected by in-depth face-to-face interviews in the older adults' homes, during autumn and early winter 2011. A constant comparative method inspired by constructivist grounded theory was applied to analyse the data.

The core category was identified as 'taking home based services into everyday life', representing a process of acting on changing capacity and characterised by emotional and intellectual aspects of participation. Two main categories included the older adults' experiences of participation with the home based services and service providers; 'balancing agency – a process of giving, taking and letting go' and 'socialising with the service providers'. The older adults' strategies for balancing agency included the subcategories 'expecting joint responsibility for appropriate service delivery', 'being understanding and indulgent' and 'making one's mark'. The older adults' understandings of socialising with the service providers included two subcategories; 'small talking in the passing by' and 'linking to society'.

In order to promote participation in older adults depending on home based services, the study highlights the importance of understanding the emotional and intellectual aspects of older adults' participation, and to recognise their strategies for balancing agency in everyday life.

**Keywords:** participation, older adults, home based services, qualitative study

*What is known about this topic:*

- Depending on home based services in old age may represent barriers to participation.
- Home based services are frequently given as passive help.

- Service providers regard social participation among older adults' most important needs in service delivery.

*What this paper adds:*

- The older adults regarded themselves as active participants in service delivery.
- They were mainly content with the service providers, but experienced organisational aspects like delays and lack of skills as barriers to participation.
- Social participation with the service providers was subordinate to practical and personal support in everyday life activities.

## **Introduction**

There is an increasing focus on activity and participation for older adults' due to the active and healthy aging policy frameworks (Ervik & Helgøy, 2005, Rechel et al. 2009, WHO 2002). An important goal for communities around the world is to support older adults' possibilities and capacity to live in their own homes as long as possible, and to participate in daily life and society. As the aging population grows, the number of older adults living in place and depending on home based services will increase (WHO 2004). Studies of older adults with reduced capacity and functional decline have found relationships between participation and increased duration of life, less illness and deferral of further functional decline (Avlund et al. 2004, Ritsatakis 2008, Visser et al. 2002). However, knowledge of how older adults experience participation when living in place and depending on home based services is limited.

In a Norwegian context, the concept of active aging (WHO 2002) is translated into active care (www.regjeringen.no 2005-2006). However, several studies have found that depending on home based services in old age may represent barriers to participation (Lyttle & Ryan 2008, McGarry 2009, Vik et al. 2007). Encounters with staff and the service system may represent barriers to control and self-determination in everyday life (Ellefsen 2001, Vik et al. 2007). Other studies indicate that home based services are given as passive help and that there is a need to explore factors promoting participation in older recipients of home based services (Witsø et al. 2011).

Participation in service delivery has frequently been understood as user involvement, co-determination, empowerment and involvement in decision making (Adams 2008, Kemshall & Littlechild 2000, Willumsen 2005, Eldh et al. 2010). Moreover, perspectives on participation range from a strong focus on civil rights for all at a societal level (Shakespeare 2004, WHO 2002, [www.regjeringen.no](http://www.regjeringen.no) 2001:22), to an individual level with a focus on participation in nursing care (Larsson et al. 2007; Sahlsten et al. 2005), participation as autonomy (Cardol 2002) and agency (Vik et al. 2008). The World Health Organisation offers a wide perspective on the concept, defining participation as engagement in life situations (WHO 2001). Therefore, the concept of participation has various meanings and different levels.

Recent studies concerning older home based service recipients' participation in everyday life have mostly taken the perspective of the professionals (Witsø et al. 2011, Vik & Eide 2011a, 2011b, Vik 2011). In a study of Witsø et al. (2011) older adults' participation in service delivery was understood by the professionals as "being included and taking part in decision-making," "socialising during service delivery" and "collaboration in keeping up or regaining functions." According to the professionals, the older adults' most prominent need was social participation with the service providers. Several studies have focused on relational aspects (Sahlsten et al. 2008, Sahlsten et al. 2005, McGarry 2009, Olsson & Ingvad 2001) and interpersonal skills (Belcher et al. 2006), and the impact on participation in interaction between professionals and older adults. McGarry (2009) found that care interactions between service providers and older adults often are disempowering. Olsson & Ingvad (2001) showed that service providers were likely to experience the relational climate with the home based service recipients with a higher degree of emotion than the home based service recipients. This finding was explained as an expression of a wish for a warm and close relationship and a desire to be kind, loving, appreciated and confirmed as competent. Other studies emphasise continuity of care (Olsson & Ingvad 2001) and time (Vik & Eide 2011a, Vik 2011) as key for professionals to facilitate and enhance participation in older home based service recipients (Vik 2011, Vik & Eide 2011b).

Although recent studies have focused on older adults' experiences of nursing care (Dale et al. 2008, 2011) there is still little knowledge of how older adults experience participation when living in place and depending on home based services. A possible discrepancy between the professionals and the older adults' perspectives of participation in service delivery may represent a barrier to older adults' participation. The current study is part of a broader study on professional service providers' and elderly persons' perspectives on participation. The

specific aim of this article is to illuminate how a group of 10 older adults experiences participation with service providers in their everyday life.

## **Methods**

In this study, researchers interviewed 10 older adults with a variety of age-related physical impairments and illnesses. The older adults received defined home based services, mostly related to the facilitation of everyday life routines, i.e., getting help to shower, getting dressed, preparing meals, receiving medicines, fetching the post and short inspection calls to assess the older adults' condition during the day. Semi-structured interviews were used to gather the data, including open ended questions. Examples of questions were: What kind of services do you receive (including follow up questions of when, how often, why and by whom)? How do you experience service delivery? Could you tell about a typical setting when you receive services? What happens? How do you experience your participation with the service providers?

Kathy Charmaz's (2006) approach to a constant comparative method was applied to illuminate the older adults' meanings, experiences and conditions influencing participation in their everyday life with the service providers.

A purposeful sampling strategy in accordance with Charmaz (2006) was applied, recruiting new informants based upon the ongoing analysis. The participants lived in a city of 170 000 inhabitants in Norway, and were able and willing to talk about how they perceived participation with the service providers in everyday life. The sample varied in living accommodations, social situations, level of care and health problems (see Table I). The interviews took place in the older adults' homes in autumn and early winter 2011. Participants were initially contacted by a municipal service provider, and they were contacted and interviewed by the first author after giving their written consent. The interviews were recorded and transcribed verbatim. The informants have been given altered names in the text. All authors have contributed to the analysis. The study was approved by the Norwegian Social Science Data Services ([www.nsd.no](http://www.nsd.no), 2010) and by the regional ethical committee ([www.sprek.no](http://www.sprek.no), 2010).

Particip.	Age	Impairments	Habitation	Walking aid/device	Home based services	Care intens.*
1 Anne (F)	79	Hip operated, stiffness	Single-unit dwelling, alone	Rollator inside/outside, wheelchair for transportation outside	Bathing/shower, on/off with support/medical stockings, getting rid of garbage, fetching post/mail, cleaning, safety alarm	middle
2 Peter (M)	86	Chronic pain in neck and shoulders, stiffness	Single flat in assisted-living block, alone	Rollator when shopping	Home nursing care (×1), cleaning, safety alarm	low
3 Christine (F)	76	Dizziness, frequent faller	Single flat in senior housing block, alone	Rollator inside/wheel chair outside	Home nursing care (×4), personal care, inspection call, cleaning, safety alarm	high
4 Tor (M)	72	Neurological disease	Single flat in senior housing block, alone	Rollator outside	Home nursing care (×2), inspection call, cleaning, safety alarm	middle
5 Mary (F)	82	Hip-operated, knee-operated, pain	Single flat in assisted living block, alone	Rollator inside/outside	Switch on/off the stove, private cleaning, safety alarm	low
6 Elisabeth (F)	84	Hip-fracture operated, visually impaired	Single flat in block, alone	Rollator inside/outside	On/off with support/medical stockings, private cleaning, safety alarm	low
7 Carla (F)	85	Brittle bones	Single unit dwelling, alone	Rollator inside, wheelchair outside	Home nursing care (×4), personal care, fetching post/mail, meals on wheels, cleaning, safety alarm	high
8 Marianne (F)	72	Visually impaired, reduced walking ability	Single unit dwelling, with husband	Rollator inside/outside	Personal care (×2), physiotherapy (×4 per week), private cleaning, safety alarm	middle
9 Ingrid (F)	89	Dizziness, fatigue	Single flat in joint senior ownership, alone	Rollator on hold	Home nursing care (×1), safety alarm	low
10 Lisa (F)	87	Neurological disease, frequent faller	Single unit dwelling, alone	Rollator inside/outside	Personal care (×2), cleaning, meals on wheels, preparing breakfast/lunch, physiotherapy (×2 per week), safety alarm	middle

**Table I: Participant characteristics**

\*Based on IPLOS (Individual Needs of Nursing or Care Services Statistics, Norway), estimating an arithmetic mean of a group of five variables: social functioning, attendance of health, housekeeping, personal care, and

cognitive functions. Giving the scores: some/restricted (low), medium/great (middle), comprehensive (high) need of assistance.

### Analysis

The data was analysed by applying a constant comparative method as described by Charmaz (2006), including a process of initial and focused coding, and by writing memos. By comparing initial codes and each interview with each other, the initial coding process resulted in preliminary focused codes. A refining process included comparison of data with data, preliminary focused codes with focused codes and with the memos and data material as a whole. The initial and focused coding process resulted in two final categories. The first category was labelled, “Balancing agency – a process of giving, taking and letting go.” Examples of preliminary focused codes embraced by this category were taking part in service delivery, being indulgent and flexible, acting and being treated with dignity, balancing control and accepting being in need of home based services. The second category, “Socialising with the service providers,” included the following examples of preliminary focused codes, being connected to society, socialising with the service providers and experiencing security. The last step identified a core category, describing older adults’ participation with the service providers as taking home based services into everyday life. (see Table II).

Taking home based services into everyday life	
Balancing agency – a process of giving, taking and letting go <ul style="list-style-type: none"> <li>• Expecting joint responsibility for appropriate service delivery</li> <li>• Being understanding and indulgent</li> <li>• Making one’s mark</li> </ul>	Socialising with the service providers <ul style="list-style-type: none"> <li>• Small talking</li> <li>• Linking to society</li> </ul>

**Table nr. II:** Core category with main and subcategories

The core category represented the older adults’ process of acting on changing capacity in everyday life and was characterised by emotional and intellectual aspects of participation.

Emotional aspects refer to the feelings evoked by receiving services and participation with the service providers. Intellectual aspects of participation included the ways in which the older adults handled the feelings evoked by participation with the service providers, i.e., ways of staying rational, and how they planned and reflected on their participation with the service providers in order to keep control and dignity in everyday life.

## **Findings**

### **Balancing agency—a process of giving, taking and letting go**

This category and its subcategories illuminate the older adults' strategies for balancing agency as the process of giving, taking and letting go, and represent different dimensions of how they upheld flexibility and control when encountering the service providers. One dimension of the category as a whole was the older adults' expressions of emotional aspects of participation such as gratefulness and being positively astonished by the variety of services being attainable, and contentedness with both services and the service providers. Anne (79) said: "*just to imagine having such a department, which one also can trust, it's fantastic,*" and Mary (82) said: "*Not in my wildest dreams could I imagine how much help it's possible to get.*"

The analysis identified the subcategories; expecting joint responsibility for appropriate service delivery, being understanding and indulgent and making one's mark, presenting the characteristics of the category "balancing agency – a process of giving, taking and letting go." The subcategories included the older adults' expectations and their own role in encounters with the service providers in order to take the services into their everyday life.

#### *Expecting joint responsibility for appropriate service delivery*

The older adults expected appropriateness and skill in accomplishment of services, which also represented the older adults' main expectation for receiving services in the first place.

Marianne (72) said, "*I expect them to do what they come for (--) to help me stay clean and be accurate about it.*" The expectations referred to the importance and role of services, most of all being a facilitating part of every day life, making it possible to fend for oneself in place, and upholding personal values such as well-being and dignity, i.e., staying clean, in Marianne's case. In the process of taking the home based services into everyday life, participants expected the service providers to be aware of their signals during service delivery, but they did not want them to passively wait for instructions. On the contrary, they

valued the service providers' initiative and appreciated confidence in carrying through the routines of service delivery. It contributed to integration of the services in everyday life and experience of safety and control.

Tor (72) said: *"I find it excellent when they get on and around by themselves. It's really ok, because worst of all is when the service provider comes in and just stands there... 'now, what was it you needed help for, again?'"*

The older adults emphasized their own role and behaviour and its influence on service delivery. One aspect of expecting joint responsibility for appropriate service delivery included taking responsibility and acting with civility themselves.

Ingrid (89) said: *"Appropriate service delivery depends on how you behave, yourself, your own attitude."*

Furthermore, the older adults did not look at themselves as passive recipients of services, but described how they gave directions to the service providers in a polite way during service delivery.

Anne (79) said: *"(-- ) and if they forget to dry my feet I just lift up my legs to them. (-- ) I don't have to say much, it just works that way by itself (-- ), and then I kindly ask them to put on my trousers and my bra."*

Another aspect of expecting joint responsibility for appropriate service delivery was collaboration to keep up the older adults' independence in daily life activities. This collaboration was mainly related to having time to accomplish the activity independently.

Tor (72) said: *"They contribute to my independence by just waiting a little so that I can try to get up from bed on my own."*

#### *Being understanding and indulgent*

The older adults differentiated between the service system on one side, and the service providers on the other side. The older adults understood that the home based service system is under organisational pressure and expressed its shortcomings such as delays and the use of temporary employment, increasing the number of different people executing services. The main reaction to this as expressed by Marianne (72):



*“One just has to take it as it comes and those who are present, and from time to time there’s a flu epidemic or something of the kind, and then they have to hire temporary staff (--), but mostly they are all good.”*

Another aspect of being understanding and indulgent was expressed by sympathising with and forgiving the service providers relating their shortcomings and great work load. Even repeated delays that could be experienced as physically unpleasant and unworthy, i.e., when waiting for help to reach the toilet, were met with understanding. The older adults were also aware of the fact that their older neighbours could be in need of urgent help, which contributed to the understanding. Tor (72) said:

*“(--) repeated urgent cases, that’s the worst situation. You know, there are all kinds of accidents in this house, people fall out of their beds and the like, but of course, that’s those peoples’ workday, they do their best.”*

The older adults were well aware of the demarcation of services, and found that the service providers were very focused on accomplishing their task. The older adults reflected on reasons for service providers’ focus on accomplishing tasks, relating it to directions and regulations of the service system. Lisa (87) said:

*“Maybe they don’t think that I can do a lot myself (laughs) (-- this morning I had already cleaned myself thoroughly when the service provider came (laughs). I told her so, and that I was expecting a visitor. When is she coming, she asked. At eleven o’clock, I answered. You really have a lot of time to shower then, she said. Very well, you’ll just have to do it, then, I said. So today, I’m really clean, actually scrubbed (laughs). I assume that they want to know that I am clean. But it was really good to have my back washed, too (-- so it doesn’t matter really, I get it the way I want, anyway, and it’s good to be a little bit coddled with, too.”*

The older adults considered the advantages and disadvantages of possible directives in order to have services carried through flexibly and to keep up their own dignity in service delivery. Furthermore, the reflections exemplified in this subcategory were expressions of intellectual aspects and strategies of participation.

### *Making one's mark*

The older adults saw home based services as a barrier to their participation in some situations, and there were limits for how understanding and indulgent they wanted to be. When the older adults experienced their dignity being violated, they made their mark about it.

Examples of frustrating situations that participants mentioned included service providers' lack of specific skills needed to carry through services, lack of initiative or lack of punctuality.

These examples represented a contrast to making home based services a natural part of everyday life. Lisa (87) said:

*“On Saturdays I go shopping with my son, between eleven and twelve o'clock. I want the service providers to come before eleven, then – yes! If they don't come in time, then they prevent me from getting to the shops with him. If the time gets half past ten, then I call them and ask if it takes long before they get here.”*

A lack of punctuality evoked emotional aspects of participation and was the main example that provoked participants. The older adults did not see a lack of punctuality as a general barrier to everyday life activities. However, delays represented a barrier for participation for those who depended on services before they could leave the house or join dated activities.

Even though the older adults shared the understanding of the service providers as meaning well in service delivery, they expressed that the service providers' intentions sometimes could be seen as a lack of tactfulness. If the older adults' dignity was threatened by their good intentions, participants rejected the service providers' suggestions in order to uphold control. Anne said:

*“(--) when they came this morning they asked if they should change the bedclothes. They have asked about that several times, and I said that without special circumstances it isn't necessary to change more often than once a month...take it easy! It's so neat and without a spot, so...”*

In summary, both emotional and intellectual aspects of participation were involved. The category included the participants' understandings, meanings of and strategies for participation related to receiving services and the organisation of services.

### **Socialising with the service providers**

This category covers dimensions of social participation beyond receiving predefined home based services. An aspect of integrating home based services into the older adults' everyday life was variations of social participation with the service providers, which reached beyond the demarcated services the older adults received. Both subcategories, small talking in the passing by and being a part of society refer to a sense of belonging in the world.

#### *Small talking in the passing by*

The older adults attached greatest importance to the services outlined, but they also emphasised the small-talk dimension of service delivery. The participants did not want or expect the service providers to stay long, and social participation was mostly related to family, friends and neighbours. However, they enjoyed small-talk with the service providers on topics such as the weather, headings in the newspapers, children or grandchildren or plans for the day, at an everyday level of social interaction.

Participation as small-talk was nevertheless related to basic human needs and social roles like enjoying the feeling of and exchange of kindness, civilities, cheer and being confirmed and recognised as a human being.

Marianne (72) said:

*“They are so cheerful and friendly, they have good manners (--), and they tell me about their kids and then I tell about my great-grandchild and show them a picture of her, and they like that. We talk about all sorts of things. I like that, because that’s the way I’m used to behave in everyday life.”*

It was additionally important for the older adults that the service providers enjoyed coming to them. The feelings evoked by the social interaction could be seen as emotional aspects of participation.

Christine (72) said: *“We talk about ordinary things (--), joke with each other (--). I have always liked a good joke, and they say they can joke with me. (--) They say they like coming to me.”*

The older adults did not expect the service providers to sit down for coffee, but an aspect of the small talk dimension was showing hospitality by offering the service providers a pastille or a chocolate on their way out.

#### *Linking to society*

The participants related their social participation to family, neighbours and friends, not the service providers. However, the service system represented diversities of gender, cultural backgrounds and ages in the service providers. This diversity represented access to the wider society, and the older adults found this interesting. Encountering the service providers also gave them access to present themselves and their own experiences.

Ingrid (89) said: *“Sometimes I tell the young nurses about the war, and during the war. I think they have something to learn from it (--). I have talked a lot with refugees and migrant workers, because there are quite a few migrant workers coming, and I find it extremely interesting. There are some Danish workers, but they are almost like us, you know, and Swedes. There are some differences there, but altogether people are people.”*

The older adults put great emphasis on the security alarm that linked them to society by creating a feeling of security for contact and getting help if and when they needed it.

Peter (86) said: *“it represents a sense of security, you know – then I know that I get in contact when I need it.”* However, participants were anxious not to misuse the security alarm, and it was used only when the older adults felt they really needed to, i.e., after a fall. Not wanting to misuse the security alarm was related to the values of fending for oneself and keeping up one’s dignity and pride as a human being. The older adults’ feelings related to linking to society also represented intellectual and emotional aspects of participation.

*In summary*, the older adults’ participation with the service providers comprised a process of taking them into everyday life and balancing agency in order to preserve control and to live life approximately as usual. The older adults held onto the person they were, and interacted with the service providers by giving and taking, and they marked their limits within their possibilities in a situation of receiving home based services. The findings identified participation with the service providers as a process of balancing agency reflecting the older adults’ different strategies for participation with the service providers, and reflecting their integrated and well established values, expressing their personalities and self-presentation. The older adults regarded interaction and receiving services a mutual responsibility of giving,

taking and letting go, a process depending on values such as mutual flexibility, understanding and indulgence, but at the same time having and marking their limits for understanding and thus preserving integrity. Furthermore, the older adults' participation in service delivery included social participation as small talk with the service providers, representing different dimensions of belonging and linking to society.

### **Discussion**

The purpose of this study was to illuminate and understand the experiences of older adults' participation with service providers in everyday life. The older adults adapted to the situation by accepting needs of home based services on one side and acted upon the changing capacity and encounters with the service providers on the other. Overall, our findings are in line with the theoretical perspective of Rowles & Ravdal (2002), who argued that older adults actively create new meanings as circumstances change. Another theoretical perspective supporting our findings is selective optimisation with compensation (soc) (Baltes & Carstensen 1996, Baltes & Baltes 1990) highlighting how individual and collective processes of selective optimisation with compensation allows older adults to engage in life tasks that are important, despite reduction in capacity and energy.

A main finding in the present study was that the participants were content with the service system and the service providers. Although other studies have found the same tendency (Dale et al. 2010, Dale et al. 2011, Bailey 2007), this finding is interesting because of recent findings that service providers' experience themselves and the service system as barriers to older adults' participation in everyday life (Witsø et al. 2011, Vik 2011, Vik & Eide 2011a). Being content could be explained by the older adults' wish not to be a burden to the service providers, their acknowledgement and appreciation of the service providers doing their best in a stressful working day, or fearing that complaints about services or service delivery could lead to sanctions or reduced quality of services. Furthermore, the older adults in the present study were actually positively astonished by the variety of and access to services. This aspect of being content could be explained as a reaction to how services tend to be focused negatively in media, as insufficient, unworthy treatment, system faults and accidents in service delivery (Huseby & Paulsen, 2009). However, expressions of being content could also represent ways of presenting oneself as a person, i.e., expressions of being active and still going strong. The older adults did i.e., not regard themselves as passive recipients of the

services, but viewed and acted upon service delivery as a mutual responsibility between the service providers and themselves. We believe the finding of being content in the present study could also represent an expression of the older adults' values, and form a basis and motivation for their strategies in balancing agency and represent a contrast to a role as passive recipient or victim.

Nevertheless, it is critical to see the older adults' expression of being content in relation to their expressions of home based services as representing barriers to their participation. Interestingly, our study found that the older adults differentiated between the service system on one side and the individuals working in the system on the other side. When they experienced barriers to participation, it was mostly related to shortcomings of the service system, not the individuals working in the system. In recent studies, the service system is also experienced as a barrier for giving sufficient services by the professionals (Witsø et al. 2011, Vik 2011, Vik & Eide 2011a). Thus, studies have found that service providers strive to give better and more services than the service system requests to feel that their work is professional and sufficient (Rønning 2004, Vik & Eide 2011b). Hence, a possible explanation to our finding is that when the participants took in the service providers' strive and workload it contributed to feeling sympathy with them. The older adults and the service providers could possibly also share experiences of shortcomings of the system level, which again could create a sense of community. Taken together, these aspects could contribute to the older adults' understanding and indulgence.

Another main finding is that, in order to fend for themselves, the older adults took the service providers into their everyday life, accepting the need for support in daily life. Other studies have found that older adults are very concerned with managing and governing daily life without support in order to keep a basis for spontaneity and freedom (Dunér & Nordström, 2005, Haak et al. 2007, Vik et al. 2008) Becoming dependent on home based services can by older adults be experienced as losing control of appointments and routines, in the sense of being in the hands of others and without control (Haak et al. 2007). Another study found that older adults feared that receiving home based services included having people poking around their homes, observing their private lives and thus influencing their control negatively (Dunér & Nordström 2005). However, in the present study, accepting the need for home based services could be seen as a compensation strategy and new means of compensation for changing capacity (Baltes & Carstensen 1996) in order to fend for oneself and preserve

freedom and control. It could be that the older adults had come to terms with their loss of functioning over time, and thus adapted to changing capacity. Another explanation could be that the participants expected themselves being worthy and in a position deserving services after having contributed to the welfare system and society by working and paying taxes during a long life. Taken together, our findings indicate that the participants had taken home based services into everyday life on their own premises, indicating that the older adults experienced to preserve control of their situation to a certain extent. This finding is interesting when taking into consideration that older adults may adopt and adapt to a picture of home based services presented and criticised as increasingly medically oriented, being based on effectiveness and at the sacrifice of preventive work, rehabilitation, social and practical services (Brevik 2010, Rønning 2004). Integrating home based services on one's own premises could thus be experienced as a main task in everyday life. However, in order to do so, and as a possible consequence, other needs could be de-emphasised.

Another interesting finding in this study is that social interaction with the service providers was considered subordinate to the practical and physical support the older adults received to facilitate their everyday life. A recent study of service providers' perspectives on older home based service recipients' participation by Witsø et al. (2011) found that service providers considered social participation with the service providers among the most important needs in older home based service recipients. Taken together with the findings in the present study this may indicate that professionals can overestimate their own role in service delivery. Nevertheless, several studies have emphasised the establishment of personal, close and continuous relationships as crucial in service delivery and preventing loneliness in older adults living in place (Bailey 2007, Olsson & Ingvad 2001). Interestingly, the older adults in this study did not find the large number of different people serving them as a problem, as long as they knew what to do and how to do it in a skilled way when they arrived. On the contrary, they said the variety offered them a connection to the larger society. Hence, and although social participation with the service providers was subordinate to practical and personal support in everyday life activities, there is good reason to dwell upon its specific meanings and functions. The small-talk dimension of participation as social interaction has previously been recognised as chatting about everyday matters and being treated as any normal human being to older adults when receiving services in place (Vik et al. 2009). In the present study, small talk with a variety of people with different cultural backgrounds, dialects and age - a characteristic of the service system - gave older adults opportunities to uphold a well known

and familiar kind of ordinary everyday conversation. Album (1994) described this dimension as the contentless meaningful chat that is important for our recognition and self-esteem. Such social interaction should not be underestimated. On one side, there may not be a solid argument in favour of an overestimation of one's own professional role in the social life of older adults. It may cause more and unnecessary stress and the feeling of insufficiency in the service providers. On the other side, this point does not excuse professionals' responsibility for the quality of care. It is important that service providers and home based services recognise and understand the meaning and importance of this dimension of social interaction, what it gives and what it takes, and facilitate it.

### **Methodological considerations**

This study took place in Norway, and the experiences of the participants were related to home based services within the Nordic welfare system. Although generalisation to other populations is not the aim of qualitative research, the traits identified in this study should be relevant for older people receiving home based services and professionals within home based service systems in general. However, a study limitation may be that the study included only a small number of participants that were interviewed only once. Follow up interviews and observations of interaction between older adults and home based service staff could have given more information about participation in service delivery. However, the findings concerning how older adults tend to be satisfied with services are supported by other studies (Dale et al., 2010, 2011; Bailey, 2007). In that respect, our findings may illuminate and give more nuances to the content of participation in older adults when depending on home based services.

### **Conclusions**

To support participation in older adults depending on home based services, it is of importance to recognise the complexity of dignity and pride, the multiple expressions of and strategies of being and staying worthy. Social interaction with the service providers was considered subordinate practical and physical support. Hence, it is important to pay attention to and not overstate the role of service providers in the older adults' lives. Depending on home based services may represent a process of keeping up agency and representing a variety of strategies for keeping up meaningful participation and dignity in everyday life. In order to understand



the meanings and experiences of and facilitate participation, professionals must show interest in the intellectual and emotional aspects of older adults' participation, representing their feelings, reflections and rationale related to their strategies for participation.

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## **6. General discussion**

The aim of this research was to enhance knowledge of how older adults' participation in everyday life is experienced and described by service providers and older adults and to discover which factors that contributes to participation in older adults, especially the professional service providers' contributions to support participation.

A key finding when interpreting across the studies is that the perspectives of participation share both similarities and variations between the service providers and older participants. The differing perspectives can be assumed to create misunderstandings or conflicting interests which also to some extent was confirmed in the empirical studies. The similarities and variations will be discussed in relation to i) the process of participation in everyday life, ii) experiences of participation in service delivery, and iii) participation as an equal right to participate in society.

Under i), the following main findings will be discussed:

- task- versus process oriented participation in service providers and older adults respectively
- central dimensions and strategies of older adults' value-based and process oriented participation; practical, emotional and intellectual, and the dynamics between them
- differing emphasis on social participation in service delivery in service providers and older adults
- 

Under ii), the following main findings will be discussed

- service providers experiences of older adults as passive recipients of services, and older adults' experiences of personal agency
- service providers' expectation of user-participation, part-taking and co-determination, and older adults' experiences of balancing agency including expecting skilled service providers with self-confidence and initiative

Under iii), the following will be discussed

- an absence of concern for equal rights in the older adults
- a general satisfaction with services in the older adults

- is there a need for an equal rights perspective anyway?

Finally, the findings with the most substantial weight will be discussed in relation to the concept of participation. Based upon the opening discussion, this final sub-section represents the substantial theoretical contribution of this research on participation in older adults receiving home-based services.

### **The process of participation in everyday life**

A key finding was the distinction between “task” oriented and “process” oriented participation, representing a synthesis of and contrasting perspectives on older adults’ participation in service providers and older adults respectively.

One way to understand service providers’ task oriented perspective on older adults’ participation is in light of organization of services. The service providers themselves felt that they were marked by standardized services and a strictly time limited service system. Accordingly, they felt that they represented barriers to the older adults’ participation in daily life. One explanation for service providers’ task oriented perspectives, and their experience of services as a barrier to older adults’ participation, could be that their experiences were based upon the actual, short meetings and interactions with the older adults during service delivery. Given these short meetings, one understanding is that the service providers had limited opportunities to observe, capture or understand older adults’ participation in everyday life beyond observable tasks carried out in situations of service delivery. Another reason could be that the service providers were not asked about participation as a process specifically in the interviews. However, the older adults did not receive questions framed in this manner, either. Thus, a more plausible reason for the tendency of task orientation among the service providers could be related to the foundation, assignment, assessment, and organization of services. The findings support recent research showing that service providers experience organizational factors as barriers to older adults’ participation in everyday life (Vik et al., 2011; Vik & Eide, 2011; McGarry; 2006). From the service providers’ perspective standardized service organization represented a barrier to process oriented participation such as socializing with the older adults, a need they believed was

prominent in the older adults. This finding will be discussed in the next subsection  
*“Experiences of social participation in older adults.”*

The main findings in studies III and IV showed that participation in everyday life was experienced by the older adults as a value-based process. This process reached beyond having tasks carried out and concerned overall maintaining of dignity and pride. From the perspectives of the older adults, incorporating service delivery into everyday life could be understood as one of several strategies to maintain participation in everyday life (paper IV). The processes of getting oneself going and keeping one’s place demonstrated how the older adults concentrated on being an agent in order to fend for themselves and live their on-going life. Compared to these findings, the service providers’ task oriented perspective on older adults’ participation seemed to include a more limited understanding of older adults’ participation in everyday life in general and as a process in particular (study I).

Understanding older adults’ participation as agency turned out to embrace the whole process of living everyday life, including practical, emotional and intellectual dimensions of participation, illuminating how the older adults engaged in order to fend for themselves. These dimensions add new knowledge to previous contributions to the conceptualization of participation. Receiving limited help in a concrete situation of daily life activities could represent a practical dimension or strategy of participation in the sense of having something done in order to do something else (e.g., having one’s back washed and receiving help with the bra before completing dressing on one’s own), while feelings such as gratitude or indulgence, depending upon the situation, could represent both emotional and intellectual dimensions of this participation with the service providers in the sense of being a way to feel and reflect on the situation. Hence, including home-based services in everyday life could represent ways of acting on and adapting to changing capacity in everyday life; this incorporation could also represent an integration of the practical, emotional and intellectual dimensions of participation.

The “practical” dimension of participation covered the older adults’ handling, organizing, reorganizing, making changes, structuring or restructuring their

participation in everyday life. The “emotional” dimension of participation embraced the older adults’ feelings and their expression of feelings relating to and in order to manage participation that was of special importance to them. The dimension of “intellectual” participation embraced thinking, planning, negotiating, making choices, and reflecting in relation to participation and other activities. This lattermost dimension of participation was also found in paper I. However, it was related to the service providers’ understanding of how older adults kept control in interaction in service delivery. According to the service providers, the properties of keeping control included active engagement, decision-making, making intentional choices, having the last word and self-determination in the sense of making demands or choosing to participate less. These dimensions of participation turned out to be less emphasized by the older adults. This finding will be further discussed in the next section “Experiences of participation in service delivery.”

Another finding that is relevant for understanding participation both as a process and in the terms of “emotional” and “intellectual,” is that in paper II, we found that older adults’ experiences of their own physical and emotional health were strong predictors of their satisfaction with participation, indicating that the experiences of participation not only depended upon the recipient’s actual health conditions but also on how one thinks and feels about his or her health conditions and adapts to his or her changing capacity. As such, the older adults’ evaluation of health and participation based on their attitudes (e.g., being optimistic) and their comparison mechanisms rather than on their actual physical or functional capacity could be examples (Borawski et al., 1996; Henchoz et al., 2008).

To varying degrees, the “practical,” “emotional” and “intellectual” dimensions of participation were related to the older adults’ ways of practicing intentionality. The process of participation in everyday life could also be understood as a process of negotiation, including a variety of strategies applied in creative and flexible ways in order to fend for oneself. These strategies could be overlapping and intertwined, as we shall see. An example from paper III was how Peter, who lived with increasing pain in his arms, maintained valued participation such as going food shopping. He had planned



to avoid situations of helplessness by making practical arrangements like shopping just a little at a time and relatively often. He could also compensate for functional decline by asking for some help at the food-store. In this way, his participation could exemplify both an integration of practical and intellectual aspects of participation and a process of SOC as described by Baltes and Baltes (1990), Baltes and Carstensen (1996) and Baltes (1997). Hence, the variety of practical, emotional and intellectual strategies could be understood as resources that the subjects used in the process of selecting valued participation, adaption and compensation for changing capacity and loss of functions.

What is important to note is that when observing the older adults' strategies out of context, the service providers might experience the examples from the findings in studies III and IV above as expressions of unwanted strive and struggle in or barriers to the older adults' participation.

The experiences of time limits, short visits, professional values and attitudes related to aging could also represent a reason why the service providers seemed to be more concerned with other parts of the process, such as the importance of and need for socializing.

In order to stay independent in daily life, many older adults strive to be independent or to retain independence from professional services (Haak, 2006; Vik, 2007; Johannesen et al., 2004; Larsson et al., 2009). The current study did not discover such a desire, but suggests the possibility that the older adults interviewed herein previously struggled to stay independent of home-based services but had reached turning points, and reconciled themselves with being in need of services in some situations and thus experienced regained control of their daily life (Duner & Nordström, 2005). As a result, they would experience the feeling of fending for themselves with this limited support in everyday life.

Another important finding was the service providers' distinction between older adults' participation inside and outside the home. The fact that these two dimensions and contexts of participation were qualitatively identified in study I and statistically explored and analyzed in study II, contributed to a validation of the distinction. The

content of these contextual dimensions of participation were further nuanced and elaborated on by older adults in studies III and IV. This represents a new approach to capturing and operationalizing the concept of participation. In general, the process of participation in everyday life included the older adults' engaging in a variety of daily life activities in different contexts: at home, in the neighborhood, alone or with friends, with neighbors and with family or service providers. These findings are in line with the research described in the background section, which generally found that older adults continue to engage in a wide variety of activities in everyday life, although the nature, context and frequency of their activities may change over time (Parisi, 2010; Paillard-Borg et al., 2009; Verbrugge et al., 1996; Finseraas et al., 2009; Haak, 2006; Larsson et al., 2009). The social contexts of participation were being alone as well as being together with neighbors, friends, family or service providers. Interestingly, study II found that frequency of home-based services bore no correlations to the subjects' satisfaction with participation. This finding will be nuanced and discussed in the next sub-section.

#### *Experiences of social participation in older adults*

This study found that both service providers and older adults felt that social participation is an important and integrated part of older adults' everyday life. However, an important finding was that service providers and older adults emphasized the role of service providers in the older adults' social life differently. The service providers expressed that the older adults were in need of social participation and that they had an important role in the older adults' social life. In addition to the need of small talk over a cup of coffee with the service providers, the service providers experienced that the older adults were in need of and wished for private conversations. This may be related to the service providers' expectations of the professional role. A study by Olsson and Ingvad (2001) showed that service providers were likely to experience the relational climate with the recipients of services with a higher degree of emotion than were the recipients of services. The service providers explained this finding as the older adult's wish for a warm and close relationship and his or her desire to be kind and loving and thus confirmed as competent. Other studies (Vabø, 2008; Vik & Eide, 2011; Wreder, 2008)

made similar findings, claiming that the service providers' job satisfaction is closely related to the experience of good care, including the service providers' expectations of their own professional role and standards to fulfill the unmet needs of a warm and close relationship with the older adults. Furthermore, Wreder (2008) found that service providers wanted their interactions and relationships with the older adults to be family-like and to include the features of intimacy, reciprocity and continuity. When service providers fail to establish such relationships, they may tend to consider the services less satisfying or even insufficient (Wreder, 2008). Taken together, the findings in these studies may all contribute to explaining the service providers' emphasis of their own role in the social lives of the older adults.

In line with the service providers' opinions, the older adults appreciated the small-talk dimension of participation in service delivery. However, the older adults seemed to relate private conversation and socializing to family, friends and neighbors, the most. Small-talking with the service providers was mostly related to the everyday level of social interaction and hospitality. The findings in study II could support the general idea that home-based services play a limited role in the social lives of the older adults in the sense that no correlations between frequency of services and satisfaction with participation were found.

The practical, emotional and intellectual dimensions of participation as described in the previous sub-section illuminate, as we shall see, the process of social participation in the older adults, too. The older adults valued highly their social participation with family, friends and neighbors, and they actively sustained their place by combining independence, dependence and social contact. Study III found that when problems with maintaining independence arose, the older adults discussed the problem in terms of how to solve it best together with for example the family member, rather than in terms of asking the family member to take responsibility for the troublesome task. It seemed that the two parties resolved obstacles in a manner that maintained the older adults' participation and agency. Thus, problem solving could represent the practical, emotional and intellectual dimensions of participation. For example, Ingrid's son had offered to do the regular shopping on Saturdays for her. However, Ingrid felt it was important to keep

her place as a competent housewife, even though she needed a lift to the store. This way of organizing everyday life could thus represent a practical dimension of participation. She wanted to see and feel the products in order to judge and decide if they had the quality she preferred, which could represent an intellectual dimension of participation. Finally, going to the shops together with her son and experiencing his support could represent both a feeling of belonging and gratitude and could thus represent the emotional dimension of participation. Furthermore, the fact that Ingrid did not hand the task over altogether could also contribute to a feeling of equivalence and continuity and of taking her place as an equal family member, representing both the emotional and intellectual dimensions of participation. These findings support a popular understanding of active aging as intergenerational (WHO, 2002), including active engagement in relation to the participation of both the older adult and the relative.

Indeed, some studies have found that older adults desire a close relationship with nurses in home-based services (McGarry, 2006). However, the older adults in papers III and IV expressed that they were generally content with the service providers' short visits and did not expect the service providers to stay long. These different findings could possibly be understood as a shared experience among the service providers and the older adults within a service system that is very strict on time limitations and standardized services. The older adults may see that this system places great pressure on the service providers, so the older adults' lower expectations for close interaction could be an expression of their sympathy with the service providers. Another reason for this finding could be that the older adults did not want to be a burden on the service providers. Nevertheless, in study II, we found that the factors that best explain the older adults' satisfaction with participation in outwards activities (study II), including social participation, were the older adults' perception of their physical and emotional health. One interpretation of this finding in relation to small-talk could be that the small-talk dimension rather should be situated in relation to its influence on older adults' general well-being, their self-presentation, and their identity as equal human beings and their linkage to society. Thus, one way to explain why the older adults did not expect the service providers to stay long, but appreciated them doing the necessary task and then leaving, could be a need of resisting unwanted intimacy or aspects of surveillance via small-talk and to keep

conversation on an everyday level. It is also possible that the drive to fend for themselves drew some lines between them and the service providers in the sense of preserving privacy and perhaps resisting sharing supplementary information about their lives with the service providers beyond the short meetings during service delivery. Findings rather indicate that the older adults' experiences reached beyond small-talk as an expression of close and warm relationships. The older adults experienced that small-talk with the service providers represented access to variety in people, age, gender and culture and was a way of linking them to society. The diversities in gender, cultural backgrounds and ages of the service providers represented access to the wider society and thus represented a way of participating in society. The interface with the service providers was found to represent possibilities for presenting themselves and their own experiences, and thus could represent a way to practice equality. These findings may support other studies that have found that older adults' participation in society is closely related to activities at home (Haak et al., 2006) and to a sense of belonging in society (Vik et al., 2007).

One explanation for the differing experiences of social participation in everyday life between service providers and older adults could be that the service providers tended to assume that the older adults were lonely and lacked social contact. Studies have found that a common impression providers have is that older adults with impairments and who are receiving home-based services are passive and lonely (Jolanki, 2009; Dale, 2008). Thus, another reason for this finding could be that the service providers lacked knowledge of the role of family, friends and neighbors in the everyday lives of the older adults. In contrast with the older adults, the service providers characterized the older adults' families as being worried and as requesting services that would contribute to passivity in the older adults (study I). In contrast, the older adults did not regard themselves as passive recipients of family support. Again, these divergent desires could possibly explain the service providers' lack of insight into the older adults' experiences of participation in general, and the contribution of family support in particular. Several studies have discussed the declining solidarity of family care (Daatland & Herlofson, 2003; Gray, 2009) and have found that family continues to represent and contribute considerable support in older adults' everyday lives. However, a recent study by Dale et

al. (2008) found that nurses in home-based services expected older adults to be lonely and that the nurses were surprised by the family support the older adults reported. Taking these studies into consideration, another probable argument for the service providers' emphasis on their own role in the older adults' social lives could be that they experienced limited time to spend on cooperation with family and relatives and thus lacked insight into their role in the lives of the older adults. Furthermore, there could be a lack of effective and integrated models that include collaboration with family in service delivery, as described in the NOU nr. 11 (2011). A lack of effective communication models between the purchaser-provider levels of a service organization could possibly also contribute to the providers' lack of information of the older adults' families.

Nevertheless, the older adults seemed to be content with their social participation in everyday life. Naturally, this could be explained by socioeconomic, social capital and cultural aspects or also by a wish not to be a burden to family or to the home-based services. In line with these arguments, I have no intent to minimize or downplay the situation with which vulnerable older adults live. However, the findings from studies II-IV have contributed to nuances in the picture of older adults' participation in everyday life and help to explain how the participants in these studies concentrated on and balanced agency in order to fend for themselves and to maintain dignity.

### **Experiences of participation in service delivery**

This section expands upon the participation in service delivery that reaches beyond the socializing aspects discussed above.

A main finding was that service providers emphasized older adults' participation as decision-making, while the older adults were more concerned with balancing agency in their everyday encounters with the service providers. Both service providers and the older adults experienced that joint responsibility and collaboration were aspects of participation in service delivery. However, the service providers experienced the older adults as passive recipients of services, in contrast with the older adults experiencing themselves as agents. These contrasting perspectives can possibly be explained by a

difference in the relative strength in the terms and rationale for “being included and taking part” as emphasized by the service providers on one side and the finding that “balancing agency in daily life” embraces the older adults’ experiences of participation, with the service providers on the other. This finding indicates that the service providers’ understanding of participation in service delivery coincides with the terms used in official policy documents. As described in the background section, Norwegian policy documents and legislation have a strong focus on participation in service delivery, expressed in terms such as user-participation, user-involvement (St.meld. nr. 47, 2005-2006) and user-influence (Prop 90L, 2010-2011). Values like equality, personal integrity and self-determination are considered as the basis for user participation (NOU, 2010:5). Furthermore, services are meant to be developed and individualized in cooperation between service providers and service users, and service users also have the right to receive adjusted and necessary information in order to support the recipient’s rights ([www.lovdato.no/all/tl-19990702-063-003.html](http://www.lovdato.no/all/tl-19990702-063-003.html)). Thus, the service providers’ understanding and wish to practice and facilitate participation in the sense of user-involvement and out of respect for recipients’ right for self-determination may be explained by a strong focus on these aspects of participation in political documents, legislation and in the organization of welfare services.

Findings in papers III and IV show that the older adults’ experiences of participation in service delivery reached beyond partaking in user-participation, decision-making, being involved or having self-determination. Rather, their participation was characterized by balancing agency in their everyday encounters with the service providers. Agency has traditionally been defined as the autonomous individuals’ potential to act and exert power on a situation through thoughts, action and language (Christiansen & Townsend, 2004; Wray, 2004). However, Wray (2004) has argued that in order to understand agency, providers need to consider the meanings attached to the underlying features of the concept, such as autonomy, control and fulfillment. To understand what constitutes agency in different cultures, one must analyze peoples’ values, beliefs and norms. Furthermore, Wray suggests that researchers should conceptualize agency as creative and relational in order to recognize the strategies that older adults use to deal with constraint and barriers to participation (Wray, 2004). Related to this thesis, papers III and IV showed that the older adults did not consider themselves as passive recipients of

services. Instead, their focus on balancing agency included the whole process of living everyday life. Hence, concentrating on and balancing agency included incorporating home-based services into everyday life in order to remain productive, keep one's place and thus to maintain pride and dignity in everyday life in general.

Taking the service providers into everyday life in the first place could, as previously mentioned, be understood as a practical strategy for fending for oneself. An intellectual strategy could be to reduce the impact of home-based services in one's everyday life, which could also be one of the explanations of the findings in paper II, in which no correlation between frequency of home-based services and satisfaction with participation was found. Another understanding of this finding could be that the older adults felt that being able to follow the routines and habits of everyday life was worth struggling and striving for based upon the value of trying and not giving up, as shown in paper III. Other studies have presented similar findings. Vik et al. (2008) found that older adults receiving home-based rehabilitation services experienced participation in occupation as individual agency (i.e., as striving to take control and make decisions on their own, choosing and acting in daily life and letting the ongoing daily life be an agent), implying a social character of participation. Furthermore, Johansson et al. (2008) found that the practical rationalities of older adults who are undergoing a home modification process could be understood as an expression of agency. Practical strategies were found to be the ways that the older adults preserved their values within an experienced scope of action, including considerable struggle on their part. These findings also coincide with those of Hammel et al. (2008), who found that participation was understood as value based and that an overall value across groups of people with impairments was dignity, which was also the case and a strong drive for the older adults in papers III and IV.

The older adults preferred service providers who were self-confident and skilled and who were familiar with the task and with taking responsibility for doing it appropriately and in accordance with the older adults' preferences. This could be understood as an appreciation of a task oriented service delivery. However, when older adults experienced their participation as hindered, they "made their mark," which could represent a practical strategy of participation. Examples of making their mark could be



making a phone call to ask for the whereabouts of the service providers when he/she was delayed. However, the decision to take such action could be based upon the emotional and intellectual aspects of participation, that is, feeling or expressing disappointment or injustice and finding a way to reflect on the situation, thus representing intellectual aspects of participation, as well. However, they equally emphasized their own responsibility for making the service delivery successful, and they were generally flexible and understanding during their encounters with the service providers. In one way, these findings represent a contrast to the understanding of “passive recipients” as described by the service providers in paper I as well as to the findings of Jolanki (2009), who claims that practitioners tend to define old age and older peoples’ agency in a narrow sense as primarily a health issue that is dependent upon individual decision-making and consequently a matter of individual responsibility. Under this definition, the agent position could be reserved for the “seniors” who live up to the expectations of a physically and socially healthy and active lifestyle. However, this thesis has shown that agency can be practiced in a variety of ways and may also be practiced by frail older adults in intentional ways.

Enabling agency has been identified as an important part of professional practice (Christiansen & Townsend, 2004; Vik et al., 2007; Johansson, 2008). Overall, the findings in papers II and IV could indicate that the older adults lived their everyday life without experiences of being disempowered by the service providers or the service system. However, these papers also made the contrasting discovery that the recipients were concerned about the time delays and the occasional lack of skills and initiative they noticed in the service providers. Other studies have found that encounters between someone needing assistance and someone providing it are sensitive and may entail a power imbalance (Clapton & Kendall, 2002; Brown et al., 2006; McGarry, 2009). Several studies have also shown that service providers tend to practice home-based services within the expert model of service delivery (Brown et al., 2006) and to keep their power and expert roles; these studies have also found that older adults believe the service providers have governance (McGarry, 2009; McWilliam et al., 2001). The service providers in paper I felt that they sometimes overruled the older adults and hindered their participation because of time limits and may thus support the claim that

the service providers could experience service delivery in terms of power imbalance. One possible understanding of the finding that the older adults' seemed not to experience power imbalance as a problem in their interactions with the service providers could be that older adults tend to downgrade their needs, goals and expectations as they continue to age and therefore experience a decrease in the distance between actual and preferred life situation (Ryff, 1991). Another understanding of the older adults' indulgence could possibly be a fear of sanctions from the service providers or the service system. Several studies have found that older adults may be afraid to complain and may strongly desire not to be a burden to service providers (Vik, 2007; McGarry, 2009). Thus, one argument could be that the older adults were afraid of possible negative reactions from the service providers whenever they complained or demanded changes in services. Furthermore, there could be a mutual fear of complaints in both older adults and service providers that could explain why they had a mutual focus on the problems with the organizational aspects of service delivery, thus representing a sense of equality in their interaction and contributing to diverting some of the possible tensions related to service delivery. However, taken together, the findings from papers II, III and IV seem to indicate that participation as a balancing agent and the strategies following this process were based upon the older adults' integrated values and were experienced and expressed as adequate in order to preserve dignity and pride.

#### *The potential for participation to maintain functions at risk*

Service providers supported the older adults' desire to take part in decision-making and fulfilled the older adults' right to practice self-determination. However, older adults' participation in order to sustain functions was shown to be at risk. This finding is interesting in relation to studies reporting that older adults receiving home-based services are satisfied with their opportunities for decision-making but less satisfied with their opportunities for participation in everyday life (Huseby & Paulsen, 2009; Næss, 2003). WHO (2002) has found that keeping up functions and participation in physical activities are vital to experiencing well-being in the long term. However, balancing agency may not necessarily coincide with keeping up functions. From the service providers' perspective in paper I, it was important that the older adults accomplished

tasks they could manage themselves. The providers experienced it as challenging when the older adults wanted the service providers to do tasks for them. On the other side of this interaction, the older adults in papers III and IV expressed that it was, indeed, important to fend for themselves, but their expectations seemed to cover a more comprehensive understanding than merely retaining/maintaining functions, independency or doing tasks without support. This finding may be seen in the light of “proxy agency,” an aspect of agency described by Bandura (1997), including a strategy of using others to carry out tasks that one personally cannot manage. While other studies have found that older adults struggle to stay independent or to achieve independence from professional assistance (Haak et al., 2006; Vik et al., 2007; Johannesen et al., 2004), the findings in study IV showed that the older adults had accepted and incorporated the service providers and the need of services into their everyday life. The individuals’ acceptance of being in need of services in order to fend for themselves could, in and of itself, contribute to their control in a situation of changing capacity. As a result they would be willing to hand over demarcated tasks. In this way, the older adults could maintain the agency. However, one may argue that although balancing agency could contribute to active aging in ways of staying engaged in social and leisure activities and keeping one’s place in life, long-term agency might be practiced at the cost of keeping up functions.

#### **Findings in relation to participation as an equal right to participate in society**

The findings did not show that the older adults were greatly concerned with their equal rights to participate in society. The absence of the older adult’s concern for equal rights may, as we shall see, have complex explanations.

Younger populations of people with impairments experience a variety of disabling barriers and have long traditions of fighting for their equal rights to participate in society (Tøssebro, 2010; St.meld. 40, 2002-2003). This perspective may possibly be unfamiliar to the generation of older adults included in this research. One explanation could be that the participants represented a frailer part of the older population, and taking on a rights perspective could possibly be too demanding for them. However, the rights perspective has previously been discussed by Vik (2007) in relation to older

adults receiving rehabilitation in their homes. She argues that a lack of rights perspective in the older adults included in her studies could be related to an experience of being participating citizens for all of their lives. Thus, they still saw themselves as such. This argument is relevant to this thesis, because the older adults included were still a part of the generation that has “built the welfare state” and may experience that they are benefitting from a pension system and a welfare system that they helped establish.

Nevertheless, the final part of the discussion section will expand on the equal rights perspective, because parallel to the rights perspective in relation to welfare services, society has higher expectations for the number of responsibilities that all citizens, including older adults, should hold. One may question if this expectation relates to the generation of older adults receiving home-based services today. As argued by some researchers, services are increasingly medically preoccupied at the cost of social and rehabilitation services (Brevik, 2008; Helgøy, 2005; NOU, 2011:11). Thus, one may question if this group of older adults is under pressure to withdraw from participation in daily life. The perspective that older adults adapt to changing capacity in a variety of ways (papers III and IV) and tend to be satisfied does not necessarily mean that they have equal opportunities for participation and self-fulfillment or that they are doing fine or as well as they could do. It may for example be difficult for frailer, older adults to keep an overview of the increasing variety of services available in the communities and the possibilities, rights and expectations that society has. Consequently, there may be a gap between policy documents and the expectations that older adults should continue to participate in all areas of life, as expressed in the active aging framework, and there may be a gap between equal rights and the possibilities to participate when it comes to practice.

Another argument for keeping an equal rights perspective could be the strong focus on care in health and welfare services for older adults, addressing frailty and needs as the bases for provision of services. Such a focus may contribute to undermine the right to participate and stay active, and create arenas for participation dominated by a care perspective which may lead to passivity in service recipients (NOU, 2011:11). Findings

from study I possibly mirror such a tendency, because the service providers expressed a vicious circle of the older adults passively waiting for services: the way that the providers delivered service contributed to passivity. Although care and participation should not necessarily be understood as opposing each other, as long as a care perspective is dominant and strongly related to a need of nursing, comfort and “being done for,” it may result in discriminating associations and consequences.

As described in the background section, participation as an equal social right is promoted by the active aging framework and in the Convention on the Rights of Persons with Disabilities (UN, 2006). One of the foci in the active aging framework is the equal right/expectation of older people to continue to stay productive, to prolong their retirement age and to continue life-long learning. However, we did not find that the older adults were fighting or striving for the rights mentioned above. A general finding was that they were mostly content with participating in everyday life activities. However, as shown, this does not mean that participation in society was not considered important; instead, it was understood in terms other than being rights-oriented by the older adults. A comparison of findings from papers I and III shows that older adults could have greater societal engagement than the service providers realized, an engagement that reached beyond following the news or attending day care centers as experienced by the service providers. The older adults’ participation in society was related to keeping one’s place in a wider context – among neighbors, friends and family through sharing stories, activities and values and feeling a connection by being a member of the same generation. Thus, the older adults’ participation in society was related to equality in the sense of continuity and a feeling of belonging rather than a fight for equal status. Both personal and environmental factors that influenced the possibility of participation in society were found, such as housing and easy access to meeting places in the immediate neighborhood and value-based adaptive strategies such as making comparisons and emphasizing gratitude (paper III).

Findings across the studies in this thesis imply that the older adults largely perceived coherence between expectations and the services they received. Paper II found no correlation between satisfaction with participation in the older adults and frequency of

home based services, and the older adults were generally satisfied with the services and the service providers as noted in paper IV. However, several researchers have proposed that older adults' satisfaction may come from low expectations, comparing themselves to people who are faring worse and often overstating their satisfaction compared with younger people (Hansen & Slagsvold, 2009). Likewise, researchers may also wonder whether they can explain older adults' general satisfaction tendency by citing the aging processes or generational differences. One possibility is therefore that individuals learn to adapt to their strengths and weaknesses and include comparison processes in order to adapt (Blanchflower & Oswald, 2008). Another explanation of the satisfaction tendency in the older participants could be that they belonged to a generation of people who were accustomed to having little financial resources ever since their early years, so they can manage and be satisfied with limited resources. Thus, the picture of satisfaction may change across generations of older adults. The oldest Baby Boomers who have experienced the Civil Rights Movement, the sexual and drug revolution and the feminist and gay rights movements may have other expectations, standards and demands (Pruncho, 2012).

While the current generations of older adults faces substantial changes in the organization of welfare services and in the foundation for the welfare state, the Baby Boomers will face even more changes and more complex pension and welfare systems (Hvinden & Johansson, 2007). Given the predicted increase in system alterations, one may question whether younger people with impairments and new generations of older adults will experience a stronger reason or drive to fight for their rights than previous generations experienced (Hudson & Gonyea, 2012). With increasingly complex organization and regulation of services and with service production including a greater variety and innovation of services, the possibilities for older adults' participation will possibly increase in one sense, while there may exist a greater pressure to make more competent choices in another sense. In order to make good choices, it is important for the recipient to have knowledge of accessible services and to know his or her rights, which will possibly increase the pressure and responsibility on both the individuals receiving services and the service providers.

### **Findings in relation to the concept of participation**

The aim of this thesis has been to achieve a better understanding of the diverse ways in which participation in everyday life in older adults receiving home based services is experienced and understood by service providers and older adults. Although studies on older adults' participation in everyday life have started to emerge, we still lack a credible and coherent body of theory to inform practice. At a substantial theoretical level, participation in older adults receiving home based services can be understood in general as *a value-based process of acting on changing capacity in everyday life*. The diversities and similarities between older adults and service providers' experiences of older adults' participation in everyday life highlight the range of meanings given to participation in this context and the importance of looking at older service recipients' participation in the context of their whole lives. It turns out that their participation cannot be understood in isolation from the cultural, social and political contexts in which it occurs.

The concept of participation has been informed by a range of theoretical sources, yet participation lacks its own distinctive theoretical framework (Malone & Hartung, 2010; Molin, 2004). Theories on aging may say something about why participation is important in older adults. However, the activity, disengagement and continuity theories (Havinghurst & Henry, 1953; Cumming & Henry, 1961; Atchley, 1972) relate mostly to the individual level and have been criticized for claiming universality, for relating to the normative successful aging concept and for ignoring the subjective experience perspective (Bowling & Dieppe, 2005; Bowling, 2007). Theories drawn from a variety of disciplines to inform the field of participation have, to a large extent, been community-based theories related to empowerment, self-determination and decision-making. These aspects of participation are also emphasized in social policy documents (St.meld 25, 2005-2006; St.meld 47, 2008-2009) and in service providers' professional practice as this study has shown. However, empowerment and decision-making did not turn out to be central to the older adults' experiences of participation. It has nevertheless been shown that older adults' participation can be about *formal decision-making* and

*involvement in service delivery* as well as about *ways of being, acting, adapting, interacting* and *maintenance*, which relate more to a *process of practicing everyday life*. Therefore, the conceptualization of participation in this research may contribute to a broader understanding of older adults' participation and as a manifestation of *individual agency* within the context of living everyday life.

The grounded theory method applied here requires researchers to engage with theories and empirical studies representing useful lenses through which to view the emergent theory (Urquhart, 2007; Charmaz, 2006). A central finding across all studies in the field, including the current studies, is that participation is contextual and is closely related to personal factors and health factors, which means that the content of the categorization of participation to which this thesis refers develops in trans- and interaction with the environment and personal factors in the on-going daily life of each person. This perspective itself supports the importance of studying participation among different groups of people empirically as well as the importance of developing theoretical perspectives, including a multidimensionality such as the transactional perspective (Cutchin et al., 2003) and a relational understanding of disability (Tøssebro, 2004). It has been useful to view the conceptualization of participation as process through the meta theory of selective optimization with compensation (SOC) (Baltes & Carstensen, 1996). As illustrated in paper III and in the discussion section, SOC can represent a useful theoretical framework for focusing and trying to understand older adults' physical, psychological and social resources and how these influence participation in everyday life. SOC processes may illuminate participation of special importance to the older adults and how older adults participate in their everyday lives. Bringing these processes to attention can also help providers understand how they take place and cooperate with the older adults, in order to explore the impact of personal and environmental factors in the older adults' lives.

The substantial theory of participation in older adults' receiving home-based services derived from this study includes *levels*, different *contexts* and *dimensions* of the concept. Molin (2004) has previously suggested that the concept of participation includes i) individual and intra personal, ii) interactional and environmental, iii) micro



and macro, iv) formal and informal belonging and v) minimum and maximum levels. He has also presented participation as a concept of dimensions, including personal, social, active and passive dimensions. When it comes to participation of older recipients in home-based services, personal as well as environmental factors such as service providers, service delivery and service organization, physical and social environmental factors such as housing, neighborhood and social networks, all have influence. These findings support distinctions of the concept including individual and intra personal, interactional and environmental levels of participation. According to Molin (2004), the intra personal level includes that participation is within the person (e.g. at an intellectual level) and depends upon the individuals' choice of participation in activities, engagement and self-determination. The interactional level of participation points at the individuals' interaction with the environment.

A main substantial contribution to the conceptualization of older adults' participation at the intra personal and interactional levels is the *practical, emotional and intellectual dimensions* giving content to participation understood as *individual agency*. The practical dimension of participation includes processes of handling, organizing or reorganizing, making changes and structuring or restructuring participation in everyday life. The emotional dimension of participation includes understanding participation as feelings or expressions of feelings relating to and in order to manage or mobilize participation of special importance. Finally, the intellectual dimension of participation in older adults includes thinking, planning, reflecting, considering, negotiating, making choices or judging in relation to participation. Another understanding of the intellectual dimension of participation found here is maintaining control. As demonstrated in the discussion section, these dimensions include *practical, emotional and intellectual strategies* as well, representing the actual and creative variety of *actions* undertaken by the older adults in different contexts. The practical dimension of older adults' participation includes physical interaction with the environment. However, also emotional and intellectual dimensions of participation at the intra personal level are closely related to the older adults' participation at the interactional level, as emotional and intellectual reactions do not appear in a vacuum but in interaction with the environment, for example, service providers, neighbors, friends or family. As we have

seen in the discussion section these strategies can be applied in intentional ways in order to adapt to changing capacity and to influence situations. Therefore, *intentionality* should be included as another dimension of participation understood as individual agency. The practical, emotional and intellectual dimensions of participation are related to ways of practicing intentionality, at intra personal and interactional levels and can be understood separately and as intertwined.

This research has shown that service providers' and older adults' understanding of participation unite at an overall conceptual level. In one sense, the older adults' experiences of participation included many of the service providers' descriptions of participation in everyday life and in service delivery. However, the content given to the concept turned out to differ when it comes to the dimensional level. Even though service providers' understanding of older adults' participation included aspects of process, it was mainly limited to interaction with the service providers. The older adults' experiences included *dimensions of agency* such as *flexibility* and *creativity* to preserve control and *adaptation* to changing capacity in every-day life. *Agency in service delivery* was found to be woven together with *agency in everyday life* in the older adults. Participation in service delivery was experienced as adopting the home-based services to everyday life, which represents a process of *acting on* changing capacity and *balancing agency* that is characterized by emotional and intellectual dimensions of participation. The older adults regarded themselves as active participants in service delivery. Passivity and passive ways of delegating tasks could represent intentional ways of compensation for reduced functioning. Thus, professionals should understand participation beyond functional independence and activity performance, and *participation in service delivery should be viewed in relation to participation in everyday life*. Following habits and routines and keeping up with daily life, including recreational activities and social participation with family, friends and neighbors, are central dimensions of older adults' participation in everyday life. These dimensions represent *meaningful doings, beings* and *interactions* and are thus at both intra personal, individual, interactional, relational and environmental levels.

ICF has proposed the following definitions of engagement; as taking part, being included and engaged in an area of life, being accepted and having access to needed resources. The subjective experience of participation is defined as belonging. Generally, understanding of older adults' participation as "taking part," "engagement," and "belonging" relates to conceptualizations of participation in the ICF (WHO, 2001). However, it is argued that the experience perspective is not necessarily limited to belonging, but is considered conceptually fundamental and may as well as more objective criteria is related to many aspects of the concept. Compared to ICF's conceptualization of participation as belonging (WHO, 2001) and belonging at informal (e.g., family and friends) and formal (e.g., organization) levels (Molin, 2004), the substantial content of belonging in older adults receiving home-based services is related to "connection," "continuity" and "equality" and to their individual agency in everyday life. The categorization of older adults' experiences of participation i) in everyday life and ii) in service delivery shows that participation conceptually understood as "a value based process" and includes "keeping up dignity and pride," "concentrating on being an agent" and "balancing agency," "getting oneself going" on a daily life basis. Older adults are also concerned with "keeping one's place; at home, in the neighborhood and in the family" involving the "practical," "emotional" and "intellectual" dimensions and strategies as explained in order to "fend for oneself, as long as possible, in place." Taken together, this study has therefore shown that understanding participation as *practical, emotional and intellectual dimensions operationalize in a new way about what* participation is understood as engagement, belonging and agency.

Participation takes place in contexts. A relevant distinction of the main *contexts for participation* in older adults receiving home-based services is found to be *inside* and *outside* the house, including the *home, neighborhood* and *family* as important places for participation. Another relevant contextualization is the distinction between *participation in domestic and private*, and *outwards oriented activities*. This study has shown that satisfaction with participation in domestic and private versus outwards activities may have different explanations and these are thoroughly discussed in paper II. Understanding older adults' participation contextually includes being aware of factors influencing the context and different understandings of the meaning of context that

service providers and older adults may have. While service providers understood the context of home as the place where older adults, for example, are doing small matters and are passively waiting for the service providers, the older adults understood home as a place, for example, being and doing meaningful activities, alone or together with others, including friends, neighbors and family. Understanding participation contextually emphasizes the importance of revealing service providers' and older adults' experiences, perspectives and rationale for understanding participation. Different rationales may be expressed in *task oriented* and *process oriented* understandings of participation. When different understandings in the interface between service providers and older adults are unspoken or not reflected on they may represent barriers for older adults' participation in everyday life, as this study has shown. Participation conceptualized as task oriented gives main focus to assigned, time limited and eligible services. This may influence on service providers' possibilities of getting relevant information about older adults' wishes for participation in everyday life and may thus lead to misunderstandings, fragmented services and misinterpretation of older adults' needs. It may also contribute to confusion about expectations in relation to the professional role in service delivery. Aspects such as delays and lack of skills and initiative are examples of experienced barriers to participation in older adults.

Participation as *interaction in service delivery* includes *social and relational dimensions* differing from personal relationships. The current studies have shown that older adults consider their social participation with the service providers to be subordinate to practical and personal support in everyday life activities. Expectations of joint responsibility, appropriateness, skill and initiative in the accomplishment of services are key to the older adults, showing a combination of task and process oriented perspectives. Variety in age, gender and cultural background in the service providers may, in combination with the small-talk dimension, represent environmental and interactional factors appreciated by the older adults and may serve as a link to society.

The conceptualization of older adults' participation in the context of receiving home-based services fall into as well as support previously proposed empirical conceptualizations of participation in other contexts. Understanding participation as a

“dynamic process” as opposed to something static, including “doings and beings,” “strategies,” “engagement,” “values,” “agency” including agency relevant terms like “choice” and “control” and “continuity” are also traits of participation across studies reviewed in chapter 3, “The concept of participation.” Furthermore, our substantial conceptualization supports the theory that participation in older adults’ everyday life involves several social aspects, such as “belonging,” “membership” and “equality,” and can take place in different contexts: together with other people or alone, including participation at intra personal and interactional, micro and macro, formal and informal levels (Molin, 2004). Hence, these understandings of participation also relate to an understanding of participation as an equal right, as defined in the Convention of the Rights of Persons with Disabilities (UN, 2006) and as extending the “productivity” aspect described in the active aging framework to include the ways in which frail older adults continue to engage in everyday life. Our substantial theory also supports that experiences of participation can be intertwined as described by Van den Velde et al. (2010), that participation is generally related to dignity and is value based (Hammel et al., 2007). Moreover, the findings in this thesis support the theory that participation can be understood in terms of being more or less “active or passive” (Molin, 2004), whereas both dimensions can represent intentionality in the interface with service providers and service delivery. Finally, conceptualizing participation as a value-based process points to the importance of including a *temporal perspective* on participation in service delivery. In order to make services fit to older adults’ individual needs and preferences of participation, it is necessary to continuously redefine services in dialogue between service provider and older adult.

#### *Future studies*

The studies in this thesis have explored the experiences of service providers and the older adults’ perspectives on their participation. The studies showed that the older adults valued their participation with their family. The service providers paid less attention to the influence of family, friends and neighbors in the older adults’ lives, but experienced that most families asked for passive services. To understand how older adults’ participation in everyday life is influenced and can be supported, research is needed on

the perspectives of older adults' participation with relatives and next of kin. It is necessary to gain knowledge of how relatives and next of kin experience their participation with older adults and to explore how collective compensation strategies possibly play out, which factors influence these strategies and how these in turn influences participation. Family members' experiences of participation with the service system could also contribute to understand older adults' conditions for participation.

This research included a limited population of older adults. The aging world is changing, so researchers must respond to this by exploring both generational and cultural differences when it comes to participation. In order to further develop theory on participation in older adults, empirical studies of participation in other groups with particular needs should also be accomplished.

## **7. Possible practical implications**

An overall intention of health and social services, including home based services, is to meet the needs defined by the users of the services. This thesis contributes with empirical knowledge and substantial theory on older adults' participation in the context of everyday life and receiving home-based services. The diversities in the perspectives of the older adults and the service providers have, as we shall see, implications for organization and development of future services. Home-based services have untapped potential for supporting and facilitating participation in accordance with older adults' preferences and values of fending for themselves and preserving dignity and pride.

The accounts of participation in everyday life given by the older persons in this study differ from the discourse of participation as a right. As the older adults' understanding and practice of participation do not "fit" the idea of participation as equal rights, there is a danger of being ignored or overlooked by service providers as well as by researchers. Consequently, to identify older adults' wishes to participate, one must actively search for it. Rather than providing older adults with means to maximize user-participation and

self-determination, policy and practice need to recognize how older adults' values and experiences of changing capacity influence their participation in daily life. A successful integration of knowledge leading to increased participation and satisfaction with participation depends upon the recognition of older adults' rationale and resources for participation as well as upon the providers' sensitivity and ability to discuss the older adults' rationales during interactions with them.

The need for new knowledge about concepts such as participation and how this can contribute to new understanding, practices and language, have been central in this research. Innovation in the health and welfare sector is widely focused on at all levels of services (NOU,2011:11; St.meld.nr.47, 2008-2009). Early intervention is stated as an innovative way to improve and renew services (NOU, 2011:11). However, if we desire an early intervention approach to represent something other than a top-down instruction or new ways for professionals to exert power in encounters with older adults, we must recognize and support agency as an important aspect of participation in older adults. The knowledge generated in this study may serve as a basis for improving the efficiency of and efforts made to work with older adults' participation in service delivery, for example to go in for early intervention. The knowledge of older adults' participation can also serve as key for developing tools for early intervention. An early intervention approach in service delivery may, at its best, contribute to the recognition and bolstering of participation of specific importance to and well-being in the older individuals. It may also retain functioning and delay or transform a transition to frailer states. Hence, an early intervention approach should focus on and recognize the person's own resources. Experienced difficulty in performance of daily life activities could therefore be a better measure of needs of assistance than functional independence. In this way, an early intervention approach may also facilitate an equal rights perspective on participation.

The findings indicate that:

- Older adults should be asked about their preferences and importance of participation.

- Older adults' preferences of participation must be understood in relation to agency and the practical, emotional and intellectual dimensions of and strategies for participation must be recognized and understood by the service providers. Service providers must be aware of the nature of changing capacity and its influence on older adults' wishes for participation and need for adjusted support.
- The findings support the importance of implementing, applying and further developing measurements that capture the content of participation in daily life for clinical use in the lives of older adults.
- If dignity is to be achieved, values must be recognized and respected. Thus, service providers need to understand how older adults express their values (e.g., through practical, emotional and intellectual strategies). Providers must understand the older adults' creativity and flexibility as resources and means to select, compensate and optimize the participation that is important for them.
- Service providers should recognize that the pattern of participation in everyday life in older adults is associated with multiple factors. In order to facilitate participation in everyday life, service providers should acknowledge the heterogeneity in the older population with regard to preferences and resources for participation.
- Educational systems and service providers should be aware of the roles of family, neighbors and friends, as representing important environmental resources in the older adults' lives. New models of partnerships between the older adults, family and service providers may generate and facilitate increased participation.
- The function of socializing in general and small talk in particular, and their potential for enabling older adults to experience equality in participation in society should be understood and facilitated by the providers. Thus, focusing on communication and relational skills together with reflections and consciousness-



raising on service providers' rationale for service delivery should be a continuous topic of organizations and research.

- In order to succeed with early intervention models, service providers must be skilled enough to recognize the needs of rehabilitation or prevention. Models of service delivery must include cooperation between professional groups in ways that increase the possibility for flexibility and the possibility for quick and effective interventions.
- IPLOS serves as a mandatory system for mapping, registering, planning and reporting health and social services in Norwegian municipalities. Consequently, and in order to increase the focus on needs of rehabilitation and health promotion, IPLOS should include the variables that cover the needs of rehabilitation services. IPLOS has potential for further development and should fully include the multidimensional perspective on functioning and health that ICF represents.
- Service providers should not only be highly skilled and keep up to date on their own professional education but also be well informed and knowledgeable of the larger organization and community in which they work. They need to use this information in ways that contribute to and facilitate older adults' rights and wishes for participation in creative ways. Service providers should be well informed of other professionals' competence in order to provide the older adults with information about alternative possibilities and services that are accessible. Different parts of the home-based service system should have flexible systems for communication across the service organization.
- User friendly information about attainable services should continuously be evaluated and adjusted, and service providers in home-based services should be skilled at providing information.

- Participation in service delivery should be understood in relation to the older adults' participation in everyday life. Thus, the research needs to include measurements of participation in everyday life in service delivery with variables of evaluative aspects. Evaluative aspects, such as satisfaction with and importance of participation, may be especially relevant to older adults' adaption and selection of the activities that are most important to them.
  
- Multidimensional frameworks and theoretical models, such as ICF (WHO, 2002) and SOC (Baltes & Carstensen, 1996), are important for understanding participation in everyday life comprehensively, for appreciating the complexity of personal and environmental influence on participation and for developing methods for recognizing the variety of functioning, and for facilitating participation.
  
- The term "care" in relation to service delivery for older adults should generally be used with caution because of its possible discriminating associations. Consequently, the multiple language of participation may represent and cover a more realistic and nuanced picture of what is going on in the everyday lives of older people as well as support a more equal discussion of it.

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Kjersti Vik  
Avdeling for helse- og sosialfag  
Høgskolen i Sør-Trøndelag  
Ranheimsveien 10  
7004 TRONDHEIM

Vår dato: 08.10.2009

Vår ref: 22550 / 2 / RKH

Deres dato:

Deres ref:

#### TILRÅDING AV BEHANDLING AV PERSONOPPLYSNINGER

Vi viser til melding om behandling av personopplysninger, mottatt 07.09.2009. All nødvendig informasjon om prosjektet forelå i sin helhet 07.10.2009. Meldingen gjelder prosjektet:

22550

Behandlingsansvarlig  
Daglig ansvarlig

*Eldre personers og tjenesteyteres perspektiver på deltakelse  
Høgskolen i Sør-Trøndelag, ved institusjonens overste leder  
Kjersti Vik*

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

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


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

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

Personvernombudet vil ved prosjektets avslutning, 31.07.2012, rette en henvendelse angående status for behandlingen av personopplysninger.

Vennlig hilsen

  
Bjørn Henrichsen

  
Ragnhild Kise Haugland

Kontaktperson: Ragnhild Kise Haugland tlf: 55 58 83 34  
Vedlegg: Prosjektvurdering



## **Informasjonsskriv: Enhetsleder**

### **Forespørsel om deltakelse i forskningsprosjektet:**

### **Deltagelse i hverdags- og samfunnsliv for eldre med funksjonsnedsettelse:**

### **”Eldre personers perspektiver på deltakelse”**

#### **Bakgrunn og hensikt**

Dette er en delstudie som har som mål å utvikle kunnskap om forhold som hemmer og fremmer eldres deltakelse i hverdags- og samfunnsliv. Målet med studien er å utvikle kunnskap om hvordan eldre som mottar hjemmetjenester er involvert og deltar i hverdagslivet, og hvordan tjenesteytere i hjemmetjenesten jobber for å støtte eldres deltakelse. Studien har som mål å teste en arbeidshypotese om at det er en kontrast i perspektiver på deltakelse mellom tjenesteytere og tjenestemottakere.

Vi har et ønske om å få intervjuere ansatte i hjemmetjenesten i ..... bydel. Ansvarlig virksomhet for studien er Høgskolen i Sør-Trøndelag i samarbeid med institutt for helsevitenskap ved NTNU.

#### **Hva innebærer studien?**

Studien innebærer fokusgruppediskusjoner med tjenesteytere. Intervjuene vil ha en varighet på 1 – 2 timer og vil bli tatt opp på lydbånd.

#### **Hva skjer med informasjonen?**

Fokusgruppediskusjonen skal bygge på informert samtykke og vil bli ledet av undertegnede stipendiat. Alle data behandles konfidensielt og er avidentifisert, og det betyr at opplysninger er oppbevart forsvarlig og adskilt fra navn.

Det er kun taushetspliktige og autorisert personell knyttet til prosjektet som har adgang til opplysningene.

Opplysninger vil bli oppbevart frem til prosjektets slutt den 31.07.2012. Etter dette vil de bli slettet.

Det vil ikke være mulig å identifisere deltakerne i resultatene av studien når disse publiseres.

#### **Frivillig deltakelse**

Det er frivillig å delta i studien. Deltakerne kan når som helst og uten å oppgi noen grunn trekke sitt samtykke til å delta i studien. Dette vil ikke få konsekvenser for tjenestemottaking.

Dersom du samtykker i at din sone kan delta i undersøkelsen, undertegner du samtykkeerklæringen på siste side.

Du har også rett til å få informasjon om studiens resultat når den er ferdig.

#### **Utdypende informasjon**

Prosjektet er finansiert av Norges Forskningsråd. Stipendiaten har faglige veiledere oppnevnt fra Høgskolen i Sør-Trøndelag og institutt for helsevitenskap ved NTNU. Prosjektet er meldt til

Personvernombudet for forskning, Norsk samfunnsvitenskapelig datatjeneste AS. Prosjektet er til behandling hos Regional komité for medisinsk forskningsetikk.

Dersom du senere ønsker å trekke deg eller har spørsmål til studien, kan du kontakte en av personene nedenfor

Vennlig hilsen

Aud Elisabeth Witsø  
Stipendiat  
Høgskolen i Sør-Trøndelag  
Tlf:.....

Kjersti Vik  
Førsteamanuensis/veileder  
Høgskolen i Sør-Trøndelag  
tlf: .....

## Intervjuguide – fokusgruppe diskusjon

Deres erfaringer med deltakelse

- hvordan forstår dere ordet deltakelse – hva er deltakelse for deg? Hva får deg til å oppleve at du deltar?
- hva er viktigst for deg å delta i?

Deres erfaringer med eldres deltakelse i arbeidet i hjemmetjenesten

- hva er deltakelse for de eldre brukerne/pasientene deres?
- hvordan deltar de - kan dere fortelle eksempler der dere erfarte at en pasient/bruker hadde mulighet for å delta
- eks der dere erfarte at bruker/pasient ikke hadde mulighet for å delta
- hva gjør det mulig for brukere å delta?
- hva gjør det vanskelig?
- kan dere fortelle om brukere som har ulike strategier for å kunne delta?

Litteraturen sier at deltakelse kan handle om

- engasjement
- opplevelse av tilhørighet
- å ha kontroll og medbestemmelse
- omgivelsene hemmer og fremmer

kjenner dere igjen dette – hva tenker dere om det?

Deltakelse for eldre som mottar hjemmetjenester – ideal og virkelighet

Hva er mulig – hva er ideal?

Samarbeid

- kan dere gi eks på samarbeid som dere mener har hatt betydning for brukernes deltakelse –
- kan dere fortelle litt om de ulike samarbeidspartnerne dere har når dere jobber i hjemmetjenesten
- faktorer ved samarbeid som hemmer eller fremmer deltakelse for brukerne –eks?
- hvordan vil dere beskrive deres egen rolle/hjemmetjenestens rolle som samarbeidspartner?

Vedtak

- Fortell litt om hvordan dere oppfatter vedtakene - formulering – innhold
- hva betyr vedtakene for eldres deltakelse?
- Kan dere si litt om egen innflytelse på vedtakene?

Oppsummering – tilføyelser - avklaringer





5. Hvor ofte mottar informanten hjelp? (Ett kryss).

Mindre enn en gang i uka ..... <sub>1</sub> Flere ganger i uka ..... <sub>3</sub>  
 En gang i uka ..... <sub>2</sub> Daglig ..... <sub>4</sub>  
 Flere ganger daglig ..... <sub>5</sub>

**FUNKSJONSMÅLING (COOP-WONCA)**






Norsk bearbeidelse: Prof. B. G. Bentsen, Institutt for allmenn-  
 medisin og samfunnsmedisinske fag, Universitetet i Oslo

6. De neste spørsmålene handler om din fysiske, psykiske og sosiale tilstand. På hvert spørsmål setter du ett kryss i boksen til høyre for den tegningen som best beskriver din nåværende situasjon.

**1: FYSISK FORM**

De siste 4 uker ...

Hva var den tyngste fysiske belastningen du greide/kunne greid i minst to minutter?

MEGET TUNGT (f.eks. løpe fort)		<input type="checkbox"/> <sub>1</sub>
TUNGT (f.eks. jogge i rolig tempo)		<input type="checkbox"/> <sub>2</sub>
MODERAT (f.eks. gå i raskt tempo)		<input type="checkbox"/> <sub>3</sub>
LETT (f.eks. gå i vanlig tempo)		<input type="checkbox"/> <sub>4</sub>
MEGET LETT (f.eks. gå sakte - eller kan ikke gå)		<input type="checkbox"/> <sub>5</sub>

**2: FØLELSESMESSIGE PROBLEMER**

De siste 4 uker ...

Hvor mye har du vært plaget av psykiske problemer som indre uro, angst, nedforhet eller irritabilitet?

Ikke i det hele tatt		<input type="checkbox"/> <sub>1</sub>
Bare litt		<input type="checkbox"/> <sub>2</sub>
Til en viss grad		<input type="checkbox"/> <sub>3</sub>
En god del		<input type="checkbox"/> <sub>4</sub>
Svært mye		<input type="checkbox"/> <sub>5</sub>

**3: SAMLET HELSETILSTAND**

De siste 4 uker ...

Hvorledes vil du vurdere din egen helse, fysisk og psykisk, i alminnelighet?

Svært god		<input type="checkbox"/> <sub>1</sub>
God		<input type="checkbox"/> <sub>2</sub>
Verken god eller dårlig		<input type="checkbox"/> <sub>3</sub>
Dårlig		<input type="checkbox"/> <sub>4</sub>
Meget dårlig		<input type="checkbox"/> <sub>5</sub>

**AKTIVITET (Sunnaas ADL-index)**

7. Nå kommer noen spørsmål om hva du klarer å gjøre av aktiviteter i dagliglivet. ⇒

*Ett kryss på hver linje.*

	Helt avhengig av personhjelp 1	Delvis avhengig av personhjelp 2	Klarer selv med hjelpemidler 3	Kan alene og gjør det 4
1. Spising .....	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
2. Toalettbesøk .....	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
3. Mobilitet inne .....	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
4. Kontinens .....	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
5. Forflytning .....	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
6. Av/påkledning .....	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
7. Daglig hygiene .....	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
8. Matlaging .....	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
9. Bad/dusj .....	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
10. Husarbeid .....	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
11. Mobilitet ute .....	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
12. Kommunikasjon .....	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>

Evt. kommentarer (COOP-WONCA, Sunnaas ADL)↓

































## SERVICESYSTEMET

21. Disse spørsmålene handler om dine valgmuligheter når det gjelder kontakten med hjemmetjenesten. *Ett kryss på hver linje.*
- |   | Ingen valg-<br>mulighet<br>1 | Liten valg-<br>mulighet<br>2 | En del valg-<br>mulighet<br>3 | Stor valg-<br>mulighet<br>4 |
|---|------------------------------|------------------------------|-------------------------------|-----------------------------|
| 1. Hvor stor valgmulighet har du hatt i hvem som skal utføre tjenester hos deg? .....   | <input type="checkbox"/>     | <input type="checkbox"/>     | <input type="checkbox"/>      | <input type="checkbox"/>    |
| 2. Hvor stor valgmulighet har du i å avslå hjelpen/tjenesten du blir tilbudt? .....   | <input type="checkbox"/>     | <input type="checkbox"/>     | <input type="checkbox"/>      | <input type="checkbox"/>    |
| 3. Hvor stor valgmulighet har du hatt i å bestemme hva personalet skal bidra med? .....   | <input type="checkbox"/>     | <input type="checkbox"/>     | <input type="checkbox"/>      | <input type="checkbox"/>    |
| 4. Hvor stor valgmulighet har du i tidspunkt for når personalet skal komme? .....   | <input type="checkbox"/>     | <input type="checkbox"/>     | <input type="checkbox"/>      | <input type="checkbox"/>    |
|   |                              |                              |                               | Ikke<br>aktuelt<br>3        |
| 5. Har du i løpet av den siste måneden ikke fått dusjet/badet når du ønsket fordi personalet ikke kunne være tilstede? .....                                  | <input type="checkbox"/>     |                              | Ja<br>1                       | Nei<br>2                    |
| 6. Har du i løpet av den siste måneden ikke fått kledd deg som du ønsket fordi personalet ikke kunne være tilstede? .....                                     | <input type="checkbox"/>     |                              | <input type="checkbox"/>      | <input type="checkbox"/>    |
| 7. Har du i løpet av den siste måneden ikke fått gå på toalettet når du ønsket fordi personalet ikke kunne være til stede? .....                              | <input type="checkbox"/>     |                              | <input type="checkbox"/>      | <input type="checkbox"/>    |
| 8. Har du i løpet av den siste måneden ikke fått spist når du ønsket fordi personalet ikke kunne være tilstede? .....   | <input type="checkbox"/>     |                              | <input type="checkbox"/>      | <input type="checkbox"/>    |
| 9. Har du i løpet av den siste måneden ikke fått stått opp/lagt deg som du ønsket fordi personalet ikke kunne være tilstede? .....                            | <input type="checkbox"/>     |                              | <input type="checkbox"/>      | <input type="checkbox"/>    |
| 10. Har du i løpet av den siste måneden ikke handlet som du ønsket fordi du ikke har hatt hjelp? ..   | <input type="checkbox"/>     |                              | <input type="checkbox"/>      | <input type="checkbox"/>    |
| 11. Har du i løpet av den siste måneden vært misfornøyd fordi husarbeidet ikke har vært gjort slik du ønsket fordi personalet ikke kunne være tilstede? ..... | <input type="checkbox"/>     |                              | <input type="checkbox"/>      | <input type="checkbox"/>    |
| 12. Har du i løpet av den siste måneden hatt problem med å ta medisiner fordi personalet ikke kunne være tilstede? .....                                      | <input type="checkbox"/>     |                              | <input type="checkbox"/>      | <input type="checkbox"/>    |

## OMGIVELSER

22. Her følger noen spørsmål om dine erfaringer med hvordan forhold i omgivelsene virker inn på din mulighet til å delta i det du vil delta i. *NB: Her setter du ett eller to kryss på hver linje, ett for hyppighet og ett for om problemet evt. har vært stort eller lite.*

- | I løpet av de 12 siste månedene, hvor ofte ...  | Hyppighet                |                          |                          |                          |                          |                          | Stort/Lite problem       |                          |
|---|--------------------------|--------------------------|--------------------------|--------------------------|--------------------------|--------------------------|--------------------------|--------------------------|
|   | Alltid<br>1              | Oftre<br>2               | vis<br>3                 | Sjelden<br>4             | Aldri<br>5               | Ikke<br>aktuelt<br>6     | Stort<br>1               | Lite<br>2                |
| 1. ... har tilgjengelighet til transport vært et problem for deg? .....   | <input type="checkbox"/> | <input type="checkbox"/> | <input type="checkbox"/> | <input type="checkbox"/> | <input type="checkbox"/> | <input type="checkbox"/> | <input type="checkbox"/> | <input type="checkbox"/> |
| 2. ... har det naturlige miljøet, som temperatur, terreng, klima, gjort det vanskelig for deg å gjøre det du ønsker eller behøver å gjøre? .....              | <input type="checkbox"/> | <input type="checkbox"/> | <input type="checkbox"/> | <input type="checkbox"/> | <input type="checkbox"/> | <input type="checkbox"/> | <input type="checkbox"/> | <input type="checkbox"/> |
| 3. ... har andre aspekter i dine omgivelser som lys, lyd, menneskemengder etc. gjort det vanskelig for deg å gjøre det du ønsker eller behøver å gjøre? ..... | <input type="checkbox"/> | <input type="checkbox"/> | <input type="checkbox"/> | <input type="checkbox"/> | <input type="checkbox"/> | <input type="checkbox"/> | <input type="checkbox"/> | <input type="checkbox"/> |
| 4. ... har informasjon som du ønsket eller behøvde ikke vært tilgjengelig i et format som du kan bruke og forstå? .....                                       | <input type="checkbox"/> | <input type="checkbox"/> | <input type="checkbox"/> | <input type="checkbox"/> | <input type="checkbox"/> | <input type="checkbox"/> | <input type="checkbox"/> | <input type="checkbox"/> |
| 5. ... har tilgjengelighet av helsetjenester og legetilsyn vært et problem for deg? .....   | <input type="checkbox"/> | <input type="checkbox"/> | <input type="checkbox"/> | <input type="checkbox"/> | <input type="checkbox"/> | <input type="checkbox"/> | <input type="checkbox"/> | <input type="checkbox"/> |
| 6. ... hvor ofte har du behøvd hjelp av andre i hjemmet og ikke lett fått tak i det? .....  | <input type="checkbox"/> | <input type="checkbox"/> | <input type="checkbox"/> | <input type="checkbox"/> | <input type="checkbox"/> | <input type="checkbox"/> | <input type="checkbox"/> | <input type="checkbox"/> |
| 7. ... hvor ofte har andre menneskers holdninger vært et problem i hjemmet? .....   | <input type="checkbox"/> | <input type="checkbox"/> | <input type="checkbox"/> | <input type="checkbox"/> | <input type="checkbox"/> | <input type="checkbox"/> | <input type="checkbox"/> | <input type="checkbox"/> |
| 8. ... hvor ofte har du opplevd fordommer og diskriminering? .....  | <input type="checkbox"/> | <input type="checkbox"/> | <input type="checkbox"/> | <input type="checkbox"/> | <input type="checkbox"/> | <input type="checkbox"/> | <input type="checkbox"/> | <input type="checkbox"/> |
| 9. ... hvor ofte har bestemmelser og reglement i kommunen skapt problemer for deg? .....  | <input type="checkbox"/> | <input type="checkbox"/> | <input type="checkbox"/> | <input type="checkbox"/> | <input type="checkbox"/> | <input type="checkbox"/> | <input type="checkbox"/> | <input type="checkbox"/> |

## BAKGRUNNSINFORMASJON

23. Til slutt vil vi stille deg noen spørsmål om utdanning og økonomi.

1. På hvilket nivå er din høyeste fullførte utdanning? ⇨
- |                 |                          |   |   |                          |   |
|-----------------|--------------------------|---|---|--------------------------|---|
| Grunnskole..... | <input type="checkbox"/> | 1 | Høgskole/universitet, inntil 3 år ..... | <input type="checkbox"/> | 4 |
| Yrkeskole ..... | <input type="checkbox"/> | 2 | Høgskole/universitet, over 3 år .....   | <input type="checkbox"/> | 5 |
| Gymnas.....     | <input type="checkbox"/> | 3 | Doktorgradsutdanning .....              | <input type="checkbox"/> | 6 |
2. Har det i løpet av *de siste 12 månedene* hendt at du / din husholdning har hatt vansker med å klare løpende utgifter til mat, transport, bolig el.l.? ⇨
- |              |                          |   |               |                          |   |
|--------------|--------------------------|---|---------------|--------------------------|---|
| Aldri.....   | <input type="checkbox"/> | 1 | Av og til ... | <input type="checkbox"/> | 3 |
| Sjelden..... | <input type="checkbox"/> | 2 | Ofta .....    | <input type="checkbox"/> | 4 |
3. Er økonomien slik at du / din husholdning størsteparten av året har mulighet til å klare en uforutsett regning på kr 10 000,-? ⇨
- |          |                          |   |
|----------|--------------------------|---|
| Nei..... | <input type="checkbox"/> | 1 |
| Ja ..... | <input type="checkbox"/> | 2 |

24. Forventninger til deltakelse framover: ↴

<table border="1"><tr><td style="width: 20px; height: 20px;"></td><td style="width: 20px; height: 20px;"></td><td style="width: 20px; height: 20px;"></td></tr><tr><td colspan="3" style="text-align: center;"><i>Informant nr.</i></td></tr></table>				<i>Informant nr.</i>		
<i>Informant nr.</i>						

## **Informasjonsskriv: Enhetsleder**

### **Forespørsel om deltakelse i forskningsprosjektet:**

### **Deltagelse i hverdags- og samfunnsliv for eldre med funksjonsnedsettelse:**

### **”Eldre personers perspektiver på deltakelse”**

#### **Bakgrunn og hensikt**

Dette er en delstudie som har som mål å utvikle kunnskap om forhold som hemmer og fremmer Eldres deltakelse i hverdags- og samfunnsliv. Målet med studien er å utvikle kunnskap om hvordan eldre som mottar hjemmetjenester er involvert og deltar i hverdagslivet, og hvordan tjenesteytere i hjemmetjenesten jobber for å støtte Eldres deltakelse. Studien har som mål å teste en arbeidshypotese om at det er en kontrast i perspektiver på deltakelse mellom tjenesteytere og tjenestemottakere.

Vi har et ønske om å få intervjuer til sammen 10-15 personer i aldersgruppen 67-100 år som er mottakere av kommunale hjemmetjenester i ..... bydel. Ansvarlig virksomhet for studien er Høgskolen i Sør-Trøndelag i samarbeid med institutt for helsevitenskap ved NTNU.

#### **Hva innebærer studien?**

Studien innebærer individuelt intervju med eldre tjenestemottakere. Intervjuene vil ha en varighet på 1 – 1 ½ time og vil bli tatt opp på lydbånd.

#### **Hva skjer med informasjonen?**

Alle intervjuer skal bygge på informert samtykke og vil bli gjennomført av undertegnede stipendiat.

Alle data behandles konfidensielt og er aidentifisert, og det betyr at opplysninger er oppbevart forsvarlig og adskilt fra navn.

Det er kun taushetspliktige og autorisert personell knyttet til prosjektet som har adgang til opplysningene.

Opplysninger vil bli oppbevart frem til prosjektets slutt den 31.07.2012. Etter dette vil de bli slettet.

Det vil ikke være mulig å identifisere deltakerne i resultatene av studien når disse publiseres.

#### **Frivillig deltakelse**

Det er frivillig å delta i studien. Deltakerne kan når som helst og uten å oppgi noen grunn trekke sitt samtykke til å delta i studien. Dette vil ikke få konsekvenser for tjenestemottaking.

Dersom du samtykker i at din sone kan delta i undersøkelsen, undertegner du samtykkeerklæringen på siste side.

Du har også rett til å få informasjon om studiens resultat når den er ferdig.

#### **Utdypende informasjon**

Prosjektet er finansiert av Norges Forskningsråd. Stipendiaten har faglige veiledere oppnevnt fra Høgskolen i Sør-Trøndelag og institutt for helsevitenskap ved NTNU. Prosjektet er meldt til Personvernombudet for forskning, Norsk samfunnsvitenskapelig datatjeneste AS. Prosjektet er til behandling hos Regional komité for medisinsk forskningsetikk.

Dersom du senere ønsker å trekke deg eller har spørsmål til studien, kan du kontakte en av personene nedenfor

Vennlig hilsen

Aud Elisabeth Witsø  
Stipendiat  
Høgskolen i Sør-Trøndelag  
NTNU  
Tlf: 73 559252/41305442

Kjersti Vik  
Førsteamanuensis/veileder  
Høgskolen i Sør-Trøndelag  
tlf: 91797245

## **Forespørsel om deltakelse i forskningsprosjektet:**

### **Deltagelse i hverdags- og samfunnsliv for mennesker med funksjonsnedsettelse:**

#### **Eldres perspektiver på deltakelse**

##### **Bakgrunn og hensikt med prosjektet**

Dette er en henvendelse til deg om å delta i en forskningsstudie for å utvikle kunnskap om forhold som hemmer og fremmer eldres deltakelse i hverdags- og samfunnsliv. Målet med studien er å få kunnskap om hvordan eldre som mottar hjemmetjenester er involvert og deltar i hverdagslivet. Dessuten vil vi vite hvordan tjenesteytere i hjemmetjenesten jobber for å støtte eldres deltakelse.

Du er valgt ut til å forespørres fordi du bor i ..., er i aldersgruppen 67+ og er mottaker av kommunale hjemmetjenester. Ansvarlig for studien er Høgskolen i Sør-Trøndelag i samarbeid med institutt for helsevitenskap ved NTNU og Trondheim kommune.

##### **Hva innebærer studien?**

Studien innebærer et samtaleintervju med deg. Spørsmålene vil dreie seg om daglige aktiviteter og deltakelse. I tillegg spør vi om dine erfaringer med hjemmetjenesten som hemmer eller fremmer deltakelse.

Intervjuet vil foregå der det passer best for deg, for eksempel hjemme hos deg dersom du ønsker det. Intervjuet vil ha en varighet på 1 ½ - 2 timer. Det blir gjennomført av en stipendiat som er ansatt ved Høgskolen i Sør-Trøndelag. Hun er underlagt taushetsplikt.

Du vil bli kontaktet av en ansatt i hjemmetjenesten (tidsperiode:...) som spør om du vil delta i undersøkelsen. Hvis du ønsker å delta vil dere da gjøre avtale om tid og sted for intervju, du må da skrive under på en "samtykkeerklæring", se vedlegg. Intervjuet vil bli gjennomført av Aud Elisabeth Witsø som er underlagt taushetsplikt.

##### **Hva skjer med informasjonen om deg**

Alle data behandles konfidensielt, opplysninger er oppbevart forsvarlig og adskilt fra navn.

Opplysninger vil bli oppbevart frem til prosjektets slutt den 31.07.2012. Etter dette vil de bli slettet. Det vil ikke være mulig å identifisere deg i resultatene av studien når disse publiseres.

##### **Frivillig deltakelse**

Det er frivillig å delta i studien. Du kan når som helst og uten å oppgi noen grunn trekke ditt samtykke til å delta i studien. Dersom du har spørsmål til studien, kan du kontakte Aud Elisabeth Witsø som er stipendiat i prosjektet, tlf: 73 559252 eller 41305442.

**Samtykke til deltakelse i studien**

Jeg er villig til å delta i studien

-----

(Signert av prosjektdeltaker, dato)

Stedfortredende samtykke når berettiget, enten i tillegg til personen selv eller istedenfor

(Signert av nærstående, dato)

Jeg bekrefter å ha gitt informasjon om studien

## **Intervjuguide- Individuelle intervju**

**Introduksjon:** Informasjon om studien, mål og hensikt

### **Tema 1 – perspektiver på deltakelse**

#### **Åpningsspørsmål:**

Kan du fortelle litt om deg selv?

Alder, helse, interesser, behov for hjelp

#### **Introduksjonsspørsmål/overgangsspørsmål:**

Hva tenker du på når jeg sier ordet ”deltakelse” og hva er deltakelse for deg?

#### **Nøkkelspørsmål:**

Hvordan ser en vanlig hverdag ut hjemme (fra du står opp til du legger deg)

Hva engasjerer deg?

Sammen med hvem?

Forhold som gjør engasjement og deltakelse mulig?

Forhold som gjør engasjement og deltakelse vanskelig?

Hvilke aktiviteter deltar du i løpet av ei uke utenfor hjemmet?

Sammen med hvem?

Hva er spesielt viktig for deg? Når er du fornøyd med egen deltakelse?

Forhold som gjør engasjement og deltakelse mulig?

Forhold som gjør engasjement og deltakelse vanskelig?

### **Tema 2 – erfaringer med deltakelse i forbindelse med hjemmetjenester:**

#### **Åpningsspørsmål:**

Kan du fortelle litt om hva du får hjelp til i løpet av en hverdag – fra hjemmetjenesten og fra andre (for eksempel familie, naboer)?

#### **Nøkkelspørsmål:**

Hvordan opplever du samarbeidet med hjemmetjenesten?

*Sjekkpunkter:*

Hva hjelper de deg med?

Hvilken innflytelse har du på tidspunkter og avtaler?

Hva skjer med deg dersom de kommer for seint?

Hvilken betydning har det hvem det er som kommer? Utdype

Hvordan vil du beskrive mulighetene for innflytelse på tjenestene?

Hvis du tenker tilbake på hva du mente var viktig for deg med tanke på deltakelse (intervjuer oppsummerer) –

Hvordan vil du si at hjelpen fra hjemmetjenesten er tilpasset ditt behov for deltakelse?

Forhold som fremmer/hemmer deltakelse?

**Avslutningsspørsmål:** Sett at du fikk bestemme akkurat hvordan du ville ha hjelpen fra hjemmetjenesten – hvordan ville du da ha det? Forslag til forhold ved hjemmetjenesten som kan fremme din aktivitet og deltakelse?

**Sluttspørsmål:**

Intervjuer oppsummerer hva som var hensikten med studien. Deretter:

Har vi glemt noe? Tilføyelser?



