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# Home, health and participation for community living people with disability

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# Home, health and participation

## For community living people with disability

Björg Thordardottir

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DOCTORAL DISSERTATION
by due permission of the Faculty of Medicine, Lund University, Sweden.

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Title: Home, health and participation for community living people with disability


Abstract

The aim of this thesis was to contribute to the understanding of aspects related to home, health and participation for community living people with disability and identify different groups with different needs for interventions. Study I used focus groups to explore aspects of importance for participation. Twenty-nine people with Parkinson's Disease participated in nine focus groups. Studies II-III utilized baseline data from an ongoing study among people applying for housing adaptations in southern Swedish municipalities. Study II investigated personal, environmental, and activity-related factors linked to participation frequency and satisfaction among 128 housing adaptation clients. Study III investigated differences in participation frequency, participation satisfaction and self-rated health between groups of housing adaptation applicants. Study IV utilized interview data and study specific questions in longitudinal mixed-method design to explore experiences of participation before and after a housing adaptation. Study I revealed that participation was experienced in a variety of situations in a complex context of home and community. Study II showed that frequency of participation had a strong association with gender, cognitive impairments and dependence in ADL while satisfaction with participation had a strong association with age, usability aspects and self-rated health. Study III identified six heterogeneous groups, differing in terms of age, ADL dependence, functional limitations, cognitive impairments, concerns about falling and usability of the home, that also showed significant differences in participation and self-rated health. In Study IV, an overall theme of struggling with participation towards satisfaction with participation emerged and revealed how the participants experienced their participation on a continuum. The findings provide insights into how participation inside and outside the home, with others or alone is related to the person, the environment, and the performance of activities. This speaks to the importance of being observant of the different aspects of restrictions to participation for each individual, especially as disability often progresses over time.



Key words: activity, community living, disability, occupational therapy, participation

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# Home, health and participation

## For community living people with disability

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*To Pála and Lúdvík*

# Content

Abstract

List of papers in the thesis

Abbreviations and Definitions

The context of this thesis

Introduction ..... 17
- Participation 18
- Disability and health 19
- Home 21
- Theoretical frameworks and models 22

Aim ..... 25

Material and Methods ..... 27
- Overview of studies I-IV 27
- Study samples and context 28
  - Participants and selection criteria ..... 28
  - Data collection methods ..... 29
  - Data analysis ..... 33

Ethical considerations ..... 37

Results ..... 39
- Experiences of participation 39
- Changes in participation 41
- Participation frequency and satisfaction 43
- Heterogeneity of home and health characteristics 47

Discussion ..... 51
- Aspects of participation 51
- Relationships of participation, activity and health 53
- Different prerequisites for participation between groups 54
- Enabling participation 56
- Methodological considerations 58
  - Sampling, procedure and analysis of qualitative data ..... 58
  - Sampling, procedure and analysis of quantitative data ..... 59
- Ethical reflections 62

Conclusion ..... 63
Implications for practice 63
Implications for future research 64
Svensk sammanfattning ..... 65
Samantekt á íslensku ..... 69
Acknowledgements ..... 71
References ..... 73
Dissertations in Occupational Therapy, Faculty of Medicine, Lund University, Sweden ..... 85
Paper I-IV ..... 87

# Abstract

The aim of this thesis was to contribute to the understanding of aspects related to home, health and participation for community living people with disability and identify different groups with different needs for interventions. Study I used focus groups to explore aspects of importance for participation. Twenty-nine people with Parkinson's Disease participated in nine focus groups. Studies II-III utilized baseline data from an ongoing study among people applying for housing adaptations in southern Swedish municipalities. Study II investigated personal, environmental, and activity-related factors linked to participation frequency and satisfaction among 128 housing adaptation clients. Study III investigated differences in participation frequency, participation satisfaction and self-rated health between groups of housing adaptation applicants. Study IV utilized interview data and study specific questions in longitudinal mixed-method design to explore experiences of participation before and after a housing adaptation. Study I revealed that participation was experienced in a variety of situations in a complex context of home and community. Study II showed that frequency of participation had a strong association with gender, cognitive impairments and dependence in ADL while satisfaction with participation had a strong association with age, usability aspects and self-rated health. Study III identified six heterogeneous groups, differing in terms of age, ADL dependence, functional limitations, cognitive impairments, concerns about falling and usability of the home, that also showed significant differences in participation and self-rated health. In Study IV, an overall theme of struggling with participation towards satisfaction with participation emerged and revealed how the participants experienced their participation on a continuum. The findings provide insights into how participation inside and outside the home, with others or alone is related to the person, the environment, and the performance of activities. This speaks to the importance of being observant of the different aspects of restrictions to participation for each individual, especially as disability often progresses over time.

# List of papers in the thesis

This thesis is based on the following papers referred to by their Roman numerals:

I. Thordardottir B, Nilsson MH, Iwarsson S, Haak M. (2014). "You plan, but you never know"- participation among people with different levels of severity of Parkinson's Disease. *Disability and Rehabilitation,* 36(26):2216-24.

II. Thordardottir B, Ekstam L, Chiatti C, Malmgren Fänge A. (2016). Factors associated with participation frequency and satisfaction among people applying for a housing adaptation grant. *Scandinavian Journal of Occupational Therapy,* Feb 8:1-10.

III. Thordardottir B, Chiatti C, Ekstam L, Malmgren Fänge A. (2016). Heterogeneity of characteristics among people applying for housing adaptations in Sweden - relationship to participation and self-rated health. *International Journal of Environmental Research and Public Health,* 13 (91)

IV. Thordardottir B, Malmgren Fänge A, Chiatti C, Ekstam L. Experiences of participation in everyday life before and after a housing adaptation; a mixed method study. In manuscript.

# Abbreviations and Definitions

| | |
|---|---|
| Activity | The execution of a task or action by an individual (ICF). |
| ADL | Activities of Daily Living |
| CMOP-E | Canadian Model of Occupational Performance-Engagement |
| Community living | Living in own home |
| Disability | An umbrella term covering negative interactions between body functions, body structures, and contextual factors which result in activity limitations and participation restrictions (WHO) |
| Environmental factors | Physical, social and attitudinal environments in which people live and conduct their lives (ICF) |
| Housing adaptations | The alteration of permanent physical features in the home and the immediate surroundings, to reduce the demands of the physical environment. The aim of housing adaptations is to enhance daily activities and promote the ability to lead an independent life (SFS:1992:1574) |
| ICF | The International Classification of Functioning, Disability and Health |
| Occupations | Meaningful activities and tasks of everyday life that are named, organized and given value by individuals and cultures. Everything people do to occupy themselves, including self-care, leisure and productivity (Townsend & Polatajko, 2007). |
| Personal factors | Personal factors include gender, age, race, lifestyles, habits, education and profession (ICF). They represent influences on functioning particular to the individual which are not represented elsewhere in ICF. |
| Participation | Involvement in a life situation (ICF) |
| Self-rated health | The self-perceived overall health-related quality of life (EuroQuol) |

# The context of this thesis

This thesis in health sciences, specializing in occupational therapy, was written at the Department of Health Sciences, Lund University, Sweden. I arrived in Lund in 2008, with my Danish degree and 10 years of work experience in occupational therapy, eager to know more about everything! I finished my master's studies in occupational therapy in 2011, and was recruited as a PhD student to a new project that intended to improve understanding of aspects of participation in everyday life among people with Parkinson's disease.

My starting point in this thesis was the concept of participation as defined by the International Classification of Functioning and Health; in my previous work as an occupational therapist in rehabilitation, however, I had used the Canadian Model of Occupational Performance as a framework and the Canadian Occupational Performance Measure with my clients. During that time, the way my clients rated their performance of occupations and their satisfaction with their performance intrigued me, especially when they were uncertain and found my questions of 'important activities' somewhat odd!

In Study I: *"You plan, but you never know": Participation among people with different levels of severity of Parkinson's Disease*, I was involved in the research process from its onset, from writing the ethical proposal, to contacting participants in cooperation with Skåne University Hospital in Lund, to planning and preparing the focus group interviews. My role in all nine focus groups was observing, taking notes, probing if needed and debriefing at the end of each session. The taped interviews were then transcribed, partly by me, and I was involved in all aspects of the analysis, writing up the study and submitting it for publication.

The main part of this thesis, however, is based on data from an ongoing project at Lund University: *Housing adaptations and mobility devices – Evaluation of a new practice strategy*. Utilizing baseline data from Studies II-IV in close cooperation with my co-authors, I developed the research questions, planned, prepared and performed the data analysis, wrote the papers and submitted Studies II-III for publication. I was also given the opportunity to participate in data collection home visits, which allowed me to get acquainted with parts of the project data from its e years and most importantlyarticipants.

Participants' experiences and perceptions of participation with disability were a great source of inspiration to me, and gave me the opportunity to review and reconnect with my earlier work experience. Their perceptions and descriptions have been my guide through the extensive research literature on participation that is available, and I hope it will continue to guide me in my future work in occupational therapy.

# Introduction

The global prevalence of moderate or severe disability is estimated to be 15% of the general population and 50% among those aged 60 years and older (World Health Organization, 2015). This means that up to 190 million adults experience significant difficulties in functioning, and as many as 1 billion people are estimated to be living with some kind of disability. In Europe, an increase in life expectancy is creating strong demographic changes, transforming the continent into an ageing society with more people who remain living at home despite their disabilities (Commision, 2009).

Disability is often seen as an inevitable consequence of ageing (WHO, 2015). The functional limitations typically associated with ageing are not simply related to a person's chronological age. Capacities and health needs of people with disabilities living in communities are indeed very diverse. Opportunities for an ageing population to remain active and to continue to participate in society are dependent on one main factor: their health. Good health fosters activity and participation. At the same time; the experience of limitations and restrictions –that is, disability – has negative implications for health. Sudden deterioration in health, or a chronic or lifelong illness, may influence activities and participation even early on in life. Therefore, young people are a non-negligible group among those facing disability in their own homes and immediate surroundings.

Like many societies, Sweden has endorsed the aging-in-place policy and the number of people with disabilities (either due to aging or illness) living in communities is increasing (Socialstyrelsen, 2015). Simultaneously, there are economic constraints putting great demands on society to allocate resources towards effective interventions that facilitate health for all people.

While some disabilities result in extensive health care needs, others may affect everyday life without requiring frequent contact with health care or social services. Disability is therefore an extremely diverse topic. Nevertheless, common denominators are limitations on activity and restrictions on participation for the individual is his context. The World Health Organization (WHO) and the World Bank have stated that specific attention should be paid to promoting participation among people with disabilities (WHO, 2011).

# Participation

Participation is well-represented in the literature on rehabilitation as an important aspect of health and well-being (Law, 2002, Perenboom and Chorus, 2003, Jette, Keysor et al., 2005, Wilcock, 2006, Hammel, Magasi et al., 2008, Noonan, Kopec et al., 2009, Dijkers, 2010, Heinemann, 2010, Magasi and Post, 2010). Optimal participation has been described as the perfect fit between activity performance and expectations of how activities should be accomplished (Rochette, Korner-Bitensky et al., 2006). Maintaining participation is viewed as both a right and a responsibility, and also as a constant act of negotiation dynamically influenced by environmental factors (Hammel, Magasi et al., 2008).

Satisfaction with participation is said to have a stronger correlation with global life satisfaction (as an indicator of quality of life) than any other objective measures of mere frequency of participation (Whiteneck and Dijkers, 2009). Instruments intended to capture participation only do so to a limited extent (Eyssen, Steultjens et al., 2011), and several scholars have emphasized the importance of including both the objective and the subjective dimensions in evaluating participation (Hemmingsson and Jonsson, 2005, Whiteneck and Dijkers, 2009, Dijkers, 2010, Bouffioulx, Arnould et al., 2011, Bright, Boland et al., 2012, Perenboom, Wijlhuizen et al., 2012).

From the perspective of policy-makers, identifying homogeneous groups in a heterogeneous sample could support the implementation of new managerial instruments and policies. However, important characteristics of functioning and health are often missing in official data. For instance, it is often lacking information about the level of dependence in activities of daily living (ADL), which is a well-established measure of functional capacity (Iwarsson, Horstmann et al., 2009), strongly related to health (Oswald, Wahl et al., 2007). This knowledge could serve as a preliminary step towards identifying clients in need of interventions for facilitating participation, for example support with activities of daily living (ADL) and mobility, both inside and outside the home.

The ability to better differentiate between clients can also be an effective method for improving the allocation of resources in times of economic constraints, for example by guiding allocation choices among different groups of potential users. By deepening our understanding of their characteristics and the heterogeneity among them, it may be possible to distinguish clients who require only a temporary or a single health intervention from those for whom a stronger integration with other care professionals – and a personalized, multicomponent approach – is required.

# Disability and health

Health is more than just the absence of disease. For many community living people with disability, maintaining functional ability is of great importance. Many of them depend on support in their activities of daily living after a sudden deterioration in health, or with a chronic or lifelong illness such as multiple sclerosis, stroke or late effects of polio (Mansson and Lexell, 2004, Ekstam, Tham et al., 2011, Lexell and Brogardh, 2012). The support can be both formal, like home services, and informal, provided by family. Even in the early stages of Parkinson's disease (PD), for example, newly diagnosed people experience difficulties in performing various activities and need support with such activities as dressing, eating, cleaning, shopping and transportation (Hariz and Forsgren, 2011).

PD, one of the most common neurodegenerative illnesses, is progressive and chronic, and is characterized by four cardinal symptoms: tremor, bradykinesia, rigidity and postural instability (Alves, Forsaa et al., 2008) . Non-motor symptoms are also common, and cognitive impairments may even antedate motor symptoms (Chaudhuri, Odin et al., 2011). Manifestation of the symptoms also varies among individuals. Even after several years of treatment, up to 40% of people with PD eventually develop motor fluctuations as a result of their medication, ranging up to 95% in long-term studies (Alves, Forsaa et al., 2008). The severity of PD is commonly based on the Hoehn & Yahr stages, in which clinical features and functional disability are described on a range from I–V: I, for example signifies mild unilateral illness, while III is moderate illness and V is severe illness, confined to a bed or wheelchair unless aided (Goetz, Poewe et al., 2004).

People with disabilities living in their own homes are at risk for reduced participation in society, health problems and declining quality of life (WHO, 2011). Although the prevalence of disability is not strongly related to higher age, the prevalence of reduced participation among community-dwelling people has shown to increase with greater age, especially as regards self-care, mobility inside and outside the home, and looking after the home and belongings (Wilkie, Peat et al., 2006). In particular, mobility restrictions are associated with lower levels of participation in activities that reinforce social ties and social roles both in and outside the home (Rosso, Taylor et al., 2013). Many people, especially the elderly, are also at risk of – and have concerns about – falling (Jellesmark, Herling et al., 2012). Falls and fear of falling are serious issues for individuals, their families and the healthcare system (Pynoos, Steinman et al., 2012), as they often lead to reduced activity and participation with negative health consequences (Dias, Freire et al., 2011).

Research has also demonstrated relations between cognitive impairment, frailty and reduced participation (Wilkie, Peat et al., 2007, Robertson, Savva et al., 2014). For example, Alzheimer's Disease (AD) predicted low social participation among community living people (Sorensen, Waldorff et al., 2008) and those who are housebound were almost twice as likely to develop AD as persons who were able to leave the home (James, Boyle et al., 2011). People living with cognitive impairments in their own homes thus have very specific health care needs, especially as regards independent living.

Reduction in participation seem to be more common for women than men (Wilkie, Peat et al., 2006) although women still tend to engage in more activities (Anaby, Miller et al., 2009). The presence of a disability also makes participation less varied (Law, 2002) and more confined to the home (Haak, Ivanoff et al., 2007). Difficulties in performing activities and levels of dependence in everyday life, for example, are the main reasons for a housing adaptation application (Johansson, Lilja et al., 2007) and the likelihood of having to make adjustments to the living environment is associated with younger age and greater disability (Gitlin, Mann et al., 2001).

Support and social activities have been found to be motivational for participation among people with disabilities (Isaksson, Lexell et al., 2007) with positive associations to self-rated health (Blazer, 2008, Ichida, Hirai et al., 2013). Self-rated health denotes the perceived health of the individual. In the literature on health research it is widely used interchangeably with perceived health and self-assessed health. Higher scores of body functions, activity and participation (indicating higher levels of functioning), for example, are positively related to higher self-rated health (Arnadottir, Gunnarsdottir et al., 2011). Perenboom et al (Perenboom, Wijlhuizen et al., 2012) concluded that perceived health could be used as a valuable indicator of a health condition, as an alternative, for example, to the number of chronic diseases or functional limitations.

Community living people with disability are thus a heterogeneous group in terms of age, gender, self-rated health, cognitive impairments, functional limitations, ADL-dependency and concerns about falling. Moreover, they differ in living arrangements, housing, level of support and use of mobility devices. They may therefore be considered as individuals at risk for reduced participation in their everyday life: inside and outside the home, in the community and in work and leisure contexts. Research on the factors associated with participation, including both frequency and satisfaction, can add important knowledge relevant for health interventions intended to facilitate participation both inside and outside the home.

Today in Sweden, there are no official standards indicating how many resources a municipality should invest for specific groups of users among community living people with disability. This leads to disparities in how they are treated in different

areas across the country. Obtaining a comprehensive view on their health is therefore crucial, as life expectancy is increasing and they may even be expected to live another 10-15 years.

## Home

When peoples' functional capacities are diminished, the context of participation often changes from outside to inside the home (Haak, Ivanoff et al., 2007, Fänge and Ivanoff, 2009). The home is thus an important place for activity and participation, especially among older people and people with disabilities (Haak, Fänge et al., 2007, Haak, Ivanoff et al., 2007, Petersson, Lilja et al., 2008, Petersson, Kottorp et al., 2009).

Significant relationships between home and health have been demonstrated (Oswald, Wahl et al., 2007), showing that people who live in accessible homes and perceive their home as useful are more independent in daily activities. Moreover, improving home environments enhances functional ability outcomes for older people (Wahl, Fänge et al., 2009). Disability may thus be reduced through the effect of housing adaptations, which also have the potential to counteract injuries in the home and contribute to increased independence (Spillman, 2004; Parker, et al., 2006).

Physical factors in the home environment can limit the individual's performance in activities and participation, or facilitate performance by counteracting restrictions. Removing physical barriers in the home environments of community living people with disability has been shown to positively affect the ability to perform daily activities and to improve performance and satisfaction with everyday occupations (Stark, 2004). Furthermore, providing client-centered housing adaptations improve activity performance and satisfaction with performance (Stark, Landsbaum et al., 2009). Usability of the home describes the encounter between the person, the environment and the activity and denotes the efficiency, effectiveness and satisfaction with activity performance in a physical context. Usability implies that a person should be able to move around, perform activities and use all facilities of the home on equal terms with other individuals (Fänge and Iwarsson, 2003). Both accessibility and usability are central in current Swedish building legislation (SFS, 2010:900 ).

In Sweden, housing adaptations are provided to people with declining functional capacity in order to remove physical barriers in the environment, with the administrative goal of independent living at home. Housing adaptations are governed by the Housing Adaptation Act (SFS 1992:1574) and are a publicly

funded intervention, administered by the municipality after an application has been submitted by the client. The full costs of housing adaptions are granted based on needs assessment and certification by a health professional, most often an occupational therapist employed by the municipality. A significant portion of housing adaptation grants are granted to community living people under the age of 70 years.

People who received housing adaptations reported a significant improvement in their self-rated ability in everyday life and increased safety, especially in tasks related to self-care in the bathroom and getting in and out of the home (Petersson, Lilja et al., 2008, Petersson, Kottorp et al., 2009). Independence in daily activities improved after housing adaptations within (Fänge and Iwarsson, 2005, Fänge and Iwarsson, 2005, Johansson, Lilja et al., 2007, Petersson, Kottorp et al., 2009, Stark, Landsbaum et al., 2009, Wahl, Fänge et al., 2009, Pettersson, Lofqvist et al., 2012) and outside the home (Petersson, Lilja et al., 2008). Clients who receive housing adaptations very often use mobility devices, both indoors and outdoors. Mobility devices are prescribed based on the assumption that they reduce falls and improve activity and participation. However, the role of mobility devices, especially in relation to participation is unclear (Salminen, Brandt et al., 2009) and there is a lack of studies that focus explicitly on participation before and after a housing adaptation.

# Theoretical frameworks and models

The work on this thesis was guided by theories and models of disability and health. The overall aim of the International Classification of Disability, Functioning and Health (ICF) is to provide a uniform, standard language for the framework of health and health-related states (WHO, 2001). The inclusion of activity, participation and contextual factors as important components of health alongside body functions and body structures was an important step towards a more comprehensive view of health that includes the context we live in, both environmental and personal factors, and our activities and participation.

From an occupational therapy perspective, however, the ICF still has limitations in capturing different aspects of participation, for example the exclusion of the individual's subjective experience (Hemmingsson and Jonsson, 2005). Personal factors, for example, are not classified in the ICF, although their influence on health is uncontested. External features (environmental factors) are classified in ICF, with barriers and facilitators as qualifiers, denoting the level of functioning, disability and health within a given environment.

In addition, ICF defines activity as 'the execution of a task or action' and participation as 'involvement in a life situation'. The domains of activity and participation are not clearly separated, since they are classified within a single list and coded with the same qualifiers (capacity and performance).

Daily living activities are a basic human need that helps people organize their time and pursue choice and control. Performance of activities is a dynamic process that develops and changes throughout our lives and provides us with opportunities that affect our health and well-being. However, performance of activities can also be an act of trial and error or recurrent attempts, depending on performance capacity and context (Christensen and Townsend, 2011). For example, society can facilitate activity and participation by creating accessible environments and by providing assistive devices, or contribute to limiting activity and restricting participation by creating barriers. Environmental factors also consist of the social and attitudinal context in which people live and conduct their lives; social support, for example, has positive associations with self-rated health (Blazer, 2008, Ichida, Hirai et al., 2013).

In order to target health in a valid manner, contextual factors and settings should be taken into account. An occupational theory perspective is based on knowledge about the relationship between the person, their environment and their occupations. Occupations consist of set of activities and tasks that are of value and meaning for the individual and bring structure to everyday life (Townsend and Polatajko, 2013). Every day, people strive to perform occupations of self-care, productivity and leisure. Being engaged in activities every day – being occupied – is a basic human need that helps us organize our time and pursue choice and control. Occupational therapy focuses on enabling individuals to participate in meaningful occupations, and by doing so improve health and well-being (Wilcock 1996). Also of importance is the acknowledgement and awareness of participation as subject to change throughout the individual's life (Edward and Christiansen, 2005). Performance of daily activities is therefore a dynamic process that develops and changes over a person's lifespan. Over time, development and changes can both provide us with and deprive us of occupations beneficial to our health and well-being.

The Canadian Model of Occupational Performance and Engagement (CMOP-E) is a theoretical model that focuses on the dynamics of occupations. The CMOP-E defines (occupational) participation as involvement in life situations through occupations. The model emphasizes that participation is not merely the capacity to perform an activity; it includes the level of importance an individual attaches to it or the degree of satisfaction it brings them (Townsend and Polatajko, 2013). Activities of high importance and satisfaction thus become our core in everyday life; they are the activities we value and therefore engage in – our occupations.

Client-centered enablement underlines how the voice of the client is central in occupational therapy. A crucial aspect in occupational therapy practice is to enable engagement in occupations by increasing accessibility, usability, safety and security in the environment and facilitating participation inside and outside the home, emphasizing that the perceived situation determines a person's participation (Townsend and Polatajko, 2013). Clients in occupational therapy can also be families, groups, communities, organizations or populations since CMOP-E also highlights enabling change at the societal level. Practice and research that focuses on enabling social change also targets social structures, systems and the built environment. It starts with a client-centered, occupation-based focus and acknowledges differences along the way towards enabling social change in a community.

# Aim

The overarching aim of this thesis was to contribute to the understanding of aspects related to home, health and participation for people with disabilities living in the community. Thus, the aim was to explore experiences and perceptions of participation in everyday life and to investigate the relationships between participation frequency and satisfaction, and personal, environmental and activity-related factors. A further aim was to identify different groups with different needs for interventions among housing adaptation clients and explore their experience of participation before and after an adaptation.

The specific aims were:

To improve our understanding of aspects of participation in everyday life for people with different levels of severity of Parkinson's Disease

To investigate the association of personal, environmental, and activity-related factors among housing adaptation applicants in Sweden with participation frequency and satisfaction.

To identify different groups of housing adaptation applicants and to investigate differences in participation frequency and satisfaction as well as self-rated health among them

To explore and describe how housing adaptation clients experience participation in everyday life before and after an adaptation.

# Material and Methods

## Overview of studies I-IV

In this thesis, different research approaches in data collection and analysis were applied. The ambition was to combine qualitative and quantitative methods in order to facilitate the understanding of different aspects of participation and their relations to the person, environment and activity, on both the individual and group levels.

Study I used focus groups to explore aspects of importance for participation. Study II investigated personal, environmental, and activity-related factors linked to participation frequency and satisfaction. In Study III differences in participation frequency, participation satisfaction and self-rated health were investigated in a set of homogeneous groups of housing adaptation applicants identified using a cluster-analysis approach. Finally, in Study IV, qualitative and quantitative data were used in an convergent longitudinal mixed-method design to explore experiences and perspectives of participation before and after a housing adaptation.

An overview of the research approach is presented in Table 1.

**Tabel 1. Overview of the study design sampling, data collection methods, and data analysis**

| | Study I | Study II | Study III | Study IV |
|---|---|---|---|---|
| **Study desing** | Focus group design | Quantitative<br>Cross sectional | Quantitative<br>Cross sectional | Longitudinal<br>mixed methods |
| **Sampling strategy** | Purposeful sampling | Recruited from existing database | Recruited from existing database | Purposeful sampling from existing database |
| **Data collection methods** | Focus group interviews | Instruments<br>Study specific questions | Instruments<br>Study specific questions | Semi-structured interviews<br>Study specific questions |
| **Data analysis** | Focus group analysis[1] | Descriptive statistics<br>Factor analysis[2]<br>Chi-square tests<br>Spearmans correlation<br>Logistic regression[3] | Descriptive statistics<br>Factor analysis[2]<br>Cluster analysis[4]<br>Chi-square tests<br>Spearmans correlation<br>ANOVA<br>Fishers exact | Case study analysis[5]<br>Content analysis[6]<br>Convergent mixed methods[7] |

Note: In accordance with [1]Krueger and Casey (2009), [2]Streiner and Norman (2008), [3]Hosmer Jr and Lemeshow (2004), [4]Everitt et al (2011), [5]Yin (2014), [6]Graneheim & Lundman (2004), [7]Creswell (2014)

# Study samples and context

The four studies of the thesis were based on different samples in order to gain broad knowledge of experiences and perspectives of participation among community living people with disability. The characteristics of the participants in the four studies are presented in Table 2.

**Table 2. Participants characteristics in the four studies**

| Variable | Study I N=29 | Study II N=128 | Study III N=124 | Study IV N=5 |
|---|---|---|---|---|
| **Age range mean (SD)** | 53-81 years 67.8 (6.2) | 35-94 years 75.3 (13.6) | 25-96 years 75.2 (13.5) | 50-91 years 68.2 |
| **Gender (male/female)** | 16/13 | 40/88 | 36/88 | 2/3 |
| **Use of MD indoors n(%)** | 8(28) | 95(74) | 95(77) | 4 |
| **Use of MD outdoors n(%)** | 10(34) | 114(89) | 115(93) | 5 |
| **Living alone n(%)** | 3 (10) | 67(52) | 68(55) | 3 |

Note: SD: standard deviation; MD=mobility device

## Participants and selection criteria

Study I was based on a sample of people with Parkinson's disease (PD), recruited among outpatients at the Neurological Clinic at Skåne University Hospital in Lund. The inclusion criteria were being diagnosed with idiopathic PD at least one year prior to the start of the study and the ability to communicate in Swedish. The one-year criterion was used as the diagnosis can change at an early stage (Hariz and Forsgren, 2011). A specialist PD nurse received oral and written information from the research team, before assisting in selecting the participants. Letters were sent out to fifty people, followed up by a phone call from the thesis author in order to present the study and answer any questions regarding the procedure. During the phone call, those interested in participating were asked to rate their PD as 'mild', moderate' or 'severe' in order to create homogeneous focus groups with regard to severity. At the same time they answered questions related to fluctuations, falls, type of housing, living arrangements, work situation, education and use of mobility devices. This was done both for descriptive purposes and for the purpose of creating heterogeneity within each group to stimulate variations in the discussion. Six focus groups were organized. Later, in order to obtain saturation in the data (Krueger and Casey, 2009), three additional focus groups were organized with letters and phone calls two months later: one comprising persons with

moderate PD and two with persons with severe PD. Reasons for dropping out were: unable to contact, refusing participation or unable to attend due to either lack of transportation, illness or both. In total, nine focus groups were planned and conducted (three groups for each self-rated PD severity level).

Studies II-III utilized baseline data from an ongoing study on housing adaptations in southern Swedish municipalities. All community-living people over 20 years of age who applied for a housing adaptation grant via one of the occupational therapists employed by the municipality were systematically considered eligible to participate in the study if they fulfilled the inclusion criteria. After a client had contacted an occupational therapist for housing adaptation, the occupational therapist asked the client whether he or she was willing to participate in the study. Participation in the study was completely voluntary; the participants received oral and written information about the study and gave their written informed consent. Reasons for dropping out were: unable to contact or unable/unwilling to receive occupational therapist for data collection.

Study IV was based on longitudinal data from the housing adaptation project. Purposeful sampling was used to ensure diversity among the participants (Creswell, 2014). The aim of the purposeful sampling for this study was to include both men and women with variation in age, living arrangements, type of housing and use of mobility devices. This information was available from the baseline data from a larger longitudinal study of housing adaptation clients in three municipalities in southern Sweden (Ekstam, Carlsson et al., 2014).

Common exclusion criteria for all four studies were living in sheltered housing and inability to communicate and follow instructions in Swedish.

## Data collection methods

### *Study I*

Prior to the focus groups, the research team developed a semi-structured interview guide. The focus groups met at the Neurological Clinic at Skåne University Hospital, which was a familiar setting to all the participants. The first question was broad: asking the participants what went through their minds when they heard the word participation. The following questions addressed the meaning of participation, important situations and contexts for participation, how PD affected their ability to participate, what would make it easier for them to participate in light of their PD and – more specifically – what made participation difficult. Finally, the participants were asked to describe what means they considered important to make participation easier for people with PD. Throughout the study, questions, probes and follow-ups addressed situations in everyday life in general,

for example at work, at leisure and in social contexts with family and friends, inside and outside the home. Each focus group met once with the thesis author present as an observer in each group.

### *Studies II-III*

Data among clients applying for a housing adaptation were collected using a self-administered and an administered questionnaire during a 90-minute home visit prior to the housing adaptation. All data was collected by occupational therapists specially trained in the data collection methodology applied.

An overview of the data collection instruments and questions is presented in Table 3.

**Tabel 3. Overview of variables, data collection instruments and study-specific questions**

| Variable | Instruments and study specific questions |
|---|---|
| Participation frequency and satisfaction | In the home, outside the home with others, outside the home alone |
| No. functional limitations[1] | Housing Enabler |
| Accessibility score [2] | Housing Enabler |
| Self-rated health[3] | EQ-5D visual analogue scale |
| Cognitive impairments[4] | Montreal Cognitive Assessment, MoCA |
| Usability (self-care, social and leisure-outdoor aspects)[5] | Usability In My Home, UIMH |
| Dependence/difficulty in ADL[6] | ADL-staircase |
| Concerns about falling[7] | Falls Efficacy Scale, FES-I, short version |
| Living alone | yes/no |
| Formal/informal support | yes/no |
| Use of mobility devices ( indoors, outdoors) | yes/no |
| Fear of falling | yes/no |

[1] Measured by Housing Enabler personal component, items A-K (Iwarsson and Slaug, 2010)
[2] Measured by the Housing Enabler (Iwarsson and Slaug, 2010)
[3] Measured by EQ-5D-5L Visual Analogue Scale (Brooks, 1996)
[4] Measured by the Montreal Cognitive Assessment (Nasreddine, Phillips et al., 2005)
[5] Measured by Usability in My Home instrument revised version (Malmgren Fänge and Ekstam, In manuscript)
[6] Measured by the ADL Staircase (Sonn and Asberg, 1991)
[7] Measured by the FES-I short version (Kempen, Yardley et al., 2008)

### *Participation*

As a proxy measure of participation, six structured, closed-end study specific questions were developed to capture both frequency of – and satisfaction with – contacts in and outside the home as well as engagement in activities inside and outside the home, with others or alone. The questions focused on how often and how satisfied the individuals were with: 1) being in contact with friends, family or acquaintances in and outside the home; 2) doing something outside the home with

friends, family or acquaintances; and 3) doing something alone outside the home. The response categories for frequency were on a 5-point scale: 'almost never', 'yearly', 'monthly', 'weekly' or 'daily'. Likewise the response categories for satisfaction were: 'very unsatisfied', 'unsatisfied', 'neither satisfied nor unsatisfied', 'satisfied' or 'very satisfied'.

*Functional limitations, environmental barriers and accessibility*

The Housing Enabler (HE) instrument was used to determine the number of functional limitations and assess the magnitude of the accessibility score. HE is a valid and reliable instrument for assessing and analyzing accessibility problems in housing. The possible range is 0-1832, with a higher score indicating more problems. The instrument is administered in three steps, utilizing a combination of interview and observation: the first step targets the individual by assessing the presence of functional limitations (12 items) and dependence on mobility devices (2 items). The second step assesses the presence or absence of physical environmental barriers in the home and in the immediate outdoor environment (161 items). Finally, based on the assessments in the first two steps, the magnitude of accessibility problems caused by a particular combination of functional limitations, dependence on mobility devices and environmental barriers can be calculated using existing algorithms (Iwarsson and Slaug, 2010).

*Self-rated health*

The EuroQol 5D Visual Analogue Scale (EQ-5D VAS), which was developed by the EuroQol Group (Brooks, 1996) together with a non-disease specific five question instrument (EQ-5D), was used for gathering data on self-rated health. The participants were asked to mark their own perceived health state on a 20-cm vertical 100-step scale with endpoints of 0 for 'worst imaginable health' and 100 for 'best imaginable health'. The EQ-VAS has been found to be predictable by the EQ-5D (Whynes, 2008); both EQ-5D and EQ-VAS are well-tested measurements with high validity and reliability, and are appropriate to use in an older population (Hickey, Barker et al., 2005).

*Cognitive impairment*

Montreal Cognitive Assessment (MoCA), a brief cognitive screening tool, was used to gather information on short-term memory, executive functions, visual-spatial abilities, language, attention, concentration, working memory, and temporal and spatial orientation. The possible range is 0-30 with 0-10=severe cognitive

impairment, 10-17=moderate cognitive impairment, 18-26 =mild cognitive impairment, and >26=normal/no cognitive impairment. The MoCA has high sensitivity and specificity for detecting moderate cognitive impairment (Nasreddine, Phillips et al., 2005).

*ADL dependence*

The ADL Staircase, used to assess ADL dependence (Sonn and Asberg, 1991) is an operationalization of independence and is thus related to the legislative framework for housing adaptations. It comprises nine items on feeding, transfer, using the toilet, dressing, bathing, cooking, transportation, shopping, and cleaning. For items where the participant is rated as independent, he or she was also asked to state whether the corresponding activity is performed with or without difficulty (Iwarsson, Horstmann et al., 2009). Additional yes/no questions were asked concerning: living alone, formal/informal support and use of mobility devices.

*Falls*

The Falls Efficacy Scale-International (FES-I) short form, used to assess concerns about falling, comprises seven items on dressing, bathing, sitting down or rising from a chair, walking on stairs, reaching for something above or below, walking up or down a slope, and attending a social gathering. For each item the participant is asked to rate their concerns about falling: 'not at all concerned', 'somewhat concerned', 'fairly concerned' or 'very concerned'. The short form is a good tool for assessing the fear of falling in older persons (Kempen, Yardley et al., 2008). In addition, fear of falling was assessed with a yes/no question.

*Usability in the home*

The Usability in My Home instrument (UIMH) is a self-rating instrument measuring client satisfaction with activity performance in relation to the design of the housing environment, e.g. responding to the question:" How satisfied are you with the physical context of your home when you prepare meals?". The instrument comprises 18 items, reflecting different personal, household, and leisure activities. The validity and reliability have been tested and the psychometric properties of the UIMH need further exploration (Fänge and Iwarsson, 2003). In order to come up with meaningful data on usability for use in a regression model, a factor analysis was conducted. The aim of factor analysis was to identify groups of variables that have a common structure and measure the same overarching construct (Malmgren Fänge and Ekstam, In manuscript). Thanks to this approach, three aspects of usability were identified for use in Studies II and III. The exploratory factor

analysis revealed 11 of the 18 original items in the UIMH, altogether explaining up to 65% of total variance. The 'self-care aspect' included 5 items: going to the toilet, managing personal hygiene, preparing meals, preparing snacks and moving around within the home with or without a mobility device. The 'social aspect' included 3 items: socializing with family and friends within the home, contacting others via telephone/Skype, and watching TV/listening to the radio. The 'leisure and outdoor aspect' included 3 items: entering the house, picking up the mail, and pursuing hobbies and leisure activities within the home.

### *Study IV*

A convergent mixed-method approach was applied (Creswell, 2014), using both qualitative and quantitative data. Data collection for the qualitative aspect consisted of semi-structured individual interviews that explored experiences of participation before and after a housing adaptation. The quantitative data consist of the study-specific questions on participation frequency and satisfaction explained above, and self-rated health on the EQ-5D VAS, before and after a housing adaptation. The qualitative and quantitative data were gathered in as parallel a fashion as possible. Each client was interviewed at home by a researcher on three occasions: before the housing adaptation, and three months and twelve months after the housing adaptation.

## Data analysis

### *Study I*

The focus groups were transcribed verbatim. The thesis author transcribed six of nine focus groups. All transcripts were double-checked through listening to the recordings while reading.

The focus group analysis was performed according to Krueger (Krueger and Casey, 2009). Immediately after each focus group, the moderator and observer reflected upon the discussions together and wrote field notes. The ambition was to capture the essence of what was being said and to incorporate it into the forthcoming focus group sessions. Both first and last author read the transcripts and listened to the recordings several times in order to reflect on the dynamics of the group discussions. They first analysed the data separately; sections of the group discussions that were relevant to the aim of the study were then identified and systematized into categories in an iterative process. Descriptive summaries were written for each category, highlighting the essence of what was being said. In the following interpretation, the descriptive summaries were abstracted into an

interpretive text. At this stage, the second author verified the analysis by reading the text and making comments, which resulted in the first author going back to the raw data to make clarifications. Finally, the third author critically read and commented on the emerging findings. Once the analysis was set, translation of selected quotes was performed by a professional, native English-speaking translator. Recruitment, data collection and analysis continued until saturation was reached, i.e. when new findings only added to the existing categories and did not reveal any new information.

### *Studies II and III*

For analytic purposes, as a proxy measure of participation, the dependent variable of participation frequency and satisfaction were reclassified (Table 4). No standardized measures exist for what accounts for frequent and satisfactory participation since that is highly subjective. From the five-point scales used, ratings of 1, 2 and 3 were defined as less frequent/less satisfying participation and ratings of 4 and 5 defined as more frequent/more satisfying participation. The dichotomized data on participation frequency and satisfaction were then used as dependent variables in each regression model in Study II.

**Tabel 4 Dichotomisations of participation in studies II-III**

| Variable: | Less frequent/satisfying: | More frequent/satisfying : |
|---|---|---|
| Participation frequency<br>- Contacts in the home<br>- Outside the home with others<br>- Outside the home alone | Almost never, yearly or monthly. | Weekly or daily. |
| Participation satisfaction<br>- Contacts in the home<br>- Outside the home with others<br>- Outside the home alone | Very unsatisfied, unsatisfied or neither unsatisfied or satisfied | Satisfied or very satisfied |

ADL dependence was rated on a 4-point scale from 0-3: ‘independent without difficulty’, ‘independent with difficulty’, ‘partly dependent’ and ‘dependent’ (Iwarsson, Horstmann et al., 2009). A sum total was produced with a possible range of 0-27, in which a higher sum total indicated greater dependence in ADL.

Usability was rated on a 5-point scale, where 1 = not at all satisfied and 5= very satisfied, for example in response to the question: “How satisfied are you with the physical context of your home when you prepare meals?” A higher sum total for each aspect indicated more satisfaction with the usability of the home (Malmgren

Fänge and Ekstam, In manuscript). The possible range within the self-care aspect was 5-25, and for both social and leisure-outdoor aspect 3-15.

According to guidelines (Kempen, Yardley et al., 2008) the final FES-I score should be summarized using the person's responses in six or seven activities, with a higher sum total indicating greater concerns about falling. In Studies II and III, an adjusted formula was used, taking those persons who responded only to 5 activities (for example, due to being unable to walk or using a wheelchair on a permanent basis) into consideration. The rationale for this choice was that the frailest group of the sample should not be excluded.

Study II applied regression analysis to explore factors related to participation frequency and participation satisfaction in two separate models. Age, gender and the questions/instruments listed in Table 3 were used as independent variables in both models. The relationship between all variables was explored beforehand and interaction terms were tested. Variables with potential associations to each dependent variable (p-value at or below 0.20 at bivariate level) were included in each regression model. After performing a stepwise multinomial logistic regression, variables were also removed manually by level of significance $p \leq 0.05$ in order to reach a well-fitted model. One interaction term was included in the final version for participations satisfaction.

Study III applied cluster analysis to identify groups similar in terms of age, dependence in ADL, number of functional limitations, cognitive impairments, concerns about falling, and satisfaction with the three aspects of usability in the home identified before conducting the study. The variables included in the clustering where checked for correlations (Pearson's $r < 0.6$) and then used as continuous variables of standardized z-scores with cluster centroids (means). In a second step, the clusters identified by our analysis were used to further explore participation frequency and satisfaction and self-rated health. In order to do so, Chi-Square and Fisher's exact tests were used when comparing clusters on categorical data on participation and self-rated health was compared with ANOVA. For both participation and self-rated health, $p \leq 0.05$ was considered statistically significant.

All statistical analyses in Studies II and III were performed using SPSS 22 for Windows.

### *Study IV*

The interviews were transcribed verbatim; the thesis author transcribed five out of fifteen. Analysis of the interviews was guided by the principles of case study (Yin, 2014), with changes in participation over time as the unit of analysis. The analysis began by listening to the interviews and creating a case description for each of the five clients respectively. The first and last author read all data to obtain a sense of

the whole and discussed the content areas based on theoretical assumptions in line with the aim of the study. In a second step, a content analysis (Graneheim and Lundman, 2004) of all interviews was done to allow for comparison across cases with focus on experiences of participation over time. The data analysis proceeded with the first and last author separately coding all interviews for one participant, followed by a discussion. The remaining interviews were then systematically read and sorted separately by the first author into condensed meaning units and labelled with a code. The codes were then compared and sorted into categories based on their differences and similarities. The tentative categories were then discussed by the first and last author and revised, supported by researchers' notes. In order to establish rigor in the findings, the second author critically examined the findings as they emerged. Throughout the analysis, the researchers made notes of their first impressions. The quantitative component was used for data-triangulation in the analysis in order to obtain a better understanding and better descriptions of experiences of participation frequency and satisfaction, as well as of self-rated health from a longitudinal perspective. Finally, the categories were discussed by all four authors and revised until an agreement was reached.

# Ethical considerations

The studies in this thesis were performed in accordance with the Swedish Act concerning the Ethical Review of Research Involving Humans (SFS, 1998:204), the Swedish Data Protection Act (SFS, 2003:460), and the World Medical Association Declaration of Helsinki (World Medical Association, 2013).

In compliance with formal ethical guidelines, the participants received a letter containing information about the aim of the respective studies/projects. Informed written consent was provided by all participants and they were assured of anonymity, as stated in the letter of information as well as orally. The participants were also informed that they could withdraw from participation at any stage up to publication of the results, without any influence on future interventions provided by health care settings – for example the occupational therapist involved in the service delivery process. No position of dependence existed in relation to the researchers.

The right to decline or withdraw from participation is based on the principle of respect for the autonomy of the individuals. Their decisions must be voluntary and based on knowledge. In the first study, the letter was followed up by a phone call from the author of this thesis, explaining the aim of the study. The venue of the focus groups was carefully chosen at a setting at the hospital, familiar to all participants. No form of incentives was offered besides payment for transport and expenses related to time off work. For Studies II-IV, potential participants were contacted by the occupational therapist involved in their housing adaptation application, either in person (during their meeting) or by phone. They all received letters of information as well, and signed informed consent. Again, no position of dependence existed in relation to the researchers.

The studies were approved by the regional Ethics Committee in Lund, Sweden: Dnr. 2012/126for Study I and Dnr 2012/566; 2013/590 for Studies II-IV.

# Results

New knowledge regarding participants' experiences and personal perceptions of uncertainty in participation emerged from the focus groups (Study I) and through the interviews (Study IV). The results of the studies included in this thesis also represent a broad knowledge of factors related to participation among community living people with disability.

## Experiences of participation

Study I revealed that participation was perceived and experienced in a variety of situations in the complex context of home and community. In general, participation was described as a feeling of being important to others and the ability to influence others, both in family life and the community (for example at work). The consequences of having PD emerged as a very central feature of the discussions, and differences in important aspects of participation, as determined by disease severity, were elucidated. Three main categories illustrating important aspects of participation emerged: PD-specific features attract attention; the unpredictability of PD causes uncertainty and affects participation; and planning is an essential strategy in the prioritization of participation.

Irrespective of disease severity, the participants stated that they felt exposed while participating in events such as meetings, birthdays or other gatherings outside their home with other people. Intensified by the fact that knowledge of PD in general was perceived as scarce, disease-specific features evoked feelings of embarrassment and stigma. The participants expressed concerns about how their PD-specific features made their family feel uncomfortable. In fact they emphasized that others sometimes suffered more from a sense of shame than they did themselves. As a consequence, the participants spoke about how they had to adjust to the fact that their family members did not want to accompany them in various social situations.

The unpredictability of PD symptoms was described as a main concern for participation in everyday life, both at home and outside of the home. Not knowing when sudden PD-specific problems, such as emotional and motor symptoms

would occur evoked feelings of uncertainty that had a negative effect on participation. Suddenly becoming tearful when among other people was described as difficult by those with both moderate and severe PD. Unpredictable PD-specific motor problems such as fluctuations, freezing, falls and cramps complicated the performance of activities. The general experience was, however, that help was usually on hand and willingly provided. Still, for those with severe PD, fear of falling and the unpredictability of cramps restricted participation in meaningful activities.

Planning was described as essential to making participation in everyday life possible. On-going internal dialogue and careful preparation in order to take part in and perform activities in everyday life was described, as daily tasks consumed more time. Adjusting the daily schedule, for example dividing activities into smaller tasks and large social gatherings into smaller events, was described as vital in maintaining some structure in a daily routine and in maintaining participation. Planning, illustrated in three sub-categories, was an essential strategy in compensating for physical and mental slowness; it helped them cope with internal and external stress and was necessary due to lack of energy and strength.

The experience of physical and mental slowness was described by all groups. The ability to take initiative was also affected by PD. One paradoxical consequence mentioned was that they also needed more time for planning; decision-making and the time required to do so were described as making them likely to end participation.

Sensitivity to stress was considered an important issue for participation because it worsened PD symptoms, in the participants' experience. Stress that had helped them perform and thrive prior to the illness was now negatively affecting participation. In general, susceptibility to stress was two-fold: it was provoked by external as well as internal factors, thereby influencing participation in everyday life and making it less manageable. Standing in line at a cash register was explicitly mentioned as a problematic situation, and shopping was therefore planned based on when shops would be least crowded. Internal factors that provoked stress were participants' own insecurities and fears of what might happen, for example when coming to the actual payment situation, and these often made the situation worse.

All groups stated that, for reasons of limited energy and strength (both physical and mental), planning was another important issue that was essential for participation. Not having the same energy and strength as before meant that careful planning was required in order to be able to take part in and perform meaningful, desirable activities. Instead wasting strength on something tedious or something they could get help with, consciously saving energy and strength was highlighted as an important prerequisite for participation. Unplanned, spontaneous

participation had become limited, especially for those with severe PD. Despite careful planning, taking part in the activities they wished to might mean only having enough energy and strength to participate for a short while.

## Changes in participation

Experiences of participation before and after a housing adaptation emerged on a continuum in Study IV. The main theme described a range of experiences along a continuum from struggling with participation to satisfaction with participation. At one end of the continuum, participants struggled with activities and participation; at the other, successfully performing activities enhanced satisfaction with participation. Three categories emerged from the data: still struggling with participation; facilitating activities at home opens up for outside activities; and satisfaction with participation.

After the housing adaptation, some of the participants still struggled more than others to perform activities due to functional limitations and remaining environmental barriers. Despite the housing adaptation to some extent facilitating performance of activities, unmet expectations sometimes ensued due to participants giving up activities, such as leisure, that were described as important. When the housing adaptation failed to enhance mobility indoors, the participants' capacity that day determined their opportunities to engage in activities and levels of support from others in these activities was the same as before the housing adaptation.

Tailored adaptations helped activity performance run 'smoothly' and facilitated getting out of the house. The ability to perform daily activities more easily fulfilled the expectations of enhanced participation in meaningful activities, both in and outside the home, for some of the participants. Becoming more self-reliant in the home after the housing adaptation was described as leading a 'normal life'. Easier performance of activities in the home was described as 'crucial' for participation outside the home, as it served as both a prerequisite and a facilitator for getting out of the house and diminishing isolation. Performing and engaging in activities at home was not only a prerequisite or a facilitator, but also a part of the activity of 'going out'.

Some participants became more satisfied with participation during the year, sometimes even beyond what they had anticipated. For example, having their homes adapted to their specific needs, made it possible to engage in activities and allowed them to continue living at home in spite of their disabilities; prior to the

housing adaptation, being dependent on mobility devices had for example meant difficulties going out.

Certain activities were facilitated through the housing adaptation, but this was not explicitly reflected in more frequent or more satisfactory participation. Participation in the home became less frequent and less satisfying or remained stable. Only one in five participants was more satisfied with participation at home one year after the housing adaptation. Participation outside the home with others only became more frequent and satisfactory for one participant and participation outside the home alone became more frequent for another participant. Moreover, changes in participation were not always in congruence with self-rated health. For example, more frequent participation did not always reflect higher self-rated health.

Overall, in Studies I and IV, participation in activities was influenced by the participants own physical capacity on any given day. The visibility and unpredictability of PD, along with difficulties in planning, made the participants in Study I uncertain in their participation. They struggled with their participation, similar to the participants in Study IV,– that is, wanting and planning to participate but not knowing if they would succeed. Participation with PD can therefore also be described as swinging back and forth on a continuum, comprising trial and error over time. Symptoms of PD, for example, could suddenly occur just before leaving the home to go out, adding to their uncertainty and even causing them to stay at home instead. Similarly, even after a housing adaptation, the clients were also dependent on their own level of capacity moving around indoors, on receiving similar levels of support in self-care as previously, and had lingering concerns about falling. Although planning was highlighted as a strategy that supported participation for people with PD, daily activities demanded a great deal of time and energy which they often didn't have. This was also an issue raised by the housing adaptation clients in Study IV; for example, showering was exhausting and left them with little energy left for pursuing participation outside the home. The experience of being physically and mentally slow was described by all focus groups in Study I, regardless of severity of PD, affecting their ability to initiate activities. Conscious saving of energy instead of using all their strength on something they could get help with was highlighted as an important prerequisite for participation outside the home. The housing adaptation clients in Study IV, on the other hand, described how their increased independence – for example, in self-care – raised their aspirations towards participation. Just knowing that their opportunities for participation within the home had been facilitated affected them mentally, lifted their spirits and made them more likely to pursue activities outside the home – for example, being able to freshen up and get ready to go out independently facilitated their perception of themselves as participators in the activity of 'going out'.

Taken together the results in Studies I and IV show that performing and participating in activities more easily in the home was described as crucial for participation outside the home, as it served as both a prerequisite and a facilitator for going out. However, participants' ratings of the frequency of and their satisfaction in participation revealed that participation remained stable overall or became less frequent and satisfactory under all conditions – at home and outside the home, with others and alone. Similar results also applied for self-rated health.

## Participation frequency and satisfaction

Gender, number of functional limitations, self-rated health, accessibility score, the self-care aspect of usability and concerns about falling were all factors related to frequency of participation in the home in Study II. The first three factors, as well as cognitive impairment, were also related to frequency of participation outside the home with others. Accessibility was not related to frequency of participation outside the home, while other environmental factors were; this is the case for living arrangements, formal or informal support, and use of mobility devices indoors. The social aspect of usability was related to frequency of participation outside the home with others. The strongest significant relationship was between dependence in ADL and frequency of participation outside the home, both with others and alone (table 5).

Age, self-rated health, use of mobility devices outdoors and concerns about falling were all factors related to satisfaction with participation in the home. Self-care and social aspects of usability had the strongest significant relationship with satisfaction with participation at home. Number of functional limitations, self-rated health, accessibility score and usability aspects were related to satisfaction outside the home, both with others and alone. Additionally, living arrangements had a strong relation to satisfaction outside the home alone. Again, the strongest significant relationship was between dependence in ADL and satisfaction with participation outside the home, both with others and alone (table 5).

**Table 5. Bivariate relations to participation frequency and satisfaction**

| Variables | At home, p-value | | Outside the home with others, p-value | | Outside the home alone, p-value | |
|---|---|---|---|---|---|---|
| | Frequency | Satisfaction | Frequency | Satisfaction | Frequency | Satisfaction |
| Gender | 0.022 | 0.60 | 0.010 | 0.50 | 0.60 | 0.40 |
| Age | 0.20 | 0.008 | 0.80 | 0.15 | 0.10 | 0.19 |
| No. of functional limitations[1] | 0.018 | 0.07 | 0.050 | 0.006 | 0.08 | 0.017 |
| Self rated health[2] | 0.018 | 0.022 | 0.006 | 0.006 | 0.80 | 0.013 |
| Cognitive impairment[3] | 0.90 | 0.29 | 0.006 | 0.90 | 0.10 | 0.50 |
| Living arrangement | 0.30 | 0.30 | 0.80 | 0.055 | 0.018 | 0.006 |
| Formal/ informal support | 0.20 | 0.50 | 0.90 | 0.30 | 0.033 | 0.90 |
| Use of mobility devices indoors | 0.80 | 0.50 | 0.60 | 0.90 | 0.017 | 0.90 |
| Use of mobility devices outdoors | 0.20 | 0.010 | 0.90 | 0.40 | 0.30 | 0.20 |
| Accessibility score[4] | 0.023 | 0.10 | 0.051 | 0.017 | 0.07 | 0.046 |
| Usability:self-care aspect[5] | 0.034 | <0.001 | 0.30 | 0.005 | 0.40 | 0.09 |
| Usability: social aspect[5] | 0.08 | 0.005 | 0.022 | <0.001 | 0.10 | 0.008 |
| Usability: leisure/outdoor aspect[5] | 0.20 | 0.24 | 0.90 | 0.014 | 0.10 | 0.013 |
| Dependence in ADL[6] | 0.30 | 0.50 | <0.001 | <0.001 | <0.001 | <0.001 |
| Conccerns about falling[7] | 0.013 | 0.047 | 0.10 | 0.09 | 0.50 | 0.30 |

[1] Measured by Housing Enabler personal component, items A-K (Iwarsson and Slaug, 2010)

[2] Measured by EQ-5D Visual Analogue Scale (Brooks, 1996)

[3] Measured by the Montreal Cognitive Assessment (Nasreddine, Phillips et al., 2005)

[4] Measured by the Housing Enabler (Iwarsson and Slaug, 2010)

[5] Measured by Usability in My Home (Malmgren Fänge and Ekstam, In manuscript)

[6] Measured by the ADL Staircase (Sonn and Asberg, 1991)

[7] Measured by the FES-I short version (Kempen, Yardley et al., 2008)

Frequency of participation had a strong association with gender, cognitive impairments and dependence in ADL (Table 6). It seems that women participate more frequently at home than men, and that better performance on the cognitive test meant more frequent participation outside the home with others.

Satisfaction with participation had a strong association with age, usability aspects and self-rated health. Being older and more satisfied with usability of the home meant being more satisfied with participation at home in Study II. Study III supported these findings in that the four groups of older adults all rated usability higher than the two groups of young-old adults and a large proportion of them were satisfied with their participation at home.

Self-rated health had the strongest relation to satisfaction outside the home with others. Higher self-rated health meant being more satisfied, and the analysis of Study III showed similar trends, as those with the lowest self-rated health (adults at risk of disability and young-old with disability) were also among those whose participation outside the home was less satisfactory. Study IV supports the results in that those with the most stable and highest ratings of satisfaction with participation outside the home with others were also those who rated their health the highest.

**Table 6. Associations to participation frequency and satisfaction**

| Variables | At home, p | | Outside the home with others, p | | Outside the home alone, p | |
|---|---|---|---|---|---|---|
| | Frequency | Satisfaction | Frequency | Satisfaction | Frequency | Satisfaction |
| Gender | 0.003 | | 0.068 | | | |
| Age | 0.26 | 0.002 | | 0.08 | 0.10 | 0.089 |
| No of functional limitations[1] | 0.64 | 0.47 | 0.16 | 0.15 | 0.28 | 0.70 |
| Self rated health[2] | 0.50 | 0.93 | 0.014 | 0.001 | | 0.47 |
| Cognitive impairments[3] | | | 0.006 | | 0.7 | |
| Living arrangements | | | | 0.1 | 0.3 | 0.053 |
| Formal/informal support | 0.063 | | | | 0.65 | |
| Use of mobility devices indoors | | | | | 0.94 | |
| Use of mobility devices outdoors | 0.58 | 0.92 | | | | 0.65 |
| Accessibility score[4] | 0.99 | 0.95 | 0.07 | 0.9 | 0.07 | 0.65 |
| Usability:self-care aspect[5] | 0.67 | 0.004* | | 0.42 | | 0.48 |
| Usability: social aspect[5] | 0.80 | 0.004* | 0.026 | 0.017 | 0.92 | 0.26 |
| Usability: leisure/outdoor aspect[5] | 0.28 | | | 0.26 | 0.018 | 0.011 |
| Dependence in ADL[6] | | | 0.017 | 0.057 | <0.001 | 0.020 |
| Concerns about falling[7] | 0.70 | 0.72 | 0.31 | 0.83 | | |

[1] Measured by Housing Enabler personal component, items A-K (Iwarsson and Slaug, 2010)
[2] Measured by EQ-5D Visual Analogue Scale (Brooks, 1996)
[3] Measured by the Montreal Cognitive Assessment (Nasreddine, Phillips et al., 2005)
[4] Measured by the Housing Enabler (Iwarsson and Slaug, 2010)
[5] Measured by Usability in My Home (Malmgren Fänge and Ekstam, In manuscript)
[6] Measured by the ADL Staircase (Sonn and Asberg, 1991)
[7] Measured by the FES-I short version (Kempen, Yardley et al., 2008)
* Interaction term

## Heterogeneity of home and health characteristics

Study III revealed six groups, differing in age, dependence in ADL, functional limitations, cognitive impairments, concerns about falling and usability of the home and results provide valuable knowledge about heterogeneity among housing adaptation applicants in terms of activity, physical and cognitive functioning, as well as the usability of the environment. The results also demonstrated differences in participation inside and outside the home – with others or alone – as well as differences in self-rated health between groups. The six groups identified were given names according to the personal, environmental and activity related factors/details that were considered to best describe them.

Participation at home was reported as frequent for all the subjects in the "Well-functioning older adults" and "Frail older with moderate cognitive impairment" clusters (clusters 3 and 5, respectively). Ninety percent of "Well-functioning older adults" (cluster 3) and 88% of "Frail older adults" (cluster 4) were satisfied with their participation at home. Least frequent and satisfactory participation at home was reported by "Young old with disabilities" (cluster 2). Differences in participation frequency and satisfaction at home were significant between clusters ($p < 0.05$). Participation outside the home with others was reported as frequent by 65% and satisfactory by 80% of the "Well-functioning older adults" (cluster 3). Least frequent participation outside the home with others – eight percent – was reported in "Frail older with moderate cognitive impairment" (cluster 5). Least satisfaction with participation outside the home with others (39%) was reported in "Young old with disabilities" (cluster 2). Differences in participation frequency outside the home with others were significant between clusters ($p=0,017$). Participation alone outside the home was reported as frequent and satisfactory by 70% among "Well-functioning older adults" (cluster 3). The lowest frequency (26%) and satisfaction (22%) were reported among "Young old with disabilities" (cluster 2). No significant differences between clusters were found. Self-rated health was lowest among "Young old with disabilities" (cluster 2) and highest among "Well-functioning older adults" (cluster 3), with significant differences between the clusters ($p = 0.001$). An overview of group descriptors is presented in Table 7.

**Table 7. Group descriptions**

| Group no./name | n | mean age | Characterized by:* |
|---|---|---|---|
| Adults at risk of disability | 15 | 49.7 | Low dependence in ADL, low number of functional limitations, no cognitive impairment and high level of concern about falling. Usability of their home was rated medium for self-care and leisure/outdoor aspects, high for social relations. |
| Young old with disabilities | 23 | 70.7 | High dependence in ADL, high number of functional limitations, mild cognitive impairment, high level of concern about falling and all aspects of usability of their homes rated low.<br>**Least frequent and satisfactory participation at home**<br>**Least satisfaction with participation outside the home with others**<br>**Least frequent and satisfactory participation outside the home alone**<br>**Lowest self-rated health** |
| Well-functioning older adults | 20 | 78.8 | Low dependence in ADL and few functional limitations, mild cognitive impairments and low level of concern about falling. Usability for all aspects of housing was rated high.<br>**All report frequent participation at home and 90% satisfied in that regard**<br>**Most frequent and satisfactory participation outside the home with others**<br>**Most frequent and satisfactory participation outside the home alone**<br>**Highest self-rated health** |
| Frail older adults | 33 | 81.5 | Medium dependence in ADL and number of functional limitations, mild cognitive impairment and low level of concern about falling. Usability of their homes for all aspects was rated medium to high. |
| Frail older adults with moderate cognitive impairments | 12 | 79.6 | High dependence in ADL and high number of functional limitations, moderate cognitive impairment and low level of concern about falling. Usability of their homes was rated low for self-care and social aspects and medium/high for leisure/outdoor aspects.<br>**All report frequent participation at home, with 67 % satisfied in that regard**<br>**Least frequent participation outside the home with others** |
| Resilient oldest old | 21 | 83.9 | Low dependence in ADL, few functional limitations, mild cognitive impairment and a high level of concern about falling. Usability of their homes was rated high for self-care, medium for social aspects and low for leisure/outdoor aspects. |

In Study II, dependence in ADL had the strongest association with frequency of participation outside the home alone. Likewise, the results of the cluster analysis indicated that those most dependent in ADL (young-old with disabilities and frail older with cognitive impairments) participate the least frequently outside the home and are least satisfied with their participation with others or alone. The results of the two quantitative studies (Studies II and III) are therefore coherent in this respect.

The results of Study III also supported the findings of Study II, in that frail older with cognitive impairments do not participate frequently outside the home, either with others or alone.

The results from Study III thus highlight that housing adaptation applicants are a heterogeneous group and can serve as a preliminary step towards identifying the clients most in need of interventions that facilitate participation inside and outside the home and allocating resources accordingly.

The participants in Study IV rated frequency of and satisfaction with participation very differently. Only participation frequency in the home was rated as ‘weekly’ or ‘daily’ among the participants. Self-rated health also varied greatly, ranging from 30-70 on the EQ-VAS for before the housing adaptation. Three months after the housing adaptation the range was 30-90 and one year after, the range was similar (30-85).

# Discussion

The aim of this thesis was to contribute to the understanding of aspects related to home, health and participation for community living people with disability. Overall, the findings confirm the complexity of contextual factors, both personal and environmental, related to participation. An association between activity factors and frequency of and satisfaction with participation indicated the need for a broader perspective in health interventions related to independent living at home. The identification of clusters in a heterogeneous sample served the purpose of finding groups with differences in characteristics, participation and self-rated health between them.

## Aspects of participation

The findings in Studies I and IV show a variety of important aspects of participation over the course of disability, both regarding severity of illness and over time. Based on the focus group interviews, experiencing a sense of exposure in public, the unpredictability of the illness, and issues relating to the planning of everyday life all emerged as important aspects of participation. However, Study I also revealed differences in important aspects of participation among the levels of severities of the illness, and participation seemed to be affected in different ways as the disability progressed, with more functional limitations making it more difficult to overcome. The findings therefore indicate that people with PD require interventions and strategies that are targeted to their individual level of PD severity, implying that rehabilitation practitioners should also be attentive to the fact that individual needs change as the illness progresses.

The visibility of PD symptoms was a major concern that gave rise to a sense of exposure when participating in social situations and in society. The findings of Study I explicitly highlight individuals' or even their families' experiences of feeling embarrassment as an important aspect of participation. The findings indicate the need for learning strategies for dealing with feelings of exposure in public among people with PD, as well as strategies for adapting to the unpredictability of the illness. Earlier, Stack and Roberts (Stack and Roberts,

2013) highlighted that recurrent fallers felt embarrassed when falling outside their home and not following certain social rules also evoked embarrassment (Nijhof, 1995). Several attempts to grasp perceived participation among people with disability have found that planning and negotiating participation is common (Benharoch and Wiseman, 2004, Borell, Asaba et al., 2006, Lund, Nordlund et al., 2007, Hakansson, Lissner et al., 2009, Fristedt, Björklund et al., 2011, Pettersson, Lofqvist et al., 2012). Bontje et. al. found, for example, that balancing struggles with desired results in daily activities was done by mitigating, planning, avoiding or changing activities (Bontje, Asaba et al., 2015). Interventions intended to facilitate participation need to address the individual's preferences and prerequisites. Structuring and planning everyday life may not facilitate participation for everyone with PD or disability, but may serve as a facilitating means for some. The findings of Study IV add to that knowledge by highlighting that maintaining participation is experienced on a continuum. In order to address and enable participation among people with disabilities, we need to look at their overall life situation and take into account that fragile groups are very dependent on facilitators and sensitive to barriers in their surroundings.

An interesting finding in Study II was that none of the environmental factors were significantly associated with frequency of and satisfaction with participation in the respective final regression models. This was especially interesting since housing adaptation applicants have difficulties stemming from physical environmental problems within the home. Study II utilized housing standards and measures to rate environmental barriers, which in the light of the findings do not seem to be of relevance for housing adaptations. Instead, it appears that other aspects that take the relationship between activity and environment – that is, usability in the home – into consideration have more impact on participation. More specifically, all three aspects of usability considered in Study II were associated with satisfaction with participation, both in the home and outside it. This was to be expected, since usability targets the interaction between performing an activity and environmental factors, and the satisfaction of this interaction. The relationship between satisfaction with usability and satisfaction with participation may emerge due to the similarity of the questions. Still, satisfaction with usability was explicit towards the physical context of the home when performing activities while satisfaction with participation is explicit towards the frequency of participation. Taken together, aspects of usability deserve more attention in interventions intended to facilitate participation inside as well as outside the home.

## Relationships of participation, activity and health

The association found in Study II between frequency of and satisfaction with participation outside the home and ADL dependence is interesting. The qualitative findings of Study IV further supported the results, as increased independence in daily activities seemed to enhance participation outside the home over time. It is known from previous research that an indoor housing adaptation can also enhance the amount of activities performed outdoors (Petersson, Lilja et al., 2008, Yang and Sanford, 2012). From an occupational therapy perspective (Edward and Christiansen, 2005, Mallinson and Hammel, 2010, Townsend and Polatajko, 2013) associations between ADL dependence and participation in general can be anticipated since activity and participation are by definition linked to each other. However, no associations were found between participation in the home and ADL dependence in Studies II-III, although dependence is assessed in activities both in and outside the home. This may be the result of individual adaptation processes aimed at managing daily activities in the home among the participants, while participation outside the home may be more dependent on support from others. It is already known that a housing adaptation grant application is often preceded by a negotiation process (Ekstam, Fänge et al., Submitted) along with individual strategies for being active and independent despite environmental barriers in the home (Haak, Fänge et al., 2007, Pettersson, Lofqvist et al., 2012). Most importantly, the results support the assertion that activity factors play an important role in frequency of and satisfaction with participation.

In Study II, self-rated health was positively associated with participation frequency outside the home with others. In Study III, those with highest self-rated health were also those who most frequently participated, with the greatest amount of satisfaction outside the home with others. Previous research has indicated that social factors reduce the risk of developing disabilities (Avlund, Lund et al., 2004) and that participation in community activities may even delay ADL dependence (Rubio, Lazaro et al., 2009). High levels of functioning are also positively related to self-rated health (Arnadottir, Gunnarsdottir et al., 2011). Thus, the findings of both studies are in line with previous research demonstrating that participation outside the home is associated with better self-rated health and more perceived participation in general, among adults of all ages (Seeman, 2000, Cherry, Walker et al., 2013).

However, changes in participation frequency and satisfaction in Study IV, after a housing adaptation, were not positive overall. Becoming or remaining dissatisfied with participation inside and outside the home was in general reflected in lower self-rated health. Other studies have revealed that struggling with desired results in daily activities affects meaningful relationships outside the home among younger

adults (Gibson, Secker et al., 2012), elderly persons (Bontje, Asaba et al., 2015) and very old people (Sixsmith, Sixsmith et al., 2014). Interestingly, one of the participants in Study IV stood out as he was more satisfied with his participation outside the home with others a year after the HA, while at the same time rating his health much lower than before. This is intriguing, since social participation often has been positively related to health (Blazer, 2008, Ichida, Hirai et al., 2013). While Study IV stresses the role of the home environment in developing personal strategies for participation both inside and outside the home despite disability, recognizing each person's right to a life with the meaning and dignity that exist in the dynamic relationship of personal, physical and sociocultural dimensions of daily activities outside the home is also important. However, people's participation in activities they find meaningful within the home is indeed much less explored than community or social participation (Chang, Coster et al., 2013, Szanton, Roberts et al., 2016). Facilitators and barriers in the home need further attention (Nilsson, Iwarsson et al., 2015) to promote participation and health for people with disability.

## Different prerequisites for participation between groups

Although the findings emphasized that planning and structuring activities is important for participation, disparate views were expressed depending on severity of illness and disability. Those with mild PD emphasized the necessity of having a personal agenda or schedule in order to get things done, whereas those with moderate and severe PD expressed that planning itself was time-consuming and energy-intensive. The latter may potentially reflect cognitive impairments which are common among people with PD but no such information about the participants was available for Study I. In Study II, more cognitive impairment was associated with less frequent participation outside the home with others, and Study III also revealed low reports of participation frequency outside the home with others among frail older with moderate cognitive impairments while all members of the group stated they participated frequently in the home. People with cognitive impairments may appear more independent in their homes where everything is familiar, since cognitive impairment had no relation to participation in the home. Most likely, however, is that outdoor activities are more cognitively demanding (Brorsson, Öhman et al., 2011) and there is also a greater need for interaction with others in general outside the home that cannot be overcome by an accompanying person. Taken together, cognitive impairments appear to influence participation outside the home. Previous studies have indicated that cognitive impairments imply low social participation (Wilkie, Peat et al., 2007, Sorensen, Waldorff et al.,

2008). However, the possibilities of participation in the home among those with cognitive impairment need further attention.

Given the age distribution among the housing adaptation applicants, it would seem obvious that the youngest participants, “adults at risk of disability”, landed in a group of their own. Still, in spite of their independence in ADL and low level of functional limitations, they were very concerned about falling. In comparison, the “young old with disabilities”, who also had great concerns about falling, were more dependent with more functional limitations and mild cognitive impairments. Concerns about falling are therefore a very relevant issue for housing adaptation, as fear of falling has been associated with pervasive activity limitations and restrictions to participation (Dias, Freire et al., 2011, Sekaran, Choi et al., 2013, Jung, Shin et al., 2015). It was also expected that “Well-functioning older adults” would be gathered into one group – a group of housing adaptation applicants who, despite their need to have environmental barriers removed, seems to be quite independent and well-functioning. Given the well-known positive relationship between housing and functioning ability in the aging population (Wahl, Fänge et al., 2009), the effectiveness of housing adaptations in preventing further functional decline might even be stronger in this group of clients.

A broad difference was found among our participants as regards the three participation aspects investigated. Low reports of participation both in and outside the home, as well as low self-rated health among “Young old with disabilities” and “Adults at risk of disability” indicated the need for investigating restrictions to participation beyond environmental barriers in and around the home, which is especially interesting since older applicants seemed less affected in their participation. Still, their concerns about falling– well known among community-dwelling older adults (Chase, Mann et al., 2012, Hughes, Kneebone et al., 2015) but less explored among young adults (Sekaran, Choi et al., 2013) – may have restricted their activities and participation. The substantial difference in ADL dependence, functional limitations and concerns about falling between the younger groups supports that it is possibly the combination of dependence and concerns about falling that restrict participation. In this context, it seems that more activity-specific characteristics should be taken into consideration when assessing and evaluation housing adaptations so that they may fully serve the purpose of facilitating independent living, as well as enhancing participation. The results of Study III add valuable knowledge about heterogeneity among housing adaptation applicants in terms of activity, physical and cognitive functioning, as well as the usability of the environment. It was the first attempt to explore heterogeneity among housing adaptation applicants, and the clusters identified in this study can be useful in future research. Other studies confirm the variability we found in the health and functional profiles of older community living adults (Parker and

Thorslund, 2007, Jacobs, Maaravi et al., 2012, Santoni, Angleman et al., 2015, Turcotte, Lariviere et al., 2015).

Study III also demonstrated more specifically differences in self-rated health, highlighting the need for targeted interventions to address the needs of these specific groups. While the results should be considered preliminary, the challenges faced by those providing interventions for participation are nevertheless complex. Moreover, the financial burden posed by the increasing need for care of the aging populations will continue to contribute significantly to dramatic increases in health care. Systematic, evidence-based assessment of the needs among applicants and how these change over time is a prerequisite for effective follow-ups.

Taken together, Studies II-IV highlight the need to consider personal, environmental and activity-specific characteristics in housing adaptation interventions into consideration in order to fulfil the goal of independent living at home, as well as the WHO goal for enhanced participation and health for people with disabilities. More specifically, the findings have important implications for client-centred home interventions that focus on the client's own self-rated health and function. Acknowledging the complexity of needs among people with disabilities living in communities is a prerequisite for more effective case-management approaches, with systematic follow-up of occupational therapy interventions. Enabling change for individuals and groups also lies on a continuum of activity performance and participation; that is, enabling change at the group level can affect participation of the individual and vice versa (Townsend and Polatajko, 2013).

# Enabling participation

The findings in this thesis imply several potential means to facilitate participation by taking the dynamics of the person–environment–occupation approach into account in community interventions of enablement. These findings are of importance to the development of such interventions, that support people with disability in maintaining their participation in everyday life, for example the need for including strategies for dealing with experiences of feeling exposed in public due disability in interventions aimed at facilitating participation in public

The thesis stresses the need to adopt a comprehensive view for maintaining or facilitate participation among community living people with disability. In housing adaptation cases, for example, there is a need to direct more attention to participation both in and outside the home. Of specific interest are aspects integrating activity and the environment, such as usability. Environmental interventions in the home need to consider activity-specific aspects so that they

may fully serve their purpose to facilitate independent living, as well as enhancing participation.

Positive health outcomes from occupation-focused health promoting and illness-preventing interventions have yielded promising results for old independent people (Behm, Ivanoff et al., 2013, Behm, Ziden et al., 2013) (Zingmark, Fisher et al., 2014) (Szanton, Wolff et al., 2015) and that low-cost modifications at home can reduce injuries from falls in the general population (Keall, Pierse et al., 2015). Over more than two decades, occupational therapy theory has progressed from focusing on performance to emphasizing the person's subjective experience of participation (Hemmingsson and Jonsson, 2005). Complex dynamics between the individual and the contextual factors have by now been well established as barriers to participation (Hammel, Magasi et al., 2015). However, the subjective experience of participation restrictions, both inside and outside the home, for those striving for independent living in their own home need further attention. Usability of housing, for example, requires regular and recurrent evaluations with both subjective and objective measurements (Fänge and Iwarsson, 2005) as independence, participation, and usability of the home are affected at different stages during the process of housing adaptations (Fänge and Iwarsson, 2005).

Of special interest is also the engagement of community living people with disability in their home. Their participation in domestic roles; relations to – for example – functional limitations, cognitive impairments, self-rated health, and use of mobility devices; and other environmental factors such as living arrangement and support need further exploration. Participation in the home is by definition different from community participation, and should therefore be addressed differently (Chang, Coster et al., 2013). Moreover, exploration of the path/link of activity limitations and participation restrictions inside the home towards participation outside the home is lacking in research; that is, how engaging in activities in the home is related to engagement in activities outside the home.

Central aspects of occupational therapy practice are enabling engagement in occupations by increasing accessibility, usability, safety and security of the home environment, facilitating participation inside and outside the home (Fänge, Lindberg et al., 2013), and emphasizing that the perceived situation determines a person's activities. Health policy and strategies to improve participation among people with disabilities should take perceived health and perceived functioning into consideration (Perenboom, Wijlhuizen et al., 2012). Moreover, involving patients in research that aim to influence clinical practice and policy-making has been advocated (Ross, Donovan et al., 2005, Gibson, Britten et al., 2012, Staniszewska and Denegri, 2013). Health policy and strategies to improve participation among people with disabilities should therefore take perceived health

and perceived functioning into consideration (Perenboom, Wijlhuizen et al., 2012) in order to develop relevant interventions that promote participation.

Investigating individual experiences of participation over time can provide knowledge for facilitating client-centered interventions, tailored according to the client's needs and preferences. Initiatives towards more client-centered interventions for housing adaptation applicants have already been proposed (Pettersson, Lofqvist et al., 2012) but knowledge of how interventions in the home may enhance participation for the individual is needed. Collecting more than one type of data can thus provide a more complete understanding of the housing adaptation as experienced by the clients, both before and after the adaptation.

An overall strategy that monitors the needs and characteristics of the clients over time is thus recommended, since clients' needs change and they can move from a cluster to another over time. Based on the findings, heterogeneity among people with disability is extensive, highlighting the need for interventions and strategies to be targeted to the individual level and indicating that health professionals should be attentive to individual needs for performing activities changing over time.

# Methodological considerations

This thesis applies different research approaches to capture perceptions and experiences of participation among people with disabilities. Qualitative and quantitative methods were used, both separately (I-III) and combined (IV).

The trustworthiness of the qualitative findings is discussed in terms of their credibility, dependability and confirmability (Lincoln and Guba, 1985). Validity and reliability of the quantitative data is then discussed for Studies II and III, followed by the methodological issues of Study IV.

## Sampling, procedure and analysis of qualitative data

Credibility was established through carefully selecting participants for Studies I and IV with differing levels of severity of disability and diversity in age, gender and living arrangements. The participants in Study I were recruited with a specific focus on their experiences of participation. It can thus be assumed that those attending were almost exclusively those who felt they had something to contribute, namely regarding their participation. In this respect, the participants were probably rich in information and thus provided both broad and in-depth perspectives on participation, home and health. However, since the focus group sessions were held

at the hospital, those confined at home due to illness or lack of transportation probably declined participation in the study altogether, resulting in a lack of their perspective. Credibility also lies in how well categories and themes cover data, which was achieved through debriefing with the intent of verifying the participants' statements.

Dependability is related to stability in questioning and the importance of addressing the same areas for all participants (Graneheim and Lundman, 2004). New insights acquired during the research process may have affected the dependability. Reflexivity is another important attribute in research since the researcher and the object under study continually affect each other and the researchers preunderstanding affects the analysis(Alvesson and Skjöldberg, 2009). The researchers' objectivity as well as reflexivity was addressed by including at least three researchers with different research and practice experiences in each analysis to ensure the confirmability of the data.

## Sampling, procedure and analysis of quantitative data

Since the aim was to study relations of frequency of and satisfaction with participation to personal, environmental, and activity-related factors and to the heterogeneity of the group in Studies II-III, large samples were needed to detect differences for the outcomes considered and to ensure the generalizability of the study results. The size of the two samples of the studies was considered adequate, considering the study hypothesis for each study.

However, some limitations should be kept in mind when interpreting the validity and reliability of the results. Individuals that were unable to communicate or follow instructions in Swedish – for example, unable to fill out the forms – were excluded. Accordingly, people with severe cognitive impairment were not included among the participants in the studies and the results should be interpreted with this in mind. The prevalence of cognitive impairments is probably higher among Swedish housing adaptation clients. As a consequence of this limitation, it is likely that the relative size of the "frail older people with moderate cognitive impairment" group identified in Study III may be higher in the real life population than is indicated in the results. Moreover, since people unable to communicate or follow instructions in Swedish were not included among the participants, this may have excluded some applicants of foreign background. Investigating cultural differences beyond language barriers might have contributed to the findings, although a more direct gathering of data in respect of cultural aspects would have been necessary.

Additionally, women were in the majority (70%) in both samples, which is representative for housing adaptation applicants in Sweden. However, this affected

– for example – the confidence interval for frequency of participation in the home in Study II, which might limit the generalizability of the conclusions about gender differences in participation frequency in the home.

Another limitation concerns the assessment of the primary outcomes under study. Participation was investigated using questions specially designed for this project, and thus their psychometric properties are unknown. Several instruments that aim to measure participation were considered for this study, but were rejected due to their lack of focus on the situation of the group under study and for being too comprehensive (Madden, Fortune et al., 2013). Considering the design of the larger trial (Ekstam, Carlsson et al., 2014), measuring outcomes of significance for the study group, as well as limiting the number of questions the participants were asked, were important.

Internal validity refers to the extent to which the independent variable can account for the results. In Studies II-III, internal validity is threatened by the fragility of the participant and the probability of other alternative factors than those being investigated. As the findings show, housing adaptation applicants are a vulnerable group; deterioration in health, falls, and the use of mobility devices constantly affect their total life situation. Considerable efforts were put into training data collectors and into providing continued methodological support; in order to increase the validity and reliability of the data the rigor of the data collection procedure must be considered a methodological strength of Studies II-III.

As regards the data collected, some data treatment issues deserve attention. We decided to aim for more specific answers to the response alternative 'independent' in ADL Staircase, namely independent "with difficulty" and "without difficulty" respectively. This decision was based on previous research indicating that such information would be important in clinical practice research (Iwarsson, Horstmann et al., 2009) That is, in Studies II and III, ADL dependence was measured by means of four response alternatives instead of three. For both ADL and usability, sum totals were calculated for the responses on all ADL items and for each usability aspect respectively. Usability has strong implications for activity (Fänge and Iwarsson, 2007, Nygren, Oswald et al., 2007) while the empirical studies of the relation between disability and usability as measured by the UIMH are few (Fänge and Iwarsson, 2005, Fänge and Iwarsson, 2005, Fänge and Iwarsson, 2007). Hence, both measures are under evaluation which needs to be considered for further use, preferably with longitudinal data.

Non-respondent analysis showed that those not participating in the study tend to be slightly older and more dependent on others in ADL ($p<0.001$) than the respondents, thus reflecting the difficulties of involving very frail older people in research activities.

Self-rated health is dependent on how and to what extent the individual has adapted to the disability. For example, older people often redefine their health and participation restrictions over time. The individual's self-evaluation of quality of life is a result of internal standards and values, as well as how the individual conceptualizes their quality of life. Changes to individuals' health may bring on behavioral, cognitive and affective processes to accommodate health deterioration. As a result, the findings should be interpreted with this in mind due to the use of self-ratings of PD severity and self-rated health on the EQ-VAS. However, since the focus of Studies I and IV was on how participants perceive their life situation and self-ratings of health this approach may thus be deemed as appropriate.

Other limitations of the data relate to concerns about falling as measured using the FES-I short version instrument (Kempen, Yardley et al., 2008). Participants using wheelchairs most often were unable to respond to the question "Are you afraid of falling when using the stairs?", since they never used them. According to the manual the questions should be responded to hypothetically, but this seemed difficult to some participants.

A mixed-method approach was chosen for Study IV. The quantitative strand was added to enhance the overall design of the thesis, and to enhance our understanding of the changes in activities of daily living that are the goal of HA as well as clients' perceptions of their participation and health before and after an HA. The quantitative strand was analysed in parallel with the qualitative findings. The relationship between the variables was not explored; rather, qualitative and quantitative data were compared in order to reach a better understanding of changes in participation and health after a housing adaptation. The findings proved divergent in that changes to participation and health in numbers were not always congruent with the participants' experiences, i.e. more frequent participation outside the home was not always reflected in higher self-rated health. Thus, although the mixed-method approach adds to empirical knowledge, it does not facilitate the understanding of changes in participation and self-rated health after a housing adaptation. Most likely, the internal validity of the findings is limited since the participants' life situations were somewhat complex. Aspects such as use of mobility devices, formal or informal support, accidents (falls), deteriorations in health, changes in work and living situations, opportunities for leisure, and opportunities for transport all emerged as important barriers to or facilitators of participation. For future investigations it would be optimal to use the study-specific participation questions in exploratory sequential mixed method design. This can facilitate the development of better measurements, for example through cognitive interviewing (Drennan, 2003) and then testing the measurements in a larger sample.

# Ethical reflections

The ethical principal of non-maleficence refers to the risk of harming the participants (Beauchamp and Childress, 2013). Although none of the studies attempted to have any impact on the participants' lives, the risk of doing harm must be considered. As mentioned above, the focus groups were held at the hospital, demanding time and effort to travel to the interviews. The participants in studies II-IV were interviewed in their homes. The interviews could take time, but the participant was reminded that at any point, he or she could terminate the data collection or take a break. Furthermore, the data collection instruments address several aspects of daily life and health, which may be perceived negatively, for example a low score on the EQ-VAS. This can stir emotions which during an interview may be dealt with professionally, while self-ratings of the participant may have gained less attention in that regard. However, the contact with a professional during data gathering may in some occasions have had a therapeutic effect, allowing the participant to reflect over their concerns and receive support. There is also a risk that data from qualitative studies, i.e. citations (Study I) or information on age, gender and living arrangement, together with interview data may reveal excess information. With the aim of ensuring participant confidentiality, the presentation of data in the qualitative studies (I and IV) was carefully considered.

# Conclusion

Participation in life situations is affected by disability. The participants' experiences extended across the domains of the home and community. More specifically, participation in self-care, household and leisure both inside and outside the home was affected by the severity of the illness. The qualitative findings in Studies I and IV confirmed a complexity of contextual factors related to participation, both personal and environmental. The quantitative findings in Studies II and III reveal new knowledge of activity factors, such as usability aspects, related to frequency of and satisfaction with participation among housing adaptation applicants. They provided insights into how participation inside and outside the home, with others or alone, is related to cognitive impairments, self-rated health, aspects of usability and dependence in ADL – that is, factors related to the person, the environment, and the performance of activities. This speaks to the importance of being observant of the different aspects of restrictions to participation for each individual, especially as disability often progresses over time.

## Implications for practice

The findings imply that interventions intended to support people in maintaining their participation in everyday life should focus on the individual in their context and take into account the specific personal activity factors of each individual. Another implication is the link between engagement in activities at home and participation outside the home. This link is present in current knowledge but needs to be explored further in order to enhance the process of further implementing the importance of participation in interventions intended to support independent living.

The findings of this thesis highlight the importance of participation as an indispensable aspect of health. With the aim of enhancing participation, a client-centered approach is important in health interventions, highlighting the subjective experience of participation and taking advantage of the clients' experiences and perspectives.

The findings in this thesis may also be considered an incentive towards optimising the practice of housing adaptations interventions towards a personal, environmental, and activity-specific perspective that may increase the usability of the home as well as increasing activity and participation.

## Implications for future research

Target individuals' functional limitations, cognitive impairments, use of mobility devices, usability and concerns about falling in relation to participation.

Explore new strategies in relation to experiences and expectations towards housing adaptations among clients, cohabitants and occupational therapists in ordinary practice.

Determine the societal effects of housing adaptions in terms of costs and health-related quality of life.

# Svensk sammanfattning

Allt fler människor med funktionshinder bor och åldras i sitt eget hem. Avhandlingen fokuserar på deras möjlighet till delaktighet i vardagliga aktiviteter. Både inne i och utanför hemmet. Delaktighet brukar lyftas fram som en viktig faktor för människors hälsa och välbefinnande. Därmed utgör det en viktig aspekt att beakta vid insatser inom hälsa, vård och samhälle.

Att kunna vara delaktig är en rättighet för alla människor. Därför behövs det interventioner inom hälsa, vård och samhälle som syftar till att personer med funktionshinder i ökad utsträckning kan bli fullt delaktiga i alla vardagliga aktiviteter. Exempelvis inom egenvård, arbetsliv och fritid.

Många faktorer påverkar dock möjligheterna till aktivitet och delaktighet. Det kan handla om både fysiska och sociala faktorer i omgivningen. Men även personliga faktorer – exempelvis kön, ålder, livsstil eller personens upplevelse av sin hälsa - spelar in.

Effekter av insatser mot ökad delaktighet mäts bäst genom hur personen själv upplever sin vardag. Avhandlingen undersökte två grupper utsatta för inskränkningar i delaktigheten. Människor med Parkinsons sjukdom och personer som sökt bidrag för bostadsanpassning.

I den första delstudien deltog personer med Parkinsons sjukdom (PS). PS utgör en av de vanligaste neurodegenerativa sjukdomarna i dag. Den är kronisk och saknar bot. Svårigheter med att utföra vardagliga aktiviteter framträder tidigt i sjukdomsförloppet. Särskilt bland de individer som får gång- och balansproblem. Jämfört med friska jämnåriga har personer med PS framförallt svårigheter med mer komplexa aktiviteter. De rapporterar delaktighetsbegränsningar inom flera av vardagslivets olika områden. Till exempel när gäller mobiliteten, det vill säga deras förmåga att förflytta sig både inomhus och utomhus. Det finns i nuläget få studier som beskriver hur människor med PS upplever och beskriver sin delaktighet. Eller vilka faktorer som underlättar respektive försvårar delaktigheten i vardagen. En sådan kunskap är därför viktig för planeringen av både vård och rehabilitering. Syftet med studien var därför att beskriva och identifiera aspekter av begreppet delaktighet med betydelse för personer med PS i deras vardag. Deltagarna fördelades mellan nio fokusgrupper om vardera två till fem personer. En homogen sammansättning eftersträvades - utifrån personernas egna

uppfattningar av sjukdomens svårighetsgrad: mild, måttlig eller svår. Anledningen var att främja känsla av samhörighet, undvika missuppfattningar och minska den tid som annars skulle behövas till att förklara och förtydliga. Däremot eftersträvades skilda bakgrunder och erfarenheter i fokusgrupperna. Till exempel gällande familje- och arbetssituation, boendeform och kön. Syftet var att främja gruppdynamiken. Varje fokusgrupp intervjuades vid ett tillfälle.

Av diskussionerna i fokusgrupperna framkom att delaktighet överlag innebar att kunna vara med som före insjuknandet, att kunna vara till nytta och göra sin röst hörd. Samtidigt beskrevs delaktighet som ett komplext samspel mellan den fysiska och sociala miljön. Två kategorier av upplevelser som påverkar delaktigheten negativt framträdde. Omgivningen lägger märke till PS-specifika symptom och symptomen är oförutsägbara vilket skapa osäkerhet. Planering identifierades som en viktig strategi för att upprätthålla delaktigheten.

Den andra studien ägnar sig åt personer som söker bostadsanpassningsbidrag. Bostadsanpassningar förväntas leda till att individen kan leva ett självständigt liv i det egna boendet. Syftet med den andra studien var att undersöka sambandet mellan upplevelsen av delaktighet och personliga, omgivningsmässiga och aktivitetsrelaterade faktorer. Data gällande 128 personer, som hade sökt bostadsanpassningsbidrag, hämtades från ett pågående forskningsprojekt. Medelåldern låg på 75 år och knappt 70 procent av deltagarna var kvinnor. Drygt hälften bodde ensamma. Närmare 90 procent fick formell eller informell hjälp med sina vardagliga aktiviteter. Dessutom var nästan 80 procent rädda för att falla. Dessa data kompletterade med enkätfrågor som berörde delaktighet i och utanför hemmet, med och utan andra. Deltagarna skattade sina kognitiva besvär, sin upplevda hälsa, fallrädsla, användbarheten i bostaden och beroendet av andra för att utföra vardagliga aktiviteter. Resultaten visade att delaktighet hade ett positivt samband med mindre beroende i dagliga aktiviteter och en högre självskattad hälsa. Även kön spelade in. En större andel av kvinnorna (47 procent jämfört med 23 procent av männen) ansåg att de ofta utförde aktiviteter tillsammans med andra utanför hemmet. Användbarhet i hemmet bidrog också till ökad delaktighet utomhus. Färre kognitiva besvär och en högre självskattad hälsa bidrog till ökad delaktighet utomhus tillsammans med andra. När det gällde att på egen hand utföra aktiviteter utomhus utgjorde den avgörande faktorn hur beroende man var av andras hjälp. När det gällde deltagarnas nöjdhet med den egna delaktigheten ledde högre ålder och en högre självskattad hälsa till att man var nöjdare. Bostadens användbarhet påverkade också nöjdheten. Ju mer beroende deltagarna var av andra för att utföra aktiviteter desto mindre nöjda var de med delaktigheten utomhus.

Syftet med den tredje studien var att undersöka variationen bland dem som söker bostadsanpassningsbidrag och titta på skillnader mellan grupperna i förhållande till upplevelsen av delaktighet och hälsa. Urvalet bestod av samma population som i

den andra studien men då det var en konsekutiv studie så bestod den studerade gruppen här av fler personer. Medelålder låg på 75 år och över 70 procent var kvinnor. Baserat på likheter i beroende av andra för att utföra dagliga aktiviteter, antalet funktionsbegränsningar, kognitiva besvär, fallrädsla, användbarheten i bostaden samt upplevd hälsa fördelades 124 individer i 6 grupper. Grupperna skilde sig signifikant åt. Främst när det gällde delaktigheten i hemmet och utanför hemmet tillsammans med andra samt upplevd hälsa.

Syftet med den fjärde studien var att undersöka och beskriva hur klienter som söker bostadsanpassningar upplever delaktighet i vardagen före och efter bostadsanpassning. Studien var longitudinell med både kvalitativa och kvantitativa metoder. Fem personer intervjuades i sina hem, före och tre och tolv månader efter bostadsanpassningen. Intervjuerna fokuserade på deltagarnas upplevelser av delaktighet. Enkätfrågor ställdes kring hur ofta man deltog i aktiviteter samt hur nöjd man var med det nuvarande deltagandet. Så väl hemma som utanför hemmet med andra och på egen hand. Frågor ställdes även om självskattad hälsa. Fokus för analysen var förändringar i delaktighet i vardagen över tid. Resultaten visade på ett kontinuum kring delaktighet som löpte från en kamp för att kunna vara delaktig till att vara nöjd med sin delaktighet i vardagen.

Sammanfattningsvis visar avhandlingens resultat att faktorn självständighet är av stor betydelse för delaktigheten. Även parametrar som användbarheten av bostaden och självskattat hälsa spelar in. Dessutom påverkas delaktigheten av individuella förutsättningar, den aktuella miljön och aktiviteternas utförande. Därför bör man vara uppmärksam på ett spektra av aspekter som kan hämma delaktigheten utifrån varje individuell situation. I synnerhet som funktionsnedsättningar vanligtvis förändras med tiden och därmed även de individuella förutsättningar.

# Samantekt á íslensku

Þeim fer fjölgandi á heimsvísu, eldri borgurum og fólki með fötlun, sem kjósa að búa á eigin heimili sem lengst. Þátttaka þeirra (e. participation) í daglegri iðju er í brennidepli hjá Alþjóðaheilbrigðismálastofnuninni (WHO) sem mikilvægur þáttur í heilsu þeirra og velferð. Mikið hefur verið ritað og rætt um hvernig meta skuli eða mæla þátttöku en færri rannsóknir miða að því að reyna að skilja þarfir og reynslu þessa hóps með því að leita svara hjá einstaklingum sem tilheyra honum.

Fyrsti hluti þessa doktorsverkefnis var að stofna til umræðu í rýnihópum um þátttöku í daglegri iðju. Markhópurinn var fólk með Parkinson sjúkdóm sem beðið var um að meta færniskerðingu sína vegna sjúkdómsins sem milda, meðal eða mikla. Alls voru myndaðir níu rýnihópar með 29 einstaklingum; þrír hópar fyrir hverja færniskerðingu. Fram kom að sjúkdómurinn hafði mismikil áhrif á líf einstaklinganna, eftir því hvort þeir mátu færniskerðinguna sem milda, meðal eða mikla. Þrjú megin þemu voru notað til að lýsa frásögnum rýnihópanna: Sýnileiki sjúkdómsins, ófyrirsjáanleg einkenni og skipulagning daglegrar iðju.

Seinni hluti verkefnisins snerist um einstaklinga sem sækja um breytingar á húsnæði sökum fötlunar. Í takti við yfirlýsta stefnu sænskra stjórnvalda eru veittir styrkir til endurbóta og aðlögunar á heimili einstaklinga í samræmi við þarfir þeirra. Markmiðið er að efla einstaklinga til sjálfshjálpar og gera þeim kleift að búa sem lengst í heimahúsi við sem eðlilegastar aðstæður. Fyrsta rannsóknin í seinni hluta studdist við gögn sem safnað var fyrir breytingar á húsnæði. Þar voru skoðuð tengsl persónulegra, umhverfislegra þátta og athafna við hversu oft einstaklingurinn tók þátt í daglegri iðju og hversu ánægður hann var með þátttöku sína. Spurt var um þátttöku innan heimilis og utan, með öðrum eða án.

Í ljós kom að sjálfstæði í daglegum athöfnum hafði sterkustu tengslin við þátttöku utan heimilis á eigin vegum, bæði varðandi fjölda skipta og ánægju. Önnur rannsóknin í seinni hluta snerist um að skipta umsækjendum niður í minni hópa (e. clusters) eftir aldri, færniskerðingu, vitrænni skerðingu, hræðslu við að detta og notendavænleika heimilisins. Sex mismunandi hópar mynduðust og var þátttaka þeirra í daglegri iðju var skoðuð á sama hátt og í fyrri rannsókninni, þ.e. hversu oft hver hópur tók þátt og hversu ánægður hver hópur var með þátttöku sína í daglegri iðju. Einnig voru notuð gögn yfir eigið mat á heilsu samkvæmt EQ-5D-VAS (visual analogue scale) og meðaltal skoðað fyrir hvern hóp. Í ljós kom að mestur

munur á þátttöku og eigin mati á heilsu var á milli yngri fullorðinna með fötlun og eldri fullorðinna með góða færni. Yngri fullorðnir með fötlun tóku sjaldnast þátt í daglegri iðju innan og utan heimilis og mátu heilsu sína verst af öllum hópunum.

Lokarannsóknin studdist við viðtalsgögn. Tekin voru viðtöl við bæði menn og konur á aldrinum 50-90 ára með mismunandi fötlun/færniskerðingu. Fimm einstaklingar sem sóttu um aðlögun á heimili voru teknir tali fyrir breytingar og síðan þremur og tólf mánuðum eftir breytingar. Viðtölin leiddu í ljós áframhaldandi erfiðleika við athafnir eftir breytingar en einnig að sjálfstæði við athafnir heimafyrir eykur bæði möguleika á þátttöku utan heimilis og ánægju.

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