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# Participation and Independence in Old Age

Aspects of Home and Neighbourhood Environments

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and Gerontology



# PARTICIPATION AND INDEPENDENCE IN OLD AGE

*Aspects of Home and Neighbourhood Environments*

Maria Haak

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Abstract  <p>The current trend in Sweden is to support older people to remain living in their own homes as long as possible. Older people spend much of their daily life within the home and neighbourhood environment. It is well known that participation and independence is important in experiencing well-being in old age. Thus, from a health promotion perspective it is of interest to uncover aspects within the home and neighbourhood environment that might relate to participation and independence in old age, in particular in very old age. The overarching aim of this thesis was to explore old and very old people's participation and independence, focusing on aspects of home and neighbourhood environments. The public facility older people considered most important to visit was department stores, and the majority of environmental problems in the neighbourhood were perceived along walking routes. Home was experienced as the locus and origin for participation and a signification of independence. Two dimensions of participation - Performance-oriented participation and Togetherness-oriented participation - emerged and were statistically validated. Moreover, objective as well as perceived home and neighbourhood variables were related to the two dimensions of participation. The concept of independence was found to be a complex construct and there is a need of further explorations as regards the differentiation between independence and autonomy. The results of this thesis have developed the knowledge base on very old people's own experiences of participation and independence as well as their relationships to the home and neighbourhood environment. The results are useful for future research on interventions on individual and societal level, foremost in community-based occupational therapy.</p>		
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# Abbreviations and Definitions of Central Concepts

## *Accessibility*

Accessibility is the extent to which an exterior or interior environment constrains or facilitates use, in relation to individual physical and/or psychological abilities. Accessibility is a relative concept, implying that accessibility problems should be expressed as a person-environment relationship. In other words, accessibility is the relationship between functional capacity and environmental demands. In accessibility the environmental component refers to official norms and standards, and the personal component is defined based on professional assessment. Thus, accessibility is mainly objective in nature (Iwarsson & Ståhl, 2003).

## *Activity*

Activity is the execution of a task or action by an individual (WHO, 2001), and in this thesis the term is used interchangeably with occupation as used in occupational therapy (Clark, 2002). Occupation refers to groups of activities and tasks of everyday life, named, organised and given value and meaning by individuals and culture. Occupation is everything people do to occupy themselves, including looking after themselves, enjoying life and contributing to the social and economic fabric of their community (CAOT, 2002). The broader academic and professional world uses the word activity instead of occupation, i.e. activity is preferable to use when several disciplines are addressed (Clark, 2002).

## *ADL*

Activities of Daily Living (ADL) are activities that serve to maintain oneself and one's lifestyle. The activities are major components of routines in everyday life, and are generally

private and personal (Kielhofner, 1997). ADL is frequently divided into personal ADL (P-ADL) and instrumental ADL (I-ADL). P-ADL includes activities such as eating, dressing and bathing, activities considered central to the person's survival. I-ADL occurs in the home and in the neighbourhood environment and includes activities such as assessing one's community, shopping and cleaning (Sonn & Hulter-Åsberg, 1991).

<i>Autonomy</i>	Freedom to determine one's own actions or behaviour (Beauchamp & Childress, 2001).
<i>Environmental barriers</i>	Physical, social and attitudinal factors in the environment that have a negative influence on individuals' performance in society (WHO, 2001). In this thesis environmental barrier is delimited to physical factors.
<i>Healthy ageing</i>	Concerns definitions of healthy ageing, highlighting aspects of physical, social and emotional health (Vaillant, 2002), or maintenance of physical, mental and social well-being and function among older people, likely to be achieved when environmental conditions are adequate (HARN, <a href="http://depts.washington.edu/harn/">http:// depts.washington.edu/harn/</a> ).
<i>Home</i>	In this thesis home is defined as the residing physical unit, where human relationships with the environments as regards cognitive orientation, emotional affiliation, and explicit involvement takes place (Marcus, 1995; Rubinstein, 1989; Sixsmith, 1986). Home is also seen as a unit separating private from public places.
<i>Housing-related control beliefs</i>	Control beliefs reflect a driving force in explaining the course and outcome of ageing (Heckhausen & Schultz, 1995). Housing-related control beliefs explain events at home either as following one's own behaviour, or based upon luck, chance, fate, and powerful others (Oswald, Wahl, Martin, & Mollenkopf, 2003).
<i>Housing satisfaction</i>	Housing satisfaction reflects the perceived quality of the home and predominantly attitude (Aragonés, Francescano, & Gärling, 2002; Weideman & Anderson, 1985) rather than behavioural or affective aspects of perceived housing (Heywood, Oldman, & Means, 2002; Pinguart & Burmedi, 2004).
<i>ICF</i>	The International Classification of Functioning, Disability and Health (WHO, 2001).

<i>Independence</i>	To be physically self-sufficient in carrying out personal and social tasks, self-direction and day to day decision-making about when and how things will be done to one's body and environment (Zemke & Clark, 1996).
<i>Meaning of home</i>	In this thesis the meaning of home represents individual meanings related to one's own experiences and personality, covering environmental, behavioural, cognitive/emotional, and social aspects (Oswald, Mollenkopf, & Wahl, 1999). The need to cope with environmental changes in old age can be linked to specific patterns of meaning connected to home. Behavioural aspects of meaning are linked to activity and can reflect familiarity and routines developed over time. Cognitive, emotional, and social aspects of meaning are manifest by means of reflecting on the past, symbolically represented in certain places and cherished objects.
<i>Neighbourhood environment</i>	Refers to the physical context close to home in which people live their everyday life and have the potential to influence people's ability of activity performance outside home. The neighbourhood environment comprises both the natural and built environment (Kielhofner, 2002; Krause, 2003).
<i>Old and very old people</i>	In this thesis, the use of old and very old people is based upon Baltes & Smith (2001) definition of Third and Fourth age. The Third age represents rather good function, whereas the Fourth age represents high level of frailty. The difference between the Third and Fourth age is a highly person-based phenomenon due to functional decline thus not strictly connected to chronological age.
<i>Participation</i>	Participation is defined out of a political perspective describing disability rights (Gustavsson, 2004) as well as out of an individual perspective defined by WHO (2001), as involvement in a life situation. On an individual level the engagement of a person's body, mind and soul (Miller Polgar & Landry, 2004) is included.
<i>Performance</i>	What a person does in the current environment, that is involvement in all life situations including the lived experience of the actual context (WHO, 2001). <i>Occupational performance</i> refers to the dynamic result of the transactions between the person, environment, and activities during a lifespan; the ability to choose, organise, and satisfactorily perform meaningful activities. (CAOT, 2002; Law <i>et al.</i> , 1996).

*Public facilities*

In this thesis, facilities in the public environment such as public medical services, banks, shops, and cultural and leisure establishments.

*UN*

United Nations.

*Usability*

The concept of usability implies that a person should be able to use, i.e. to move around, be in and use the environment on equal terms with other citizens. Taking into account user evaluations and subjective expressions of the degree of usability, the concept is mainly subjective in nature. Usability is a measure of effectiveness, efficiency, and satisfaction (Iwarsson & Ståhl, 2003). The concept comprises an activity component distinguishing usability from accessibility, relating to the personal repertoire of activities defined for the actual situation. A personal component relating to functional capacity adaptive strategies etc., and an environmental component relating to e.g. barriers in the home and neighbourhood environment.

*WHO*

The World Health Organisation.

# List of Publications

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

## The Neighbourhood Project

I. Valdemarsson, M., Jernryd, E., & Iwarsson, S. Preferences and frequencies of visits to public facilities in old age – a pilot study in a Swedish town center. *Archives of Gerontology and Geriatrics* 40(1), 15-28, 2005.

## The ENABLE-AGE Project

II. Haak, M., Dahlin Ivanoff, S., Fänge, A., Sixsmith, J., & Iwarsson, S. (in press). Home as the locus and origin for participation. Experiences among very old Swedish people. *OTJR: Occupation, Participation and Health*.

III. Haak, M., Fänge, A., Iwarsson, S., & Dahlin Ivanoff, S. (in press). Home as a signification of independence and autonomy. Experiences among very old Swedish people. *Scandinavian Journal of Occupational Therapy*.

IV. Haak, M., Fänge, A., Horstmann, V., & Iwarsson, S. Two dimensions of participation in very old age and their relations to home and neighbourhood environments. Manuscript submitted for publication.

**Figure 1.** Projects and publications building up the thesis.  
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# Participation and Independence in Old Age

## *Aspects of Home and Neighbourhood Environments*

Maria Haak

### Introduction

It is well known that participation (Christiansen & Baum, 2005; Kielhofner, 2002; Law, 2002; Miller Polgar & Landry, 2004; Nelson, 1997; Rudman, Cook, & Polatajko, 1996; Wilcock, 1998) and independence (Spiriduso & Gilliam-MacRae, 1993; Wilcock, 1998) are important in experiencing well-being. Given the fact that most of the daily life of older people is spent in the home (Alan & Crow, 1989; Baltes, Maas, Wilms, Borchelt, & Little, 2001; Bhat & Misra, 1999; Heyl, Wahl, & Mollenkopf, 2005; Hillerås, Herlitz, & Winblad, 1999) and neighbourhood environment it is interesting from a health-promotion perspective to uncover aspects within the home and neighbourhood environment that might relate to participation and independence in old age, in particular in very old age. When it comes to recent research, such issues are rather unexplored.

In spite of the fact that occupational thera-

pists and other health care professionals work in the homes of older people and many interventions target situations in daily life, the current debate and recent research have mainly taken a care perspective. For example, researchers have investigated patients' perceptions of participation in their rehabilitation process, (e.g. Larsson Lund, Tamm, & Brännholm, 2001; Wressle, Olofsson, Marcusson, & Henriksson, 2002) while Sacco-Peterson and Borell (2004) investigated independence and participation in personal care activities among people living in nursing homes. Further, Ball and co-workers (2004) explored the meaning of independence for people living in nursing homes. In spite of the fact that international guidelines specify that it is a basic human right to have the opportunity to take part in society on equal terms, e.g. by living independently and participating in all aspects of society, regardless of functional condition (UN, 1993), research on how old and very old people experience participa-

tion and independence within the home and neighbourhood environment is scarce. The UN guidelines outline the support given to persons with disabilities in Sweden, irrespective of age. General national guidelines (Regeringens proposition, 1996/97:60) position priorities for health care and stipulate that quality-of-life related needs, such as participating in leisure and social relationships, are equally important as medical needs. The national action plan for disability policy from patient to citizen (Regeringens proposition, 1999/2000:79) and the action plan for policies on older people (Regeringens proposition, 1997/98:113) strives for full participation and equality in living conditions. There is an obvious need to make implementation of these guidelines in society possible, explicitly including old and very old people, while evidence-based strategies are lacking.

Despite considerable frailty and need of extensive care and social services, the current trend in Sweden is to support older people to remain living in their own homes as long as possible (SFS, 2001:453; SOU, 2003:91). Sweden has the greatest share of people above the age of 80 in the world (Socialstyrelsen, 2005), and currently about 9% of the population of 9 million in Sweden, is 75 years or older. A majority is women and just over half of the aged population is living alone. A great majority of those (about 95%) live in ordinary housing (SCB, 2006a). The use of home help services increases above the age of 80 (Socialstyrelsen, 2005) and among those 75 years and older, 59% receive some kind of home help services (SCB, 2006a). Further, an increased number of older people are expected to live longer (SCB, 2006b) and try to remain independent in their home (Dehlin, Hagberg, Rundgren, Samuelsson, & Sjöbeck, 2000; Marcellini, Mollenkopf, Spazzafumo, & Rouppila, 2000; Socialstyrelsen, 2005). It should be emphasised that, there is an increased risk of health decline in old age (Sörensen, Axelsen, & Avlund, 2002) and older

people display heterogeneous and complex health problems (Femia, Zarit, & Johansson, 2001), e.g. in terms of functional limitations (Carlsson, Iwarsson, & Ståhl, 2002). Despite such heterogeneity, older and very old people are active in their everyday lives and will increasingly demand to participate in society, posing a substantial challenge to community planning.

From a community planning perspective, many different challenges ought to be dealt with, including current building and planning traditions. Further, Swedish housing policy requires municipalities to provide supportive home environments on equal terms for all citizens (SFS, 2001:453). In accordance with Swedish housing regulations and policy (SFS, 1987:10; 1994:847; 2001:46) as well as national and international standards (Regeringens proposition, 1999/2000:79; UN, 1993), all buildings should be accessible and usable for everybody. In spite of this, old and very old people living at home are at risk of becoming excluded from being able to live an independent life and participate in society. Here, occupational therapy is essential in contributing to the development and fulfilment of participation since its interventions are geared to enabling people and groups to participate in everyday occupations that are meaningful to them, providing fulfilment, and engaging them in everyday life with others (Townsend & Landry, 2005). Furthermore, several studies show that activities outside home are important among older people (Agahi & Parker, 2005; Banister & Bowling, 2004; Legarth, Ryan, & Avlund, 2005; Silverstein & Parker, 2002). However, Hovbrandt, (2006) found that environmental barriers negatively influenced participation in activities in the neighbourhood environment. Another recent study emphasised the importance of accessible environments (Michael, Green, Stephanie, & Farquhar, 2006) when it comes to the possibility to live an independent life and participate in society. In order to plan for efficient actions



supporting participation and independence in old and very old age (WHO, 1991), we need to know how older people experience participation and independence. The present thesis emerged out of the need for occupational therapists to better understand how old and very old people themselves experience participation and independence in the home and whether and how aspects of home and neighbourhood environment relate to participation.

## Aspects of Ageing

### Old and Very Old People

Growing old can be viewed differently; from a chronological, biological, psychological and social perspective. Chronological age specifies the number of years from birth, but does not say anything about e.g. functional ability. Biological age represents cell changes affecting the functional capacity of the body organs. Psychologically, growing old means ongoing accumulation of experiences and impressions, and from the social perspective changes in roles and positions during the life span are emphasised (Dehlin *et al.*, 2000; Tornstam, 2001). There is no easy way to define old age; the most common approach is to use chronological age. The retirement age of 65 (in Sweden) is often adopted as an arbitrary point for defining people as older, although older people constitute a heterogeneous group with different capabilities. Several researchers (e.g. Baltes, 1997; Baltes & Mayer, 2001; Field, 2001) have emphasised the importance of separating the youngest old from the oldest-old. For example, Dehlin *et al.* (2000) and Field (2001) suggested that people aged 65–75 could be considered as younger old, people 75–85 as mid-old, while the old-old are 85 years and above, however this grouping of older people does not take e.g. social age, psychological age or biological age into account. Since there is no obvious grouping of old and

very old people, another approach has been suggested by Baltes and Smith (2001), differentiating the Third from the Fourth age. One of their suggestions is a chronological transition from the Third to Fourth age when 50% of the birth cohort is no longer alive, which in Western countries is roughly at the age of 80–85. Though, it should be noted that Baltes' differentiation emphasises a highly individualised process based on functional characteristics, thus not strictly connected to chronological age. That is, the Third age represents rather good physical and mental function, a high level of emotional and personal well-being and efficient strategies for gains and losses of late life, whereas the Fourth age represents considerable cognitive losses and a high level of frailty. A major part of this thesis targets very old people above the age of 80, referred to as the Fourth age, while people above the age of 75 in this thesis is called old people, thus referring to the Third age (Baltes & Smith, 2001).

Since long occupational therapists working with older people have been informed by several theories of ageing concerned with activity engagement in later life. Havighurst and Albrecht (1953) developed the activity theory arguing that older people are motivated to maintain the activity levels of mid-life and replace lost relationships, roles, and activities with new endeavours, of course of interest for occupational therapists. The disengagement theory (Cumming & Henry, 1961) proposed that social, psychological, and activity disengagement in later life leads to greater introspection, withdrawal, and limited replacement of lost activities. The continuity theory of ageing (Atchley, 1999) attempts to explain why continuity of ideas and lifestyles is central to the ageing process and presumes that most people learn continuously from their life experiences. The continuity theory deals with processes of adaptation that people experience and apply, as they grow older. According to this theory despite significant changes in

health, functioning and social circumstances, do many older people present considerable consistency over time in their patterns of thinking, activity, living arrangements and social relationships. The disengagement theory and the activity theories are each others opposites and none of them cover all aspects of ageing. For example, none of them has their starting point in the older persons own experience of growing old (Bengtsson, Burgess, Parott, & Mabry, 2002). Another theory gaining increasing attention during the last years is Tornstams (1994) theory of gerotranscendence, describing how the old person experience the ageing process. This theory suggests that the ageing process is characterised of changes in perceptions of self, relations to others time, space, life and death. Growing old encompasses a final stage towards wisdom, a shift emerge that is the transcendence from materialistic to cosmic beliefs with increased life satisfaction. Older people's abilities to achieve gerotranscendence might differ in relation to their own and environmental resources but can be improved by supportive interventions.

Another theory emphasising continuity and adaptation is the theory of selection, optimisation, and compensation (Baltes & Baltes, 1990), emphasising people's use of strategies to maintain continuity in activities and habits as they age. Selection means the choices and priorities people make when activities are limited due to e.g. functional limitations; optimisation refers to means to achieve desired outcomes; and compensation represents compensating strategies in order to maintain participation in chosen activities.

## **Theoretical Considerations**

Within environmental gerontology there has been a continuous strive towards better insights in to the role of the home and neighbourhood environment as people age (Wahl, 2001; Wahl & Iwarsson, in press). One of the

models which has had a great impact when it comes to person-environment (P-E) interactions historically, is Lawton's ecological model (Lawton & Nahemow, 1973) and the docility hypothesis (Lawton & Simon, 1968), (see also Scheidt & Norris-Baker, 2004). The ecological model (Lawton & Nahemow, 1973) derives from Lewin's definition of behaviour as a function of the person and the environment (Lewin, 1951). In the ecological model the person is defined in terms of a set of competencies and the environment is defined on the basis of its demands, labelled environmental press (Lawton & Nahemow, 1973). Turning to the docility hypothesis (Lawton & Simon, 1968) adaptation, i.e. the balance between the person's competence and environmental demands, is emphasised. That is, people with low competence are more vulnerable to environmental demands than those with high competence. Theories developed and used in environmental gerontology (Wahl, 2001) are closely related to theories and models in occupational therapy. The theories just presented are not sufficient for this thesis. Instead, considering them in relation to, or in combination with theories and models within occupational therapy (Wahl & Iwarsson, in press), focusing on the transaction between people, environments and activities (P-E-A) (Christiansen & Baum, 2005), could be a fruitful approach for research on older peoples everyday life in the home and neighbourhood environment. Thus the combination of theories from both environmental gerontology and occupational therapy works as the theoretical point of departure for this thesis.

One occupational therapy model explicitly targeting P-E-A transactions is the Canadian Model of Occupational Performance, CMOP (CAOT, 2002). CMOP takes the activity component in account and focuses on occupational performance, i.e. performance of activities of daily living. Within the model, activities are seen as basic human needs, which are significant for health and give a source of

meaning, choice and control, and in interaction with the environment the person's capacity develops throughout life. It is emphasised that the dynamic and transactional relationship makes it hard to separate the components from each other. The personal component (P) involves physical, cognitive, and affective aspects. The environmental component (E) refers to cultural, economic, institutional, physical and social aspects, while activities (A) are organised and given value and meaning by the people and the cultural context. Due to changes in environmental demands the person has to adjust the activities. Thus, activity has been added as an essential component when targeting the dynamic relationship between the three components. Consequently, everyday activity acts as connections between the person and the environment.

Turning to the International Classification of Functioning, Disability and Health, ICF (WHO, 2001), several of the concepts used in theories and models within environmental gerontology as well as within occupational therapy are reflected in this conceptual model. The ICF model is useful for understanding and describing health and health-related states across disciplines, thus also reflecting the core concepts of this thesis. Most importantly, in the ICF it is stated that knowledge and understandings about disruptions or imbalance in daily life is necessary to promote environments supporting participation. The ICF includes two parts, (1) Functioning and Disability and (2) Contextual factors, each containing two separate components; The umbrella term Functioning includes all body functions and structures as well as activities and participation, while Disability acts as an overall term for impairments, activity limitations or participation restrictions. Contextual factors include the environmental and personal components. Within ICF, activity and participation are treated as being virtually the same components. Activity is defined as a person's performance of a task or occu-

pation, and participation is involvement in a life situation. It is a challenge to distinguish activities from participation and to separate the individual perspective from the social perspective.

## Core Concepts

### Participation

Research studies over the last few decades have operationalised and defined participation in different ways, and the terminology used has not been consistent (Bath & Deeg, 2005). It is obvious that participation is a very broad concept, and just one of many concepts used to represent various types of social interaction (WHO, 2001), alongside e.g. "social engagement" (Mendes de Leon, Glass, & Berkman, 2003), "social networks" (Holtzman *et al.*, 2004) and "social contacts" (Drageset, 2004).

Historically, participation has been developed and utilised within the disability movement, and thus has become a political term to describe disability rights (Gustavsson, 2004). More recently, however, participation has been defined from an individual perspective. For example, in ICF (WHO, 2001), participation is defined as "the person's involvement in a life situation", with a list of nine domains of participation: e.g. communication, mobility, self-care, domestic life, interpersonal interactions and relationships, and social and civic life. Thus widening the definition, Miller Polgar and Landry (2004) claim that participation also includes the engagement of a person's body, mind, and soul. Furthermore, skills and competencies are acquired through participation, thus being necessary for our connection with others, and a way of finding purpose and meaning in life (Law, 2002). Moreover, Borell, Asaba, Rosenberg, Schult and Townsend (2006) advanced the understanding of participation and its relation to activity, finding that participation has to do

with agency, being active, and being social. Participation is thus closely related to activity, i.e. a person's performance of a task (WHO, 2001), while this relationship remains to be explored in more depth.

Given the lack of consensus as regards the definition, there is also a paucity of assessment instruments capturing participation. When it comes to different attempts to capture participation, one of the instruments available is the LIFE-H (Noreau *et al.*, 2004). This is a comprehensive instrument evaluating participation in significant social role domains, such as recreation and community life (Noreau *et al.*, 2004). Furthermore the Participation Survey/Mobility, PARTS/M (Gray, Hollingsworth, Stark, & Morgan, 2006) targets participation for people with mobility limitations. The instrument is composed of 20 major life activities categorised in six domains according to the ICF. Yet another instrument is the self-reported Impact on Participation and Autonomy (IPA) questionnaire (Cardol, de Hahn, van den Bos, & de Jong, 1999), reflecting different life situations such as autonomy outdoors, family roles, social relationships, and work and education. As illustrated above, there is a considerable inconsistency in vocabulary among the instruments.

## Independence

In the Western world the notion of independence is grounded in the ability to be physically self-sufficient in carrying out personal and social tasks. Self-direction and day-to-day decision making about when and how things will be done to one's body and environment are also included in the concept of independence (Rogers, 1982; Zemke & Clark, 1996). In the field of occupational therapy, independence has historically been identified as a central concept, defined as having adequate resources to perform everyday activities (Christiansen & Baum, 2005). A general trend in the literature is not solely to include

physical independence in the definition but moving towards broader definitions, including cognitive abilities and interdependence between ADL ability and environmental aspects (Gitlin, Corcoran, Winter, Boyce, & Hauck, 2001; Hoppes, Davies, & Thompson, 2003).

Within occupational therapy and rehabilitation, independence is often measured as independence in ADL and a wide variety of ADL-instruments is available (for a more comprehensive review, see Törnquist, 1995). One of the earlier instruments developed to measure independence was Katz's ADL Index (Katz, Ford, Moskowitz, Jackson, & Jaffe, 1963) measuring independence/dependence in personal activities of daily living (P-ADL). A development of Katz's ADL Index is the ADL Staircase (Hulter-Åsberg, 1990; Sonn & Hulter Åsberg, 1991) applying the same assessment principles. The ADL Staircase includes five P-ADL from Katz's ADL-Index and four instrumental activities of daily living (I-ADL) (cleaning, shopping, transportation, and cooking) often considered crucial for independent living in the home and neighbourhood environments (McColl, *et al.*, 1999).

## *Previous Research on Participation and Independence in the Home and Neighbourhood Environment*

In spite of the fact that our knowledge is limited on whether and how aspects of the home environment influence health among older people (Spillman, 2004) we know that the home (Tamm, 1999) and neighbourhood environment (Krause, 2003; Oswald, Hieber, Wahl, & Mollenkopf, 2005) are important places for health throughout life (SOU, 2003:91; WHO, 1991). Further, many people connect their home environment with memories and a sense of belonging (Sixsmith & Sixsmith, 1991), thus indicating the importance of emotional dimensions of the home.

Over the years, results of this kind have been supported by several researchers (Oswald & Wahl, 2005; Rowles, 2000; Rubinstein, 1989; Shenk, Kuwahara, & Zablotsky, 2004). Consequently, in order to develop optimal home and neighbourhood environments for older people, there is an obvious need to increase our understanding of participation and independence. Since participation in daily life is essential for leading a satisfactory and independent life at home in very old age (Avlund, Lund, Holstein, & Due, 2004) it is important to investigate how older people relate these concepts to their home and neighbourhood environments.

Since long, previous research in occupational therapy and environmental gerontology has pinpointed the need to focus participation and its relationship to the home among old people, however recent empirical research is scarce, especially when it comes to focus people aged 80 years and above. Available literature concerns older people from the age of 65 and activity in general, and most literature about older people and activities is based in nursing homes, day care centres and similar settings rather than the ordinary home and neighbourhood environment. For example, Andersson Svidén and Borell (1998) found in their study that participation in activity centres contributed to health and well-being. More recently Tse and Howie (2005) examined reasons for attending adult day groups and found that older people emphasised the importance of companionship and of being occupied in activities not manageable at home. It looks as if staff play an important role in providing residents with suitable activities, especially in nursing homes (Green & Acheson Cooper, 2000). Such motivation and encouragement to engage in activities is not often present in the home environment for older people living alone, but there is scarce knowledge about the consequences this has for older people's experience of participation and independence at home. Further, relation-

ships between social participation and disability (Mendes de Leon, Gold, Glass, Kaplan, & George, 2001), functional ability (Sörensen *et al.*, 2002) between participation and survival (Glass, de Leon, Marottoli, & Berkman, 1999), as well as between participation and mortality (Lennartsson & Silverstein, 2001) have been investigated. In addition, Mollenkopf *et al.* (1997) found that physical aspects of the neighbourhood affected out-of-home mobility and social relationships. Since there is a growing population of old and very old people living in their own homes, it is important to explore the relationships between participation and their home environment. From the literature it is obvious that there is a considerable lack of studies specifically highlighting participation in relation to the home from the perspective of very old people themselves.

Previous and current research on relationships between home and independence has indicated that with increasing age, the home environment becomes a critical determinant for independence (Iwarsson, 2005; Oswald, Wahl, *et al.*, in press; Wahl, 2001). Together with associations with the past, proximity to family, or long-established neighbours, familiarity, and a sense of being a part of neighbourhood life (Kellaher, 2001), the home environment supports the self as people age (Shenk *et al.*, 2004). However, even if there are studies indicating important links between independence and aspects of housing (Fänge & Iwarsson, 2005a, 2005b), little in-depth knowledge is available on how very old people themselves experience the relationships between home and independence in daily activities (Oswald & Wahl, 2004). Obviously, the home environment plays a particularly crucial role in very old age, the main argument being that in this period of the life span functional limitations and disability are major threats to independent living in ordinary housing (Iwarsson, Wahl, & Nygren, 2004). In order to develop more efficient client-

centred and goal-directed occupational therapy interventions enhancing independence and healthy ageing among very old people living in their homes in the community, research exploring the concept of independence based on very old people's subjective perspective is called for.

## **Research Needs**

Given the close interactions between activity, participation restrictions, and decreased well-being in very old age (Law, 2002), investigating very old people's experiences of participation and independence can provide knowledge useful for occupational therapy interventions within the home as well as out of home.

Since an important goal within occupational therapy practice is to enhance the performance of necessary and desired everyday activities, and to enable participation (Christiansen & Baum, 2005; Kielhofner, 2002; Law, 2002; Zemke & Clark, 1996), there is a need for a common language to describe and capture participation. This is further a prerequisite for future methodological development within the field and the profession.

In addition, independence in daily activities is considered an important health indicator (Iwarsson, 2003; WHO, 1991) and occupational therapy interventions in order to enhance independence are directed towards the person, the home environment or both (CAOT, 2002; Iwarsson, Sixsmith, *et al.*, 2005). Though traditionally, most occupational therapy interventions are carried out in the home environment, while several activities important for the everyday life are carried out in the neighbourhood or community.

Hence, as the profession develops, occupational therapists has to broaden their view and consider all aspects of the environment affecting the lives of old and very old people with reduced capacity. In sum, research elucidating what participation and independence

really means to older people from their own perspective is limited and thus a motivating factor behind this thesis.

## **Aims**

The overarching aim of this thesis was to explore participation and independence among old and very old people, focusing on aspects of home and neighbourhood environments.

The specific aims were:

- To investigate older people's preferences and frequencies of visits to public facilities in the neighbourhood.
- To generate knowledge on older people's perception of problematic and favourable physical conditions in public facilities and outdoor environment in the neighbourhood.
- To explore very old people's experience of participation in the home and neighbourhood environment.
- To explore very old people's experiences of independence in the home.
- To investigate how to capture and operationalise participation among very old people.
- To investigate relations between home and neighbourhood aspects and participation among very old people.

## **Material and Methods**

This thesis comprises four papers based on two different projects (Figure 1). Paper I is based on a project describing old people's preferences and frequencies of visits to public facilities in the neighbourhood, labelled The Neighbourhood Project. Papers II–IV is based on the cross-national project "Enabling Autonomy, Participation, and Well-Being in Old Age: The Home Environment as a Determinant for Healthy Ageing", ENABLE-AGE (Iwarsson, Sixsmith, *et al.*, 2005). The

ENABLE-AGE Project investigated the interplay between objective and perceived aspects of housing and very old people's experiences of health in terms of autonomy, participation and well-being.

In this thesis both quantitative and qualitative designs have been used. An overview of the papers is given in Table 1. Using a combination of the two methods in research gives advantages because the different methods have complementary strengths and weaknesses. The combination can also strengthen knowledge on a general as well as an individual level (Polit & Beck, 2004). When using both qualitative and quantitative methods the researcher's perspective on complex phenomena, difficult to capture is widened, and according to (Morse & Field, 1995), the strongest research findings are obtained when combining both methodological approaches.

In both project included in this thesis I

took an active part in the research process. In the Neighbourhood Project I conducted all interviews and run the project myself. As regards the ENABLE-AGE Project, early on, I was employed as a project assistant with data collection for the Swedish part of the project as my main task, while later I was employed as a doctoral student analysing part of the Swedish data for this thesis. During the project, international meetings have been conducted and a final conference in which I have been involved. I have accomplished a substantial part of the data collection, in the Survey Study as well as in the In-depth Study. In all, the Swedish team of project assistants carried out 1,108 Survey Study home visits, and out of those I accomplished 390. As regards the In-depth Study, I co-ordinated sampling and documentation, and I accomplished ten of the first 40 in-depth interviews (Paper III) as well as the eight following interviews (Paper II).

Table 1. Thesis overview

	Sample	Data collection	Data analysis
Paper I	$N=39$	Structured interview questionnaire: "My visit preferences to public facilities" <sup>a</sup>	Descriptive analyses Qualitative categorisation
Paper II	$N=8$	In-depth interview	Constant comparison <sup>b</sup>
Paper III	$N=40$	In-depth interview	Constant comparison <sup>b</sup>
Paper IV	$N=314$	Structured interview questionnaire, including observational assessments: "The ENABLE-AGE Survey Study Questionnaire" <sup>c</sup>	Transformation of response patterns into ranks <sup>d</sup> Spearman's rho Mann Whitney U Test

<sup>a</sup>Fänge, Iwarsson, & Persson, (2002)

<sup>b</sup>Charmaz, (2006)

<sup>c</sup>ENABLE-AGE, <http://www.enableage.arb.lu.se>

<sup>d</sup>Iwarsson & Lanke, (2004)

## **The Neighbourhood Project (Paper I)**

The Neighbourhood Project (Paper I) originated from my own experiences working as an occupational therapist in a south Swedish municipality. My interest in older people, their home and neighbourhood environments and their possibilities for participation in daily life resulted in the Neighbourhood Project. Thus, this was a first project investigating aspects of participation, namely older people's preferences, frequencies, and experiences of visits to public facilities.

At the time of the project the demographic characteristics in the study district were similar to those of the rest of Sweden. In the municipality there were 74,500 inhabitants, 28,000 of them were living in the town centre. Twelve percent of them were 75 years or older.

The town centre was built in the seventeenth century with its typical style of architecture. It is split by a canal, which gives it two main sections, two city gates, two squares, two main streets, two narrow or back streets, and two pedestrian precincts. One of the squares in the town centre is today's market square. The commercial area is a highly appreciated shopping area located between the two pedestrian precincts, well known for its choice of clothes shops, restaurants, cafés and cultural establishments. Within the commercial area, the walking surface materials are mostly paving stones, and most of the shops have one or several steps at their entrances.

### **Sample**

The project concentrated on inhabitants living in a few blocks within the area of the town centre. Inclusion criteria were men and women aged 75–84 with recent experiences of visiting different facilities in the town centre. Through the Swedish Central Population Register I found 128 inhabitants aged 75–84 years living within the defined geographic

area, with information about addresses and sex (male and female). The sample was divided into strata based on geographic location and sex. For the stratified sampling procedure the area was divided into three blocks: north, south, and centre. The study sample was then defined applying simple random sampling (Depoy & Gitlin, 2005). Fifty per cent of the population in each stratum was drawn, resulting in 64 intended participants; 26 men and 38 women. Excluded were individuals who had moved to an address outside the area, lived in nursing homes, or reported when contacted that they did not leave their homes ( $N=8$ ). In total, 17 individuals declined to take part in the study. The final sample comprised 39 persons 26 women and 13 men (Figure 2). There were no differences regarding sex and geographic location between those who agreed and those who did not agree to participate in the study ( $p<.05$ ).

### **Interview Questionnaire**

Data were collected using the pilot questionnaire "My visit preferences to the public environment" (Fänge, Iwarsson, & Persson, 2002).

The first section of the questionnaire comprised questions concerning age, gender, living alone or not, and personal assistance needed. The prevalence of functional limitations and dependence on mobility devices in the sample were identified through a combination of interview and observation as described in the Housing Enabler (Iwarsson & Slaug, 2001), adjusted as suggested by Jensen, Iwarsson, and Ståhl, (2002).

The second section of the questionnaire concerned user opinions of problems experienced in the public outdoor environment in the town centre and comprised open-ended questions covered in eleven environmental aspects.

The third section targeted visit preferences and perceived conditions in public build-



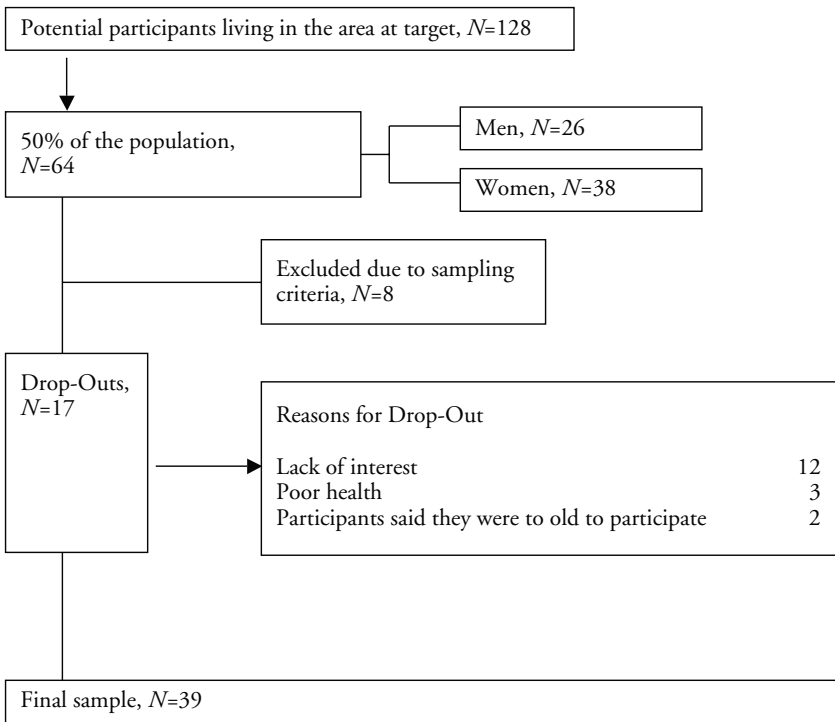


Figure 2. Description of the Neighbourhood sample, (Paper I).

ings. In all 319 facilities, e.g. food stores, restaurants, and pharmacies, were classified into 65 different categories. During the interview, each individual’s visit preferences to specific facilities were identified. Three questions were asked about facilities that the participant were visited; “Which of the facilities included in the category do you usually visit?” “How often?” and “Perceived problems?” Two questions were asked about facilities the participant wanted to visit: “Perceived problem?” and “How often do you want to visit?” The questions about how often the participants either visited or wanted to visit a facility had four response alternatives: every day, once a week, twice a month, and once a year. In order to get a uniform measure of frequencies, the estimated number of annual visits was then calculated. During the interview the partici-

pants were asked to point out favourable environmental conditions, whether personal assistance was needed to enable visits, and whether they had ideas about changes to improve the usability of the public facilities. Thereafter, the participant was asked to rank, in descending order, the five most important facilities for him/her to visit. Finally, an open question was asked to elicit additional options.

### Procedure

A letter was sent to the potential participants with information about the study, asking them to agree to an interview. They were then contacted by telephone to confirm an appointment. In order to obtain information about the dropouts, prevalence of functional limitations were identified over the phone.

The interviews were conducted at home visits during a three-month period. The interviews were performed according to the questionnaire as described. All responses were carefully registered and each home visit lasted one to two hours.

### **Data analysis**

Data analysis of perceptions of environmental conditions was performed by means of qualitative categorisation (Depoy & Gitlin, 2005). Preferences and frequencies of visits to public facilities were descriptively analysed. Along with their respective visit frequencies, the 15 most preferred categories of facilities, as well as categories of facilities preferred by only a few participants but with high visit frequencies, were graphically displayed.

### ***The ENABLE-AGE Project (Papers II–IV)***

The ENABLE-AGE Project was a major three-year, cross-national, interdisciplinary research project, including five European Union (EU) member countries, i.e. Sweden, Germany, the United Kingdom (UK), Latvia, and Hungary. The main objective of the ENABLE-AGE Project was to examine the home environment as a determinant for autonomy, participation, and well-being in very old age from a longitudinal perspective and exploring perceived and objective aspects of housing and their impact on health and ageing (Iwarsson, Sixsmith, *et al.*, 2005). The ENABLE-AGE Project comprised three major studies: The ENABLE-AGE Survey Study, The ENABLE-AGE In-depth Study and The ENABLE-AGE Update Review. The three studies all contributed to the main objectives of the project in a complementary manner. The design of these three studies will be briefly described, while this thesis is based on the Swedish part of the ENABLE-AGE Project, the Survey Study and the In-depth Study.

### **Brief description of the ENABLE-AGE Project**

The ENABLE-AGE Survey Study was based on a comprehensive, project-specific questionnaire, administered at home visits with each participant by means of interviews and observational assessments. The questionnaire comprised a variety of instruments covering demographic questions, several standardised instruments and a number of project specific questions, with different degrees of standardisation (ENABLE-AGE, <http://www.enableage.arb.lu.se/>). The database is unique, with its variety and wealth of details on objective and perceived aspects of housing and neighbourhood environments included. Applying a longitudinal design approach the questionnaire was first (T1) administered during two home visits with very old people living alone in their private urban homes. Follow-up (T2) was conducted one year later, when a modified and shortened version of the questionnaire was administered.

The first data collection of the ENABLE-AGE Survey Study was conducted prior to the ENABLE-AGE In-depth Study (Figure 3). As they were interviewed for the ENABLE-AGE Survey Study, participants were asked if they would like to take part in the ENABLE-AGE In-depth Study as well. The Survey Study participants varied in terms of health status, degree of participation and accessibility problems, thus giving the research teams access to a diverse sample for the In-depth Study. In this way, a sample of 40 participants in each country was identified for in-depth interviews. The qualitative design was driven by a grounded theory framework (Charmaz, 2006) aiming at deepening understandings of the meaning and experience of home in relation to the key concepts of the project: autonomy, participation, and well-being. Initial in-depth interviews were followed by a number of interviews to deepen understandings of the relationships between home and healthy ageing. In Sweden

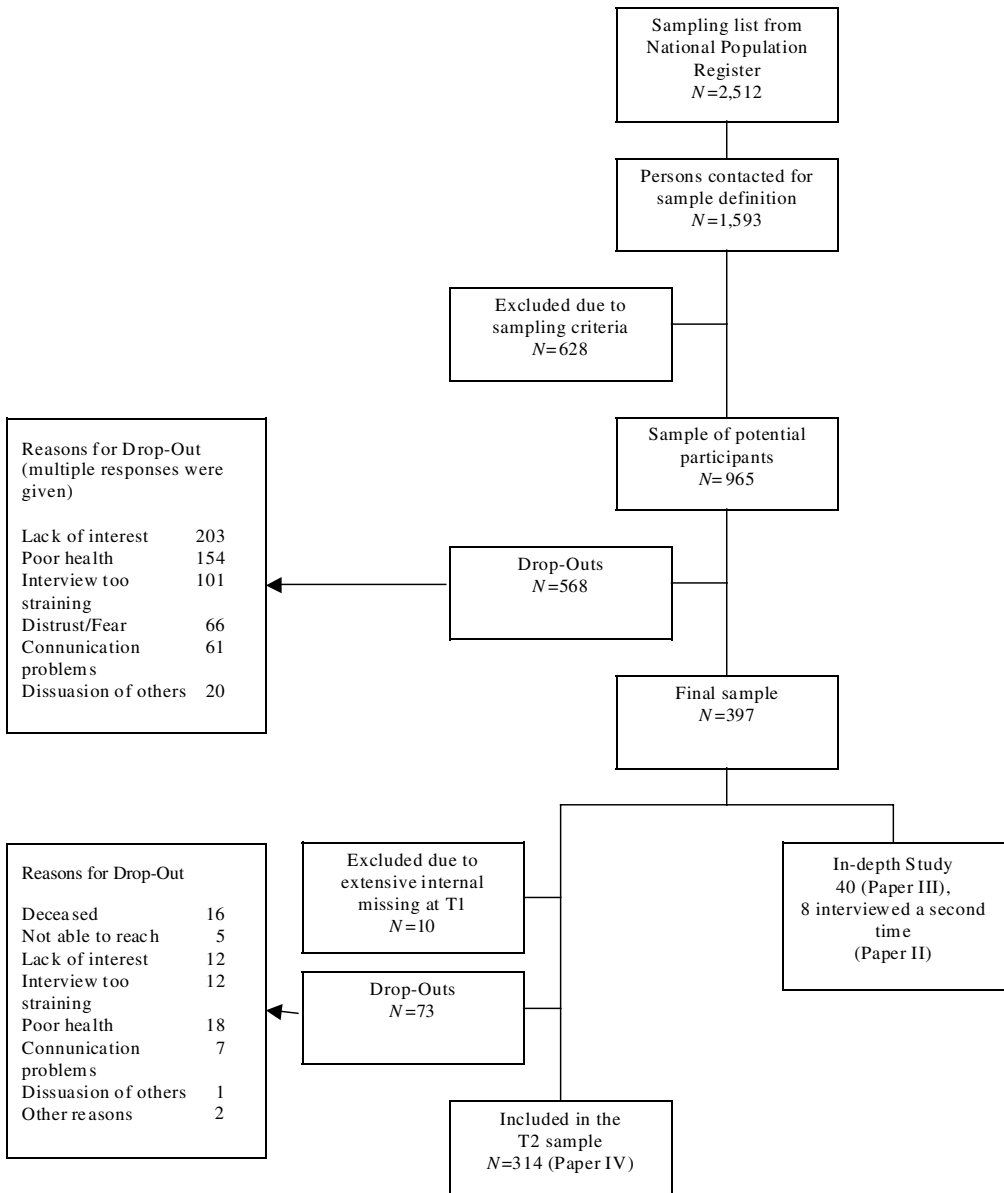


Figure 3. Description of the Swedish ENABLE-AGE sample, (Papers II–IV).

these interviews in particular focused the relationship between home and participation. As the work progressed, it was possible to utilise insights generated by the in-depth interviews to help modify the design of the ENABLE-AGE Survey Study Questionnaire at T2. For

example, the interviews pinpointed the lack of survey data relating to participation. As a result, issues of participation were more fully developed at T2.

The ENABLE-AGE Update Review aimed to explore key policy issues in the five

countries, thereby being the starting point for the whole project. The first component of this review concerned a detailed documentation of building norms and guidelines in each country, underfeeding the methodology development for the ENABLE-AGE Survey Study. Second, each country identified key policy topics, which in turn were compiled into a policy topic list at cross-national level, concluding with a macro-level, critical analysis of current policies and housing trends (Sixsmith, Pimor, Ball, & Széman, 2004).

### **Description of the Swedish Study Districts**

The study districts for the ENABLE-AGE Project encompassed three municipalities of different sizes and compositions of population, located in the very south-west of Sweden, i.e. one of the densest populated areas in the country. All three municipalities chosen encompassed both urban areas and rural outskirts; in 2001 the largest was Helsingborg (118,512 inhabitants), followed by Lund (99,622 inhabitants), and Halmstad (85,742 inhabitants). In Helsingborg and Halmstad, in 2004 18% of the population was aged 65 years or more, while in Lund this proportion was 13%. In Lund and Halmstad 4% of the total population was 80 years or older, while in Helsingborg 6% belonged to this age group (SCB, 2006c).

## ***The ENABLE-AGE Survey Study***

### **Methodological development and training**

The first phase of methodological development was the steps taken in the Update Review (Sixsmith *et al.*, 2004), necessary in order to revise the sections of the instrument that covered accessibility assessment for cross-national use (Iwarsson, Nygren, & Slaug, 2005). Then, all instruments and questions

were translated into five languages (Swedish, German, English, Hungarian and Latvian), while parts were translated into a sixth language (Russian). Iterative piloting in all countries followed. Three-day interviewer training courses followed in each country, focusing on reliable administration of all instruments. The interviewer teams in Sweden, Germany, and Latvia consisted solely of occupational therapists, while the UK and Hungarian interviewer teams were multi-disciplinary (Iwarsson *et al.*, 2004). In each country, the national project leader arranged further interviewer team training in their own language. After completed training courses, iterative pre-tests were administered. Older people, not included in the ENABLE-AGE Survey Study sample, were asked to answer the survey questionnaire, followed by subsequent revisions. After several months of pre-testing, the ENABLE-AGE Consortium reached consensus and agreed upon the final ENABLE-AGE Survey Study format (Iwarsson *et al.*, 2004). Finally, an inter-rater reliability study of the accessibility instrument, based on 64 pair-wise assessments, was carried out (Iwarsson, Nygren, *et al.*, 2005). The results demonstrated moderate to good agreement across research sites.

### **Sample**

The sampling was based on lists from the Swedish Central Population Register and for each municipality included, random sampling was performed. The sampling criteria were: persons registered in single households, 50% had to be born between 1913 and 1917 (85–89 years old), and the other 50% between 1918 and 1922 (80–84 years old). Each age group had to have a proportion of 75% women and 25% men. In total 2,512 addresses equally divided between the three municipalities were sampled and listed. Potential participants were consecutively enrolled. In order to reach the targeted sample ( $N=400$ ),

**Table 2.** Description of the study sample at T1,  $N=397$ 

Variable		
Age, 80-89 years, Md (q1, q3)	85	(81, 87)
Gender, n (%)		
Men	101	(25)
Women	296	(75)
Number of Functional limitations <sup>1</sup> , Md (q1, q3)	3	(1, 5)
Mobility devices, n (%)		
Use of mobility device	224	(58)
No use of mobility device	165	(42)
Housing, n (%)		
Ordinary housing	359	(90)
Sheltered housing	38	(9)
Number of diseases, Md (q1, q3)	5	(3, 7)
Self perceived health <sup>2</sup> , n (%)		
Excellent	54	(14)
Very good	105	(26)
Good	127	(32)
Fair	97	(24)
Poor	14	(4)

<sup>1</sup> According to the Housing Enabler (Iwarsson & Slaug, 2001)

<sup>2</sup> According to SF-36 (Sullivan, Karlsson, & Ware, 1994)

1,593 persons needed to be contacted. Excluded due to sample definition criteria were 628. Due to various reasons 568 dropped out, thus resulting in a sample of  $N=397$  at T1. A description of the Survey study sample at T1 is shown in Table 2. The participants sampled for the T2 Survey were those people that had completed visit 1 and visit 2 in the T1 Survey (Figure 3). The total sample of T2 consisted of  $N=314$ . Paper IV in this thesis is based on the T2 sample ( $N=314$ ).

## Interview questionnaire

The ENABLE-AGE Survey Study Questionnaire comprised several well validated and reliable instruments aiming to assess objective and perceived housing and neighbourhood environments, supplemented by outcome variables such as dependence in ADL, subjective well-being, and depression. In addition, information on assistive devices, aspects of health, and social participation were collected by means of project-specific questions.

As regards the instruments and questions used in Paper IV, a set of variables describing aspects of objective and perceived housing was selected from the T1 Survey Study Questionnaire. The rationale for selecting objective housing aspects was based on previous research, identifying a number of variables significant to healthy ageing (Iwarsson, Horstmann, & Slaug, in press; Oswald, Wahl, *et al.*, in press). The perceived housing aspects were also selected based on previous research identifying a valid four-domain model of perceived housing (Oswald, Schilling, *et al.*, in press).

The variables selected describing aspects of objective housing were as follows: Responding to the question "How long have you lived in this neighbourhood?" the participant was free to stipulate number of years lived in the neighbourhood (Iwarsson, Sixsmith, *et al.*, 2005).

Number of environmental barriers in the home and the magnitude of accessibility problems were assessed using the Housing Enabler instrument (Iwarsson & Slaug, 2001). The instrument is administered in three steps, the first is the dichotomous assessment of the personal component of accessibility, administered by means of interview and observation and covering functional limitations (13 items) and dependence on mobility devices (2 items). The second step is the assessment of the environmental component of accessibility, administered as a detailed observation assessing the presence or absence of environmental barriers in the home and the immediate outdoor

environment (188 items). The results of the second step constitute the variable “number of environmental barriers”. The third step of the Housing Enabler is the calculation of the magnitude of accessibility problems. That is, for each environmental barrier item the instrument includes predefined severity ratings (Steinfeld *et al.*, 1979), operationalised as points (1 to 4, higher denotes more problems). On the basis of the assessments in steps 1 and 2, with use of a complex matrix including the predefined 1 to 4 scores, the profile of functional limitations identified for each person is juxtaposed with the environmental barriers present. The total score is the sum of all the predefined points, constituting the variable “accessibility problems”. In cases in which no functional limitations or dependence on mobility devices are present, the score is always zero; higher scores mean more accessibility problems (for details see Iwarsson, 2005).

The selected perceived aspects of housing were as follows: Usability was assessed by the 16-item Usability in My Home Questionnaire (Fänge & Iwarsson, 1999; Fänge & Iwarsson, 2003), addressing the degree to which the physical housing environment supports the performance of activities at home (scored 1–5). The items used for this study address different aspects of usability; activity aspects (4 items;  $\alpha = .84$ ) and physical environmental aspects (6 items;  $\alpha = .84$ ).

The 28-item Meaning of Home Questionnaire was used to assess self-perceived physical, behavioural, cognitive/emotional, and social meaning of home (scored 0–10) (Oswald *et al.*, 1999). The items in each area were purposefully selected to represent a wide range of topics, thus internal consistency was expected to be rather low (Kline, 1993). Internal consistency for each of the four meaning of home sub-scales was as follows: Physical aspects (7 items,  $\alpha = .69$ ); Behavioural aspects (6 items,  $\alpha = .67$ ); Cognitive/emotional aspects (10 items,  $\alpha = .66$ ); Social aspects (5 items,  $\alpha = .55$ ).

External housing-related control beliefs were assessed with the Housing-related Control Beliefs Questionnaire (Oswald *et al.*, 2003), using data collected by means of a 16-item sub-scale (scored 1–5;  $\alpha = .72$ ). External control means either some other person is responsible or things happen by luck, chance, or fate.

Housing satisfaction was assessed with the single item evaluation “Are you happy with the condition of your home?” (scored 1–5), adapted from the Housing Options for Older People Questionnaire (Heywood *et al.*, 2002; Sixsmith & Sixsmith, 2002) (for details of all these instruments, see Oswald, Schilling, *et al.*, in press).

Perceived aspects of neighbourhood attachment reflect the bonding to the outdoor environment (Oswald *et al.*, 2005). The environmental characteristics of the instrument included in the Survey Study Questionnaire were differentiated in three domains: Amenity-oriented basic physical conditions and needs; Comfort-oriented higher-order physical conditions and needs; Social conditions and needs. Seven items out of 27 were included in the analysis. The rest of the items were excluded due to lack of variation in answers or because they were beyond the scope of Paper IV.

## Procedure

Potential participants were contacted through mailed letters with information about the ENABLE-AGE Project, and an inquiry about participation in the study. After 4–5 days the interviewer contacted the potential participant, if the person fulfilled the inclusion criteria, i.e. lived alone and understood the information; she asked whether the person consented to participate. If so an appointment for the first home visit at T1 was made. The duration of the T1 survey data collection at home visit one was 1.5–2 hours. The second home visit was accomplished within two weeks, and

lasted another 1–1.5 hours. If the participant found the sessions too long and strenuous, the data collection was divided into three home visits instead of two. The data collection for T2 started one year later. This was the sample used for Paper IV.

## ***The ENABLE-AGE In-depth Study***

### **Methodological development and training**

The five national ENABLE-AGE teams varied in terms of their experience in qualitative research, disciplinary backgrounds and gender. In light of this, two-day training courses were conducted in each country by the In-depth Study leader. The training course covered basic principles of epistemological issues and the grounded theory framework. Most importantly, practical sessions targeting interviewing skills and ethical considerations relating to working with very old people were held.

### **Sample**

A subsample of 40 people (Paper III) was drawn from the 397 participants in the Swedish ENABLE-AGE Survey Study participants at T1. Most of the sample was to be derived from the dominant ethnic group, with an ambition to select a few people from other ethnic groups. The main aim was to achieve as large diversity among participants as possible with respect to health, magnitude of accessibility problems in the home, and type of dwelling. Diversity in health was achieved by means of different levels of dependence in ADL and self-rated perceived health. Diversity in participation was accomplished by means of self-reported participation in clubs or other organisations.

The median age of the 40 participants was 85 years, and out of them 17 were men and 23

were women. The majority of them lived in multi-dwelling blocks, although the sample also included a few participants living in single-family houses. Fifteen participants rated their health as very good or good, while 19 participants rated it as fair or poor. Fifteen participants were independent in ADL, 25 were dependent in I-ADL, and six were dependent in both P-ADL and I-ADL. About 50% of the participants were active in clubs, organisations, or the like. There was also a variety among participants in terms of accessibility problems in their homes.

In order to deepen and broaden the knowledge about very old people's experience of participation at home, eight participants out of the 40 from the in-depth sample were selected for a second interview (Paper II). The eight participants were purposefully selected by the interviewer team, principally guided by the desire to include the most information-rich cases.

Out of the eight participants (five women and three men), one claimed to be in excellent health, four participants rated their health as very good or good, while three participants rated it as fair or poor. Five participants were independent in ADL, while three were dependent in I-ADL and one was dependent in both I-ADL and P-ADL. Six participants were engaged in an organisation or the like, while two were not. There was also a variety in terms of the magnitude of accessibility problems in the home. The eight participants lived in different types of multi-dwelling blocks.

### **Study approach**

The qualitative approach of Papers II and III was inspired by grounded theory (Glaser & Strauss, 1967; Strauss & Corbin, 1990) as described by Charmaz (2006). The 40 in-depth interviews in focus for Paper III were accomplished not earlier than 6 month after the ENABLE-AGE Survey Study by a team of four experienced occupational therapists. The

themes guiding the in-depth interviews derived from the key concepts of the ENABLE-AGE Project, i.e. aspects of the home environment, autonomy, participation and well-being in very old age (Iwarsson, Sixsmith, *et al.*, 2005). An interview schedule was developed, based on the concepts of meaning of home, independence, social and community participation, health and well-being, and societal supports for ageing in place.

## Procedure

About six months after the T1 data collection a letter was mailed to the potential participants who had signalled their interest and agreement to participate in the In-depth Study (Papers II and III). A time and date for the interview was arranged over the telephone, at the participant's convenience, and the interviews were conducted at home visits. Each interview lasted around one hour (30–85 minutes), following the themes decided in advance. In order to adapt the interview situation to each participant's thoughts individually adapted follow-up questions were utilised (Charmaz, 2006).

The eight interviews (Paper II) were accomplished approximately five months after the first 40 interviews. The interview schedule used during the first interview was developed in order to focus on issues concerning participation in more depth. More specifically the themes included the very old people's experience and personal meaning of participation, kinds of activities they participated in, and the ways in which the home environment enabled or constrained participation. Before each interview, the transcripts as well as the tapes from the initial 40 interviews were carefully reviewed, in order to arrive at a deepened understanding of the particular relationship between home and participation during the second interview. All 48 interviews were taped and transcribed verbatim during the interview procedure and soon after the interview.

## *Data Analysis (Papers II–IV)*

The qualitative analysis in Papers II and III was inspired by grounded theory as described by Charmaz, (2006). Immediately after each interview the interviewer made field notes. These were used to document the interviewer's interpretations of the context of the interview, the key points were revealed in relation to the research questions, initial ideas for analytical themes, relationships between themes, and the general tone of the interview was written down. It was in fact a first step of analysis. During the process of conducting the first 40 interviews the interviewer team of four persons had regular meetings, successively analysing the interviews in an iterative process, thus feeding forward into interview schedule amendments in order to obtain as much information as possible in forthcoming interviews. During the first two meetings, the team discussed one interview by each interviewer, while at the third meeting two interviews by each interviewer were discussed. At the next two meetings three interviews by each interviewer were discussed.

Due to the rich and comprehensive data that emerged out of the interviews it was decided to conduct four separate analysis, focusing on participation (Paper II), independence (Paper III), meaning of home and health, respectively. The analysis of participation and independence is included in this thesis, while the other two are manuscripts in progress for publication. In each analysis procedure the interviews were listened to several times and analysed using line-by-line coding, followed by focused coding. This is a selective phase, aiming at synthesising data through constant comparison of raw data and emerging categories (Charmaz, 2006; Strauss & Corbin, 1990).

As a result of the qualitative analyse targeting participation at home (Paper II), two dimensions of participation emerged (see re-



sults, Figure 5). These findings were subsequently utilised as the conceptual basis for further analyses (Paper IV). More specifically, in order to investigate how to capture and operationalise participation among very old people data from the ENABLE-AGE Survey Study was used. Based on current literature and their experiences in the field, the four researchers independently scrutinised the T1 and T2 questionnaires in order to identify items in the ENABLE-AGE Survey Questionnaire that reflected these two dimensions, and thus could be included in the analyses. Most important for this step of analysis, it was obvious that the T1 questionnaire did not include variables capturing participation to a sufficient extent, while such data was available at T2. On the other hand a comprehensive set of variables on objective and perceived aspects on housing and neighbourhood was only available at T1. After several rounds of discussions a set of items and variables from the T2 questionnaire was finally agreed upon, illustrating the two dimensions of participation. For each of the two dimensions, the selected items and variables were aggregated into a smaller number of new variables that were used to order all individuals in the sample according to their level of participation. As part of this process, the original response alternatives were aggregated into new response alternatives in order to allow for the ranking procedure. This procedure is a generalisation of the procedure used in the Mann-Whitney test (where pair-wise comparisons are based on only one variable), and similar generalisation has been used in connection with ADL assessments (Iwarsson & Lanke, 2004). Thereafter, Spearman's rank correlations were calculated between variables in each group of aggregated variables used in the ranking procedures. Further, for each of the two dimensions of participation, the aggregated variables were all correlated to the rank scores again, using Spearman's rank correlation. Finally, the two rank scores repre-

senting the two dimensions of participation were correlated. Restricted by the differences in instrumentation between the T1 and T2 data collections already accounted for, this analysis was of necessity designed to investigate whether and how aspects of housing and neighbourhood environment at T1 were related to participation at T2, i.e. one year later. Accordingly, all objective and perceived aspects of housing and neighbourhood environment at T1 were related to each of the two dimensions of participation at T2. The relations between the housing aspects and the rank scores were analysed, either with Spearman's rank correlation coefficients for aspects measured on an ordinal scale, or with the Mann-Whitney test for the dichotomous housing aspects.

All results were statistically significant at  $p < .05$ ).

### *Ethical Considerations*

In this thesis the projects were performed according to the ethical principles for medical research (World Medical Association, 2004) During the data collection process, for both projects a substantial number of very old people were visited in their homes. In order to achieve a general awareness in the study district the local newspaper wrote an informative article about the Neighbourhood Project. As regards the ENABLE-AGE Project, press releases about the project were sent to local and national news agencies, resulting in newspaper articles. In addition, the police and different clubs for senior citizens in each study district were informed by post mail and by phone. For both projects, before the interview a letter comprising information about the aim of the study as well as the names and photographs of the interviewer (Neighbourhood Project) and interviewer team (ENABLE-AGE Project) were sent to the participant. In compliance with formal ethical guidelines, the following measures were taken. First, in-

formed written consent was received from all participants, and they were assured of anonymity, as stated in oral as well as written information. Second, the participants were informed that they could withdraw from the interview at any time, including withdrawal of all data at any stage up to publication of results. The Neighbourhood Project as well as the ENABLE-AGE Project were accomplished after the approval of the Ethics Committee, Lund University, Sweden.

## Results

### *Preferences, Frequencies, and Perceived Neighbourhood Conditions (Paper I)*

When it comes to participation in terms of out of home activities in the close neighbourhood Paper I elucidated older people's visit preferences and frequencies to public facilities. Department stores were the most preferred and the most frequently visited category reported. Pharmacies, post offices, clothes shops, and banks were preferred by most of the participants, but they were not among the most frequent actually visited facilities. Cafés and cultural establishments were preferred by somewhat fewer participants, but with higher visit frequencies (see Figure 4). Six categories adult education facilities, pet shops, leisure establishments, tobacconists, corner shops, and kiosks were preferred by only a few participants, but highly frequently visited.

When it comes to the individual ranking of the most important facilities, Departments stores was shown to be the most important to visit followed by pharmacies, medical centres and banks. It should be noted that environments not included in the questionnaire, such as parks and squares, were also reported as important environments to visit.

As concerns neighbourhood conditions,

perceived as the most problematic were difficulties with surface materials ( $N=31$ ), in particular in areas of the town centre which all the participants mentioned, and outside their own apartments. Well above 60% of the participants reported paving stones as a major problem. Steps at entrances were perceived as a common problem ( $N=22$ ), together with too few seating possibilities along pathways, especially during summer months ( $N=16$ ) and lack of banisters ( $N=11$ ).

When it comes to favourable environmental conditions, prefabricated concrete slabs were generally perceived positively and they were appreciated as guiding lines in areas with paving stones. Further, entrances with automatic doors or door openers and facilities with levelled entrances or ramps were appreciated and reported by almost half of the participants as favourable.

### *Two Dimensions of Participation (Paper II, IV)*

Based on findings resulting from using the qualitative approach (Paper II), participation was described as being part of a larger context, and as being committed or devoted to something. Home emerged as the origin of participation as long as the person actually participated in activities out of home, as well as within the home. With declining health the participants' role changed from actor to spectator. In this process participation became more focused on the home thus emerging as the locus for everyday life; the hub for participation in everyday life. More specifically two dimensions of participation emerged: Performance-oriented participation and Togetherness-oriented participation (Figure 5). Performance-oriented participation was experienced when engaging in performance of activities for others, for example by helping others, by meaning something for someone else, and by taking responsibility for something. One woman said:

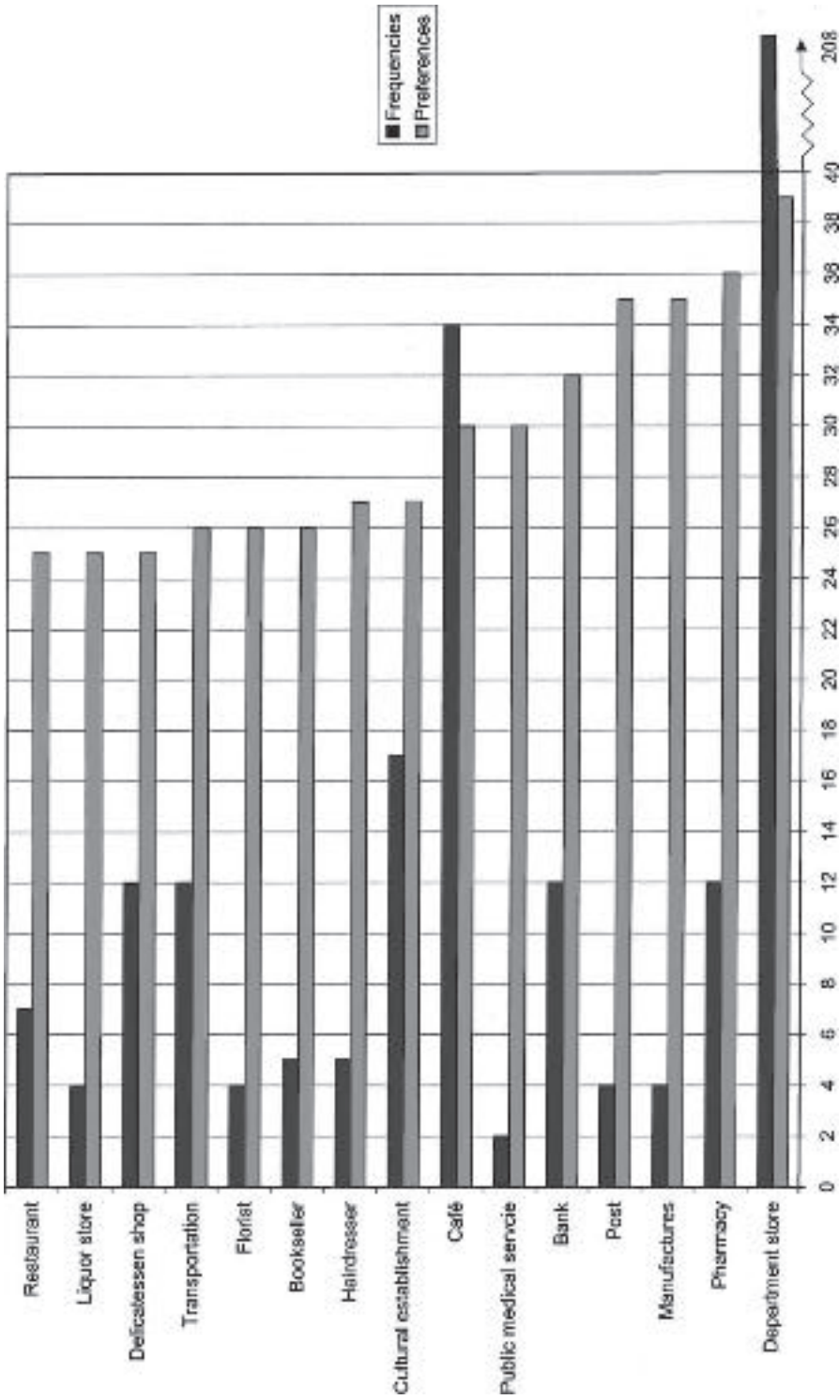


Figure 4. Preferences and frequencies of visits within the 15 most preferred categories,  $N=39$

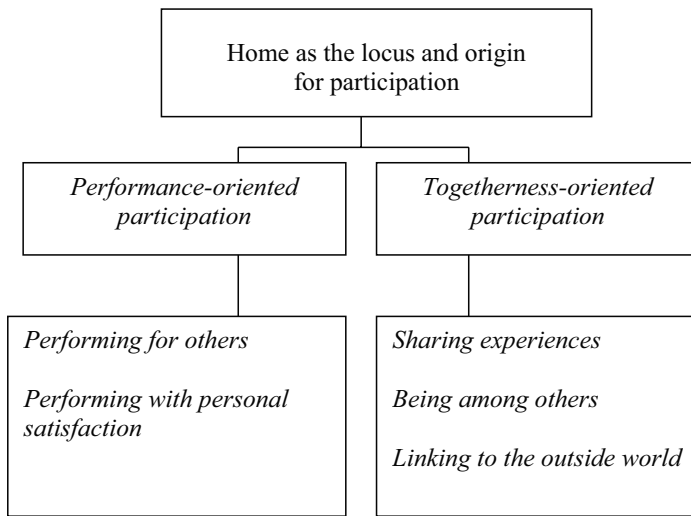


Figure 5. Home as the locus and origin for participation

*"I'm there and I do what I can, it's not much but I take charge of this canasta group and there are keys and cards and the lie, so that's responsibility too. And I can't be away because then they can't get in, so I think that's participation too."*

Other descriptions of participation were that participation was experienced as long as activities were performed with personal satisfaction. If personal satisfaction was no longer achieved, performance was restricted to very familiar activities where the risk of failure was considered minimal. A great acceptance and adjustment to situations of functional decline followed by participation restrictions was expressed; one has to accept that sooner or later one falls behind. One woman with hearing problems explained:

*"As I said, I'm realistic enough to know when I'm no longer able to enjoy it (concerts) as I did before, I know that you see. And then, I take it as it is. I may think about it that it would have been fun to accompany them but then I know, that, that afterwards I'm going to be a little disappointed, not with anybody else, only with myself because I'm not able to enjoy it as before."*

When it comes to the other dimension of participation, that is, Togetherness-oriented participation it was most often experienced by sharing experiences with others, as in meeting friends and family, or in participation in different group activities. Talking about her experiences in a reading circle, one woman who spent most of her days confined to the home said:

*"We read the same book and discuss it... And then you feel of course you take part in that way... It means a great deal. It does... well, it's not easy to describe what you feel. You experience community."*

Another way of describing Togetherness-oriented participation was just by being among other people outside home, without having to interact with them directly. One of the men illustrated this by saying:

*"The other day when I crossed the bridge to go and do a bit of shopping, it was aha, I'm suddenly in the town. There's a completely different movement, people and that... a kind of, you feel that you're part of the whole, somehow... yes indeed, you're part of it just by feeling 'Here I come'."*

In addition, when being confined to home, having things of interest to follow, such as persons in younger generations e.g. next-door neighbours' children or own grandchildren's careers, interests or life choices created a link to the outside world and thereby feelings of still being part of a larger context were experienced.

When it comes to the findings in Paper IV, they were based on the two dimensions of participation emerging from Paper II. That is, based on data from the ENABLE-AGE Survey Study Questionnaire it was possible to capture and operationalise participation. Sixteen items were found to represent Performance-oriented participation, subsequently aggregated into six new variables: Performance for others, Performance of fitness activities, Performance of leisure activities, Outdoor walking, I-ADL, and Perceived independence. Based on these variables the participants achieved their rank score of Performance-oriented participation.

Likewise, 18 items were found to represent Togetherness-oriented participation, and subsequently aggregated into four new variables: Participation outside home, Participation in leisure activities with others, Participation at home, and Participation at social activity centres. From these variables the rank scores of Togetherness-oriented participation were calculated.

All correlations between the variables contributing to Performance-oriented participation and all correlations between the variables contributing to Togetherness-oriented participation were strongly significant, with p-values ranging from .007 to values smaller than .0005. Furthermore, a medium-significant correlation ( $r_s = .325$ , p-value  $< .0005$ ) between the rank scores for the two dimensions of participation was found.

When further investigating whether objective and perceived home and neighbourhood aspects were related to participation, significant relations with both dimensions of

participation were found. More specifically, social aspects of the meaning of home, accessibility problems, living close to friends and relatives, and having cultural opportunities were related significantly to both Performance-oriented and Togetherness-oriented participation. In addition, activity aspects and physical environmental aspects of usability, behavioural aspects of the meaning of home, and external housing-related control beliefs correlated significantly with Performance-oriented participation. Having good local transportation related solely to Togetherness-oriented participation (Table 3). No statistically significant relations between the two dimensions of participation and years in the neighbourhood, number of environmental barriers within the home, physical environmental aspects of meaning of home, satisfaction with housing conditions, living where the action is, access to shops and services, medical care in the vicinity and feelings of neighbourliness were demonstrated (Table 3). Due to differences in scale construction, higher values of years in the neighbourhood, usability, meaning of home, housing satisfaction, and perceived neighbourhood aspects indicate higher levels of participation, while higher values as regards environmental barriers, accessibility problems, and external housing-related control beliefs indicate lower level of participation.

### *Independence at Home (Paper III)*

Among the very old people interviewed, the home was seen as a prerequisite for independence. That is, the familiar context that the home implies and being familiar with the environment was thus a kind of guarantee of independence. Two main categories emerged, Struggling for independence and Governing daily life. That is, on the one hand independence was viewed in terms of independent performance of activities, while on the oth-

**Table 3.** Relations between housing and neighbourhood variables and Performance- and Togetherness-oriented participation

	Performance-oriented participation		Togetherness-oriented participation	
	$r_s$	$p$	$r_s$	$p$
<i>Objective housing aspects</i>				
Years in the neighbourhood	-.094	.096	-.103	.068
No. of environmental barriers	-.064	.256	.072	.200
Accessibility problems	-.565	<.0005	-.172	.002
<i>Perceived housing aspects</i>				
UIMH 1, <sup>a</sup>	.258	<.0005	.061	.282
UIMH 3, <sup>b</sup>	.286	<.0005	.039	.490
MOH 1, <sup>c</sup>	.017	.769	-.047	.415
MOH 2, <sup>d</sup>	.368	<.0005	.086	.133
MOH 3, <sup>e</sup>	.048	.399	.035	.541
MOH 4, <sup>f</sup>	.140	.014	.166	.003
External HCQ <sup>g</sup>	-.314	<.0005	-.027	.639
Housing satisfaction	.029	.607	-.039	.491
	mean ranks yes/no	$p$	mean ranks yes/no	$p$
<i>Perceived neighbourhood aspects</i>				
Living where the action is	152/161	.384	160/153	.489
Good access to shops and services	161/164	.014	153/162	.093
Good medical care in the vicinity	163/138	.040	163/138	.032
Living close to friends and relatives	173/130	<.0005	168/130	<.0005
Cultural opportunities in the vicinity	164/136	.007	168/130	<.0005
Neighbourliness	155/145	.328	156/145	.312
Having good local transport	157/132	.072	161/111	<.0005

<sup>a</sup> Usability in My Home, activity aspects.

<sup>b</sup> Usability in My Home, physical and environmental aspects

<sup>c</sup> Meaning of Home, physical environmental aspects.

<sup>d</sup> Meaning of Home, behavioral aspects.

<sup>e</sup> Meaning of Home, cognitive/emotional aspects.

<sup>f</sup> Meaning of Home, social aspects,

<sup>g</sup> External housing-related control beliefs.

er hand the making of decisions about their daily life was emphasised. More specifically, the category Struggling for independence described the age-related process of functional decline experienced by the participants as a threat to independence. In this respect, Struggling for independence contained an ongoing struggle by stretching one's own physical limits in order to manage activities in the way they had always been performed. One of the women explained it as:

*"The most important thing about home is that I am independent, which means that I must force myself to manage. Even if it is hard I have to do it. And if I couldn't manage it would be a mess, and I would not be able to live."*

In order to maintain performance of highly valued activities, actions were taken to change various conditions. Different courses of actions such as housing adaptations, use of assistive devices or other purposeful equipment were considered to support independence; for example, as one woman expressed it:

*"Well, I think I have all the possibilities here... and I only do what I enjoy doing... the kitchen is really good... the kitchen is so small, when it comes to walking distances... I've got everything around me. I just thinking of something. I lift my arm and take out a glass... when I first saw it I thought, my goodness, what a small kitchen. Such a small kitchen when I'm used to a bigger one... But I discovered that it's perfect."*

In order to avoid dissatisfaction with performance quality, the participants described how they lowered their demands on performance or voluntarily gave up activities when they were no longer able to perform them satisfactorily. When it comes to the other independence category, Governing daily life, the participants emphasised the importance of being able to make one's own decisions without being controlled or restricted by anyone. As one woman expressed it:

*"...I live as I want to live and as I choose, and live by myself and decide by myself."*

In order to feel that they were independent persons, deciding when, how, where, and what kinds of activities should be performed, became more important with declining function. When giving examples describing experiences of both being able to govern their daily life, as well as the opposite, many of the older persons mentioned home help services. More specifically, the participants sometimes perceived that the organisations and administration around home help service controlled appointments and routines, to an extent that it affected the participants' lives both negatively and positively. One of the women having extensive home help service said:

*"So it's the council that decides when you have a pee (laughter)... now they've started nagging that you can't pee too often because then your bladder will get lax. But I said, you have to see to it that you pee when they come... three days a week we go out and before they go I usually have a pee. Otherwise they come around three o'clock and then I usually have a pee. You're not always able to go then, so you just have to forget it."*

As long as the participants were in charge and in control, i.e. experienced independence, the help received was positively perceived and influenced a continuous sense of independent life at home. On the other hand, if the older persons were not able to decide about different activities in daily life, they considered that their freedom decreased and that their spontaneity became restricted.

## Discussion

The main findings in this thesis are that two dimensions of participation in very old age Performance-oriented participation and Togetherness-oriented participation were

identified and statistically validated. Another important finding is that the home was experienced as the locus and origin for participation, and access to public facilities and the neighbourhood in general was found to be important for participation as well. Home was also seen as a signification of independence, as in independent performance of activities without the help from others as well as in being able to make autonomous decisions about daily life at home.

The fact that two dimension of participation in very old age Performance-oriented participation and Togetherness-oriented participation were qualitatively identified and statistically validated is a new approach to capturing and operationalising participation. Relating these two dimensions and the included variables to other studies, Sörensen *et al.* (2002) operationalised social participation into three variables: paying visits to others, receiving visitors at home, and participating in social activities outside home. Among other attempts to capture dimensions of participation, Brandt, Iwarsson, and Ståhl (2003) emphasised that mobility is a prerequisite for participation, thus suggesting mobility-related participation as one dimension of participation. These dimensions of participation to some extent mirror the dimensions of participation captured and operationalised in this thesis, thus supporting the validity of our results. Still, it should be kept in mind that on an overarching level, the concept can be defined from a societal or an individual perspective (Gustavsson, 2004) and the two dimensions identified and operationalised in this thesis mirror a mix also of these perspectives. Thus, there is an obvious need to continue the process of conceptual definition and refinement since there is no consistent and widely accepted understanding of participation.

When it comes to relationships between the two dimensions of participation and objective and perceived home and neighbourhood aspects, our findings that they are related are

worth discussing more specifically. In this thesis, access to good local transport in the neighbourhood is related to Togetherness-oriented participation, while lack of cultural opportunities in the neighbourhood contributes to restrictions of both dimensions of participation. These results were to some extent expected and are in line with previous research: Mollenkopf *et al.* (1997) and Mollenkopf *et al.* (2004) found that good availability of and satisfaction with public transportation influenced out-of-home mobility positively, thus presumably contributing to participation. Moreover, participation in cultural activities has been associated with lower mortality (Bygren, Konlaan, & Johansson, 1996; Konlaan, Bygren, & Johansson, 2000), and declining risk of depressive symptoms in old age (Braam *et al.*, 2004). Since participation in different cultural activities often requires travel by car or public transportation, at least using public transportation is often too demanding for many older people (Jensen *et al.*, 2002). Indicating the necessity of usable public transportation's to facilitate for very old people to move about in the neighbourhood.

Another important result was that perceived aspects of housing such as having a usable home were significantly related to Performance-oriented participation, while no such relationships were found with respect to Togetherness-related participation. Performance-oriented participation to a high extent comprises variables that could be considered activities, while also many aspects of perceived housing relate to activities. Oswald, Wahl, *et al.*, (in press) obtained similar results from the ENABLE-AGE Survey Study data involving several European countries, finding that perceived aspects of housing were related to independence in daily activities. The results of this thesis likewise indicate a relationship between participation and independence. However, there is a need for further investigations.

As found in Paper II, with declining



health, activities in which participation is experienced changes from activities in which the participant is actively involved to activities in which the participant takes the role as a spectator. Activities also changes from out-of-home activities to participation in activities at home. The finding confirms that the home becomes central and very old people's major living space, in terms of the increased time they spend at home, as well as in terms of the number of activities that take place inside the home (Baltes *et al.*, 2001; Oswald *et al.*, 2003; Rowles, 1981). However, more research explicitly targeting the role of the home as the locus for participation is needed. In this respect, the findings of this thesis indicate that occupational therapists working in the homes of older people need to pay more attention to and facilitate the use of latent abilities by means of enabling old people to do what suites them best.

When it comes to visit preferences and frequencies to specific public facilities in the neighbourhood, department stores where it is possible buy groceries, clothes, flowers, etc., or to get something to eat are shown in this thesis, together with e.g. pharmacies and post offices to be a highly important facility to visit within the neighbourhood. With respect to environmental conditions, more problems are perceived along outdoor walking routes than within the public facilities per se. This finding is in line with previous research targeting very old people (Hovbrandt, 2006) concluding that older people's mobility in the local community is dependent on accessibility and usability along "the entire travel chain", i.e. the entire way from origin to destination (Carlsson *et al.*, 2002; Jensen *et al.*, 2002). It should, however, be kept in mind that in Paper I, 16 persons included were not very old people, but younger. Accordingly, there is an increased risk that people due to accessibility problems outdoors are being excluded from important domains of society (Lilja & Borell, 1997), thus, accessibility and usability seems

to be prerequisites for participation. Hence, the results of this thesis indicate that being able to experience participation in activities outside home is facilitated if the neighbourhood is pleasurable and feels safe, public facilities and services in the neighbourhood are accessible and usable, and it is possible to engage in leisure activities. Thus, by enabling participation in society, well-being (Law, 2002), and quality of life (Gabriel & Bowling, 2004) in old age is enhanced.

Hence, in order to plan for efficient interventions supporting very old people's daily life in their ordinary homes with preserved life satisfaction and positive health perceptions, it is important for occupational therapists and other health care professionals to take into account that an independent life at home for very old people also means being able to be in charge and make one's own decisions. If very old persons are provided with meaningful information, and environments are created to facilitate participation and independence, they gain a sense of control over their daily life at home, even when they hand over decisions to others (Cardol, de Jong, & Ward, 2002). Once again, it is obvious that participation and independence are intertwined but separate concepts, each needing to be accounted for in order to enable well-being processes (Christiansen & Baum, 2005) at home.

The fact that, in order to experience participation, the participants put a lot of value and effort into performing activities the way they had been performed earlier, is closely linked to the finding that the very old people were continuously struggling to remain independent. Hence, Performance-oriented participation seems to be closer related to independence than Togetherness-oriented participation. Though it can be assumed that Togetherness-oriented participation might be related to autonomy. The results highlight the complexity of ageing in the way that loss of activities is much more than loss of performance capacity (Russel, Fitzgerald, Williams, Man-

or, & Whybrow, 2002). Loss of performance capacity makes the participants define themselves differently in what they are able to perform (Jackson, Carlson, Mandel, Zemke, & Clark, 1998). The finding that people gave up activities if they were dissatisfied with performance, and developed new strategies, point in the direction of Baltes and Baltes' (1990) theory of selection, optimisation and compensation when growing old. In addition, active selection of which activities to maintain or give up is very frequent in old age (Schultz & Heckhausen, 1997).

Referring to the results of Paper III, autonomy appeared to be important even though the focus was on independence. That is, the concepts of independence and autonomy seem to be closely related to each other. More specifically, as demonstrated by our results the participants' view of independence changed from physical independence to actual decision-making. Reflecting upon this result, the participants view of independence seem to be close to Nosek and Fuhrers (1992) definition of independence. They define independence in terms of four major components: perceived control on one's life, physical functioning, psychological self-reliance and environmental resources. Though, if the result of Paper III is a differentiation of independence or if the result is about independence and autonomy remains to be further investigated. However, a reflection one could make is that it is important for occupational therapists to be more aware of how older people perceive independence since this differentiation is crucial in order to enhance participation.

In addition, in spite of fewer activities to be involved in, the participants seem to maintain participation because they are able to make decisions regarding their own lives, in other words, they feel autonomous (Beauchamp & Childress, 2001). Thus, participation seems to be about belonging and identity: it says something about who you are in interaction with the environment. Reflecting over the concepts

of participation and autonomy Cardol and co-workers (2002) argued that a person-centred understanding of participation requires that autonomy is taken into account. They also argued that autonomy is central and a prerequisite for participation, and should be conceived of as a basis for participation. Autonomy is defined by Beauchamp & Childress, (2001) as freedom to determine one's own actions or behaviour. Another similar definition within occupational therapy, is to successfully make activity choices that bring personal satisfaction and meaning (Kielhofner, 2002). WHO (2002) defines autonomy as the perceived ability to control, cope with and make personal decisions according to own rules and preferences. From a psychological perspective, Ryff, (1989) describes autonomy as self-determining, being able to resist social pressures to think or act in certain ways, regulates behaviour from within and evaluates self by personal standards.

Out of the results of this thesis it is obvious that participation and independence are distinguished concepts but seems to be inter-related to each other. Though the concepts of independence and autonomy often are used interchangeably in gerontology as well as in occupational therapy literature, without explicit definition and differentiation. Since our understanding of autonomy within occupational therapy, is unclear and insufficient further research is needed.

In sum, very old people try to preserve links to their previous patterns of activity performance (Atchley, 1989). At the same time, being forced to abandon highly valued activities non-voluntarily tends to have negative effects on a person's well-being (Wilcock, 1993). This illustrates that finding the best strategy to support performance of highly valued activities, while still achieving personal satisfaction, is a complex and important task for occupational therapy practitioners since it is the basis for maintaining participation and independence in old age.

## Methodological Considerations

Working as a project assistant with data collection as the main task in a large European inter-disciplinary project has its pros and cons. Its highly instructive and inspiring to have the opportunity to be involved in this greater whole, to take part in workshops engaging occupational therapists, sociologists, psychologists, etc., from different European countries. By doing fieldwork very close to the target population, a sustainable amount of opinions as regards how the very old people understand and respond to questions included in the Survey Study Questionnaire emerge. On the other hand, even though the advantages outweigh the disadvantages, being a project assistant with little influence on consortium-decisions as regards instruments to be included or excluded in further steps of the project can sometimes be rather frustrating, even more since this influence the design of the own doctoral work.

A complex, inter-disciplinary, cross-national research project like ENABLE-AGE involves a number of challenges (Iwarsson *et al.*, 2004). Even though this thesis is based on the Swedish part of the ENABLE-AGE Project, the implications of the cross-national context for the project as a whole needs to be considered if future research compares the results of the papers included in this thesis with findings from other countries included in the project. It would be possible to perform comparisons between the Eastern and Western European countries, or between specific countries. There are opportunities to collaborate with all of the ENABLE-AGE teams. For example, the German as well as the Latvian ENABLE-AGE teams has PhD students working with ENABLE-AGE data. One of the German team members has recently completed her PhD thesis based on the German part of the In-depth Study (Naumann, 2006) while an Latvian PhD has work in progress based on qualitative data (Tomson, Zalkalns, Nygren & Iwarsson, submit-

ted). Hence, in order to accomplish successful research collaboration on issues of participation, independence, and home and neighbourhood environments, challenges such as differences in housing and demographic situations across countries need to be considered. When it comes to occupational therapy research overall, very few cross-national projects have been accomplished, and in this respect, this thesis represent a major step towards increased future knowledge on a European level concerning participation and independence in the home and neighbourhood environments, underfeeding professional development on a individual as well as on a societal level.

Turning to this thesis, a unique methodological strength is that participation was targeted by qualitative and quantitative data from the same project. Using qualitative as well as quantitative methods is a powerful approach to strengthening the validity of a study since the weaknesses of one method are juxtaposed with the strength of another (Patton, 1990). Further, the researchers' perspective on complex phenomena that are difficult to capture could be widened when using a mix of complementary qualitative and quantitative methods, and the strongest research findings are obtained by combining the methods (Morse & Field, 1995). At the same time, different methods capture different aspects of the phenomenon of interest (Sale, Lohfield, & Brazil, 2002). When it comes to combining in-depth interviews with quantitative survey data, as in this thesis, some previous studies have utilised different samples in the same study (see e.g. Clarke, 2003), while others combine data from the same sample (Chan, 2001). Both approaches have their drawbacks. In this thesis an innovative yet valid and efficient approach was applied. Accordingly, data collected with a substantial sample of very old people were available, collected with the participants at several occasions, using different approaches. That is, all participants took part in a major survey study, while a sub-sample participated

in a qualitative in-depth study as well. Bearing in mind that the two dimensions of participation, identified in a sub-sample of eight participants, were possible to operationalise and validate using the survey study data must be considered a strength.

In addition, using qualitative and quantitative methods to explore and capture the same concept displays a solid ground and could be considered as a first important step towards instrument development targeting participation old age.

When it comes to the sampling procedure, one reason for targeting very old people in the ENABLE-AGE Project was that major studies investigating this at-risk segment of the ageing population (see e.g. Baltes & Mayer, 1999; Myers, Juster, & Suzman, 1997) have focused on variables related to the person and his/her social environment, but not on the home environment. Very old participants living alone in their own homes were selected due to the increased risk of declining participation and independence as well as social isolation (Iwarsson *et al.*, 2004).

The participants included in the ENABLE-AGE Project had a better perception of health than the persons who declined to participate did (Nygren, Johannisson, & Iwarsson, 2004), thus the most vulnerable group might not have been reached. Though it should be kept in mind that the ENABLE-AGE Project did not strive for representativity; it was explicitly explorative in nature (Iwarsson, Sixsmith, *et al.*, 2005). In opposite to the Neighbourhood Project where the sample seems to represent a frailer group than those who declined to participate. Even if the characteristics of the sample might mean a threat to generalisability in both studies, one should keep in mind that data were collected with persons who had practical, personal experiences of functional limitations and environmental barriers and hence were able to report validly on problems experienced.

Further it is worth considering the fact

that the sample lived in urban areas. Most major research projects as regards older people have predominately been conducted in urban areas (Baltes & Mayer, 2001; Mollenkopf *et al.*, 2004). Only national studies are found when it comes to older people in rural areas (Constance, Antonio, Ignácio, & Joao, 2003; Ding, 2004; Iwarsson, 1997; Savikko, Routasalo, Tilvis, Strandberg, & Pitkala, 2005). Research on rural elderly similar to the ENABLE-AGE Project is scarce. Indicating a further research need on older people in rural areas at an international level.

When it comes to the sample of the ENABLE-AGE In-depth Study, it is important to consider the implications the characteristics of the sample might have for the findings. More specifically, those cohabiting, living in sheltered housing or different care facilities were excluded. As regards the housing situation, aspects influencing the relationship between home, participation, and independence in ordinary or sheltered housing probably differ substantially and require separate investigation. In addition, the situation of very old cohabiting people presumably is very different in terms of experience of participation and independence and remains to be investigated. It is also important to bear in mind that the frailest group of very old people living at home was difficult to reach. For this purpose alternative sampling strategies could be considered in further research, e.g. by using different health care agencies in order to reach this frail group.

When it comes to selection of items to be included in Paper IV as mentioned earlier the ENABLE-AGE Survey Study Questionnaire comprises a considerable range of variables of potential value for that specific study. In spite of this, certain types of items and variables were lacking in one and same wave of data collection, which could be considered a drawback for the study. Due to the fact that the Survey Study was accomplished and finalised before the analyses for Paper IV were

initiated, the original items and variables was not possible to influence.

Turning to the time span between the two measurement occasions, one year is a considerable time in very old age, and one could rightfully question the appropriateness of this design using items from two data collections. However, since previous studies indicate that objective (Iwarsson, 2005; Iwarsson, & Wilson, 2006) and perceived housing aspects (Nygren *et al.*, 2004) are rather stable over time, it was not considered as a major drawback. Instead, this approach generated results with potential to underfeed hypotheses for forthcoming longitudinal studies based on ENABLE-AGE data. In addition, even if it was not the aim of Paper IV, an interesting way to interpret the results would be in terms of whether and how aspects of housing and neighbourhood actually can predict participation in very old age. Such questions remain to be investigated.

Reflecting upon the interviewer team composition in the ENABLE-AGE In-depth Study, the composition of an interviewer team of four people conducting in-depth interviews is a somewhat unusual approach. In the Swedish ENABLE-AGE In-depth Study the team consisted of researchers, all female and all occupational therapists, with different prior experiences of conducting qualitative research. This particular composition might have affected the interviews with respect to traditional gender roles, and personal experiences and perspectives. In qualitative research the interviewer's prior understanding may strengthen or bias the quality of the findings, therefore these aspects are important to take under consideration (Patton, 1990; Strauss & Corbin, 1990). In order to ensure consistency with respect to the research aims, such concerns were continuously discussed within the Swedish interviewer team as well as within the ENABLE-AGE consortium. Thus potential threats to the trustworthiness due to interviewer team composition were handled in a very conscious manner. Importantly, the in-

terviewer team perceived the chosen approach as fruitful both for the interview process and for the data analysis. Working in a team of four interviewers reduced the risk of bias, and we had regular meetings for analyses and discussion between rounds of interviews. Then, having two of the interviewers to analyse data independently (myself and one of the senior researchers with prior experience of qualitative research) in both studies strengthened the interpretations of the data. Further, due to the multidisciplinary approach in the ENABLE-AGE Project there was to some extent input to the emerging analysis from other professions within the project. Accordingly, the risk that any prior understanding from anyone included in the interviewer team would influence the findings was reduced (Glaser & Strauss, 1967). In addition, it is worth mentioning the interviewer team's acquired knowledge of working with very old people in their own homes, enhancing a trusting communication situation. Further, the interviewer team displayed sensitivity in understanding and giving meaning to the thoughts of the very old people that came out of the interviews. Further, the fact that all participants at the time of the interview had already been involved in the ENABLE-AGE Survey Study, as well as the fact that the interviews were conducted in the participants' homes, made it likely that credible findings and interpretations would emerge. These circumstances most probably strengthened the quality of the findings.

A large sample and a comprehensive interview guide made it impossible to accomplish a solid coherent analysis. Therefore, due to the richness of data after the interview process and the first step of analysis, it was considered necessary to undertake several separate analyses processes in order to explore the key concepts of the ENABLE-AGE In-depth Study in sufficient depth. Each analysis focused on one of the key concepts, i.e. independence, participation, meaning of home and the relationships between home and health result-

ing in four different papers. Out of these, two are now in press and are included in this thesis, while another two will be published elsewhere. By treating the data in this way, an in-depth picture of each of the key concepts was gained. When the assembled results of these four papers are available, a more comprehensive picture of very old Swedish people's home and health situation will emerge.

### ***Implications for Practice***

The results of this thesis supplement the growing body of knowledge on the significant relationships of participation and independence at home and in the neighbourhood, thus it has implications for occupational therapy and public policy on housing and neighbourhoods. Accordingly, the results are important to consider in community planning, supporting old and very old people's participation and independence.

In order to ensure that a range of options to experience participation in old age are available, it is imperative for occupational therapists and other health care professionals as well as policy-makers to understand how participation is experienced among very old people. It is also imperative to be aware of the significant role the home and neighbourhood environment plays in experience of independence. Furthermore, within the multidisciplinary teams that have come to characterise the current organisation of Swedish health care, resource allocation and evaluation of geriatric care and rehabilitation, occupational therapists have a particular responsibility for targeting participation and independence issues in intervention planning and evaluation. With this in mind, it is important for occupational therapists to consider not only the functional aspects of the individual situation, but also previous and current activity preferences and priorities, in order to come up with interventions enhancing participation and independence, and thus healthy ageing.

It is, for example, of the utmost importance to take into account when, where, and in what way old persons want to participate and be independent. It is urgent that occupational therapist not only consider traditional interventions in order to enhance participation and independence. For example the results indicate that a social aspect of doing something for someone else is perceived as critical for Togetherness-oriented participation. This has direct implications for occupational therapists and other health professions, because if participation is not solely an observable individual event, but rather a more collectively situated transaction based on a specific process between inner and outer phenomena connected to human relations, then it is possible that some dimensions of participation are currently not being captured within practice frameworks (Stamm, Cieza, Machold, Smolen, & Stucki, 2004). In addition, another domain of concern for occupational therapists is to increase interest in community planning processes focusing on housing provision for old people, involving different housing alternatives such as ordinary housing, sheltered housing, institutions, or in-between solutions. Besides housing issues, interventions targeting neighbourhood environments in a very concrete sense, such as improvement of walking surfaces or placement of benches in the outdoor walking environment could influence old people's maintenance of health (Brandt *et al.*, 2003; Hovbrandt, 2006) and have specific implications for experience of and possibilities for participation and independence.

Applying a European perspective taking the growing population of older people into account, the policy in several European countries is to support older people to stay in their home environment (Committee for Science, 1998; WHO, 2002). Even if the welfare systems differ among countries, increased attention is being paid to the local authorities' responsibility to meet the citizens needs. Across Europe occupational therapists

are working to enhance older people's possibilities to maintain performance of activities of daily living in different cultures, while seldom based on research findings. The meaning of different activities is specific to each person and influenced by e.g. environmental factors (Watson, 2006) either promoting or preventing independence and participation. Different individuals have different methods of adjustment, and each phase of rehabilitation generates choices and strategies for maximising participation and independence. Thus the results of this thesis indicate the need to enable for older people to take part in different activities out of home.

### ***Summary and Conclusion***

The results of this thesis have further developed the knowledgebase on very old people's experiences of participation and independence and their relationships to the home and neighbourhood environment as a basis for interventions at both individual and societal level, chiefly in community-based occupational therapy. The main conclusions are:

- Some of the most important public facilities to visit in the neighbourhood were shown to be important for participation and independence.
- There is an increased risk that older people are excluded from participation due to environmental problems in the neighbourhood, foremost in the outdoor neighbourhood environment but also in public facilities. The majority of the problems are perceived along walking routes. To make it possible for older people to participate in desired situations in society it is important to enable them to get to desired places independently and to move about once they get there.
- Home is the locus and origin for participation and a signification of independence in very old age.
- Two dimensions of participation emerged:

Performance-oriented participation and Togetherness-oriented participation.

- It is important for occupational therapists to take the two dimensions of participation into account and to be sensitive to the very old person's self-defined goals for a meaningful life.
- Independence is a complex construct, and there is a need for further validation as regards the differentiation between independence and autonomy. Occupational therapists should be aware of this differentiation and its implications for intervention planning.
- If ageing is to be a positive experience, a longer life should be accompanied by continuing opportunities for participation and independence.
- To capture and operationalise participation statistically by means of the two dimension qualitatively emerged is a conceptual methodological development, and an early first step towards instrument development aiming to capture participation in very old age.
- Objective as well as perceived home and neighbourhood variables were related to Performance and Togetherness-oriented participation.
- Traditional occupational therapy interventions should have the potential to enhance Performance-oriented participation, while in order to promote Togetherness-oriented participation new kinds of engagement in community planning, e.g. public transportation, housing provision or improvement of neighbourhood environments, could be considered.
- A model of healthy ageing should be based on concepts derived from older people themselves. This dissertation is a first step to theory building about participation and independence and very old age, but in order to build theory, relations between the concepts of participation and independence have to be further explored.

## Svensk Sammanfattning/ Summary in Swedish

Det övergripande syftet med denna avhandling var utforska de allra äldstas upplevelser av delaktighet och självständighet med speciellt fokus på hemmet och närmsta omgivningen.

Dagens debatt om åldrandet handlar mestadels om kvaliteten i vård och omsorg, dess kostnader men också om bristande omsorg. Även boendefrågor debatteras, men då är det oftast bristen på särskilt boende som är i fokus. De allra äldsta som bor kvar hemma och kanske inte kan röra sig i någon större utsträckning utanför hemmet debatteras i media men är nästan helt osynliga i forskningen. Äldre som bor kvar hemma konsumerar både mer och oftare vård av olika slag jämfört med dem som bor i särskilt boende. Rätten att bo kvar i det egna hemmet – kvarboendepincipen – är en viktig princip i svensk äldreomsorg, men kunskapen är begränsad om de allra äldstas egna upplevelser om det dagliga livet i det egna hemmet. Vi vet dock att grundläggande mänskliga behov är att känna sig delaktig och självständig i vardagen. I takt med att allt fler blir allt äldre och dessutom också mer aktiva ute i samhället är det viktigt att undersöka hur de allra äldsta själva upplever delaktighet och självständighet i hemmiljön och den närmsta omgivningen. Tidigare forskning när det gäller de allra äldstas upplevelser är mycket begränsad.

Avhandlingsarbetet omfattar material från två projekt. Delstudie ett baseras på ett projekt med fokus på äldre personers prioriteringar vad gäller besök i offentliga lokaler i närheten av bostaden. Urvalet bestod av 39 personer mellan 75–84 år; samtliga bodde inom ett geografiskt avgränsat innerstadsområde i en medelstor skånsk stad. De övriga tre delstudierna baseras på den svenska delen av det europeiska projektet ENABLE-AGE, vars huvudsyfte var att undersöka hemmil-

jöns betydelse för delaktighet, autonomi och välbefinnande bland de allra äldsta. I Sverige deltog totalt 397 ensamboende personer i åldern 80–89 år.

Syftet med den första delstudien i avhandlingen var att undersöka vilka offentliga lokaler äldre personer önskade besöka, hur ofta, samt vad de tyckte om sin närmsta utomhusmiljö. Fler problem rapporterades utomhus längs gångstråk än inomhus i de olika offentliga lokalerna. Exempelvis rapporterades problem med ojämn beläggning pga gatsten, lutande trottoarer och för få bänkar längs gångstråken. Även förekomst av ett eller flera trappsteg, avsaknad av ledstänger och tunga dörrar in till offentliga lokaler upplevdes som hinder. Resultaten visade att de offentliga lokaler som ansågs viktiga att besöka var t ex. varuhus, post, och apotek, dvs ställen som är viktiga att kunna ta sig till för att självständigt klara vardagen. Andra ställen som ansågs viktiga var t ex. sporthall och studiecirkellokal, ställen där man ofta upplever gemenskap med andra dvs delaktighet.

Olika sätt att uppleva delaktighet fördjupades i delstudie två. Djupintervjuer med fokus på de allra äldstas upplevelse av delaktighet i hemmet och den närmsta omgivningen genomfördes. Deltagarna beskrev att de upplevde delaktighet genom att känna att de var en del i ett större sammanhang. Hemmet visade sig vara mycket centralt och så länge delaktighet i aktiviteter upplevdes både utanför och i hemmet fungerade det som utgångspunkt. Ju mer deltagarna kände sig begränsade till hemmet pga sviktande hälsa, desto mer förändrades upplevelsen av delaktighet – från att uppleva delaktighet genom att aktivt delta i olika aktiviteter till att uppleva delaktighet genom att inta rollen som åskådare. I denna process växte hemmet fram som den fasta punkten för delaktighet i dagliga livet. Ur djupintervjuerna växte två dimensioner av delaktighet fram: Utförandeorienterad delaktighet och Samhörighetsorienterad delaktighet. Utförandeorienterad delaktighet



upplevdes tex i samband med att man hjälpte till med något. Det kunde vara att ha ansvar för nycklarna till studiecirkellokalen eller att hjälpa grannen att handla. Det var dock viktigt att aktiviteterna utfördes med sådan kvalitet att det tillfredsställde de äldre själva. Den andra dimensionen, Samhörighetsorienterad delaktighet, upplevdes genom att känna samhörighet och gemenskap och att dela upplevelser med andra. Detta skedde dels på en aktiv nivå, som i att träffa familj och vänner eller delta i olika gruppaktiviteter, dels på en mer passiv nivå genom att befinna sig bland andra människor utanför hemmet utan att direkt interagera med dem. Samhörighetsorienterad delaktighet upplevdes dessutom genom intressen såsom att följa yngre generationers liv och leverne. De yngres intressen gjorde att de äldre upplevde sig vara en del av ett större sammanhang och fungerade således som en länk till världen utanför hemmet.

Delstudie tre baserades också på djupintervjuer och hade till syfte att fördjupa kunskapen om de allra äldstas upplevelse av självständighet i relation till hemmiljön. Hemmet visade sig vara starkt sammanlänkat med upplevelsen av självständighet och att vara självständig var högt värderat. Självständighet beskrevs av deltagarna dels som en ständig strävan att klara det dagliga livet, dels som vikten av att ha möjlighet att styra och bestämma över sin vardag. Synen på självständighet förändrades, från att klara sig själv utan hjälp från andra till möjligheten att ta beslut och ha inflytande över det dagliga livet, även om det innebar att man var beroende av andra. Så länge deltagarna upplevde att de hade möjlighet att vara med och fatta beslut om tex mat och dryck, toalettbesök och promenader beskrev de sig själva som självständiga. Resultaten indikerar att självständighet är ett komplext begrepp och att de allra äldstas syn på självständighet tangerar autonomiprincipen. Autonomiprincipen innebär att man har möjlighet att vara med och fatta beslut som rör det egna livet. Att vara beroende av någon annan

borde inte behöva innebära att man fråntas sin valfrihet och inte heller ens rätt att vara med och fatta beslut inom ramen för vad man faktiskt kan besluta om.

Syftet med delstudie fyra var att undersöka huruvida det var möjligt att i ett stort data-material finna variabler som representerade de två dimensionerna av delaktighet som framkommit i delstudie två samt att statistiskt verifiera dem. Ytterligare ett syfte var att undersöka hur de två dimensionerna av delaktighet var relaterade till de allra äldstas syn på hemmet och närmiljön. Resultaten verifierade de två dimensionerna av delaktighet statistiskt. När det gäller förhållandet mellan delaktighet och olika delar av hemmiljön och den närmsta omgivningen visade det sig att Samhörighetsorienterad delaktighet framförallt upplevdes av dem som bodde nära släkt och vänner och/eller hade tillgång till lokala kommunikationer. Lägre grad av Samhörighetsorienterad delaktighet återfanns bland dem som uppgav att det kulturella utbudet i närmiljön var magert. Att bo nära släkt och vänner hade också betydelse för Utförandeorienterad delaktighet. Att uppfatta det egna hemmet som användbart var också av betydelse, dvs de som bodde nära släkt och vänner och i en miljö som upplevdes användbar hade också lättare för att hjälpa till med barnpassning, lättare trädgårdsarbete, matlagning, etc.

Sammanfattningsvis visade sig hemmet vara mycket betydelsefullt för de allra äldstas upplevelser av delaktighet och självständighet, på många olika sätt. I mötet med de allra äldsta räcker det inte med vetskap om deras olika förutsättningar och förmågor och vilka åtgärder som behöver göras. När man inte längre har kapacitet att utföra saker utan hjälp från andra behöver man för bibehållen känsla av både delaktighet och självständighet, ha möjlighet att ta egna beslut när det gäller den egna vardagen. Det finns betydande insatser att göra för att de allra äldsta ska kunna leva ett aktivt och så självständigt liv som möjligt, inte bara i hemmet utan också i andra miljöer

där äldre vill utföra sina vardagliga aktiviteter. Med tanke på att insatser inom kommunal arbetsterapi till största delen fokuserar på äldres bostäder är det viktigt att öka medvetenheten om på vilka sätt delaktighet och självständighet upplevs bland de allra äldsta. Denna avhandling visar att både hemmet och närmiljön

är viktiga aktivitetsarenor bland de allra äldsta. I förebyggande och hälsofrämjande arbete som syftar till att främja ett självständigt, autonomt liv bland de allra äldsta är det en stor utmaning att utvidga insatser inom kommunal rehabilitering till att inte bara gälla hemmet utan även samhället i stort.

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