CASE Graduate School

Doctoral and Licentiate Graduates 2007-2017

and Current Graduate Students
# Table of Contents

**Preface** .................................................................................................................................................. 3

**Doctoral Graduates  2007-2017** ............................................................................................................. 5
  - Charlotte Löfqvist ................................................................................................................................. 7
  - Eva Månsson Lexell ............................................................................................................................... 8
  - Hanna Wennberg .................................................................................................................................... 9
  - Henrik Ekström ....................................................................................................................................... 10
  - Björn Slaug ............................................................................................................................................ 11
  - Nina Waara .......................................................................................................................................... 12
  - Tina Helle ............................................................................................................................................ 13
  - Vanessa Stjernborg .............................................................................................................................. 14
  - Maria Söderberg .................................................................................................................................. 15
  - Cecilia Pettersson ................................................................................................................................ 16
  - Marianne Kylberg ............................................................................................................................... 17
  - Marianne Granbom .............................................................................................................................. 18
  - Cecilia Winberg ................................................................................................................................... 19
  - Terje Sund ........................................................................................................................................... 20
  - Björg Thordardottir ............................................................................................................................ 21
  - Berglind Hallgrimsdottir ..................................................................................................................... 22
  - Stina Jonasson ...................................................................................................................................... 23
  - Sophie Jörgensen .................................................................................................................................. 24

**Licentiate Graduates  2007-2017** ......................................................................................................... 25
  - Kerstin Wendel .................................................................................................................................... 27
  - Jenny Rosenkvist ................................................................................................................................... 28
  - Emma Newman ..................................................................................................................................... 29

**Current Graduate Students** ................................................................................................................ 31
  - Emma Carlstedt ..................................................................................................................................... 33
  - Anna Norlander .................................................................................................................................... 34
  - Lizette Norin ......................................................................................................................................... 35
  - Maya Kylén ........................................................................................................................................... 36
  - Manzur Kader ...................................................................................................................................... 37
  - Jean Ryan ............................................................................................................................................. 38
  - Kristina Rosqvist ................................................................................................................................. 39
Preface

One of the goals stated for the Centre for Ageing and Supportive Environments (CASE) for the 10-year funding period starting in 2007 was to train future scholars with excellent skills for interdisciplinary user-oriented research, well trained in a creative research context and prepared to initiate and take part in qualified national and international research activities. This leaflet is a compilation of doctoral and licentiate graduates and current PhD students affiliated with CASE Graduate School.

Facing the fastest increase of population ageing ever, it is of utmost importance to train scientists with knowledge on ageing and supportive environments and strong skills for interaction with practice contexts and society at large. Fostering competence for interdisciplinary research, all PhD students at CASE are supervised by interdisciplinary teams of senior and junior scholars. Summarizing our achievements during 2007-2017, 18 PhDs and three licentiates have successfully defended their degrees, and seven PhD students are currently working on their dissertations.

Summarizing the CASE track record in graduate education, we are very grateful to the main funder of CASE – the Swedish Research Council for Health, Working Life and Welfare (Forte). Other important funders are the Faculties of Engineering, Medicine (including the Strategic Research Area of Neuroscience, MultiPark) and Social Sciences at Lund University, and the Ribbingska Foundation. In addition, we are thankful to many different funders contributing to the wide range of PhD student projects presented.

Thanks also to the vast array of colleagues – at Lund University as well as other universities in Sweden and abroad – acting as co-supervisors and/or co-authors in the publications presented in the PhD dissertations, or members in CASE Scientific Advisory Boards.

Lund University, September 2017

Professor Susanne Iwarsson
Director of CASE
Doctoral Graduates 2007-2017
Charlotte Löfqvist
Reg. Occupational Therapist

PhD defence: 26 September 2008
Health Sciences
charlotte.lofqvist@med.lu.se

Doctoral Thesis
Mobility Devices in Everyday Life among Very Old Europeans: Aspects of Use and Changes over Time.
Department of Health Sciences,
Faculty of Medicine, Lund University

The aim of this thesis was to expand the knowledge regarding the use and need of assistive devices, in particular mobility devices, and to investigate how, from a European perspective, the use of them changed during the ageing process. An additional aim was to explore the use of mobility devices in everyday life among very old Swedish women during a five-year period. Further, the aim was to contribute to methodological development with regard to assistive device interventions and to investigate the basic psychometric proprieties of a new instrument for evaluating mobility-related participation. This thesis was based on two research projects; the ENABLE-AGE Project and the Nordic Assisted Mobility Evaluation Project (NAME). The results of this thesis give an overview of the situation regarding assistive devices across five European countries: Sweden, Germany, the United Kingdom, Hungary and Latvia. Cross-national analyses show that the proportion of users, as well as the number of assistive devices in use per person, varied among the five European samples included. Overall, a higher proportion of very old people in the West European countries used assistive devices when compared to people in the East European countries. The use of mobility devices increased over a short period of time, this was most prominent in the Western European countries, and moreover the pattern of use changed during the one year study period. The findings in this thesis also highlight the heterogeneity and complexity of being a mobility device user at a very old age. The case study revealed that for three Swedish women the use of mobility devices impacted on activity and participation aspects, such as domestic work, shopping and socialising, during the ageing process, in complex and dynamic person-environment-activity transactions. In particular rollators were found to offer support for both transportation and activity performance. Further, the findings showed that complementary use of, e.g. a walking stick or walking frame, in different situations, enabled these women to manage everyday activities in spite of their functional limitations which were increasing over time. As to methodology contribution, an outcome assessment instrument, The Nordic Mobility-Related Participation Outcome Evaluation on Assistive Devices (NOMO 1.0), is presented. The instrument has a novel approach to outcome evaluation, targeting mobility-related participation outcomes after mobility device interventions. In addition this thesis contributed to theoretical development as regards assistive device research. Overall, the knowledge generated is relevant to support optimisation of mobility device use along the ageing process. From a European perspective, the findings give implications for future policy-making, planning and organisation of health care and social services, including provision of assistive devices and advancing occupational therapy practice across Europe.
The overall aim of this thesis was to increase our knowledge of engagement in occupations in persons with Multiple Sclerosis (MS) in order to develop client-centred occupational therapy and rehabilitation. In study I, observations of the performance of self-care and household occupations were pursued in 44 participants, and study II identified self-perceived problems in performance of occupations in 47 participants. In studies III and IV, in-depth interviews with ten participants revealed experiences related to engagement in occupations and to the process of adaptation of engagement in occupations. The results showed that persons with MS can perceive problems related to all areas of occupations, and at different hierarchical levels. They can be dissatisfied with performance in occupations, especially related to self-care and household occupations and observational assessments confirm that performance in these occupations is impacted on. Furthermore, they can be independent in self-care but dependent in household occupations, and can have problems in their performance regardless of their age, disease severity, or their living arrangements. They can experience that they need to struggle continuously to manage occupations, and that this changes them as a person and make them live their lives differently than they had anticipated. In addition, they experience their adaptation of engagement in occupations as an ongoing, non-linear process, involving both themselves and their family, and they consider who would benefit the most, before they choose their adaptation of engagement in occupations. In summary, this thesis has shown that engagement in occupations in persons with MS is a complex phenomenon. All areas of occupations can be affected, and need to be addressed within occupational therapy and rehabilitation. Clients’ own experiences needs to be elucidated in order to facilitate the reconstruction of self, identity and support the process of adaptation of occupations.
Accessibility throughout society has been gaining interest on both international and national levels in order to meet the transportation needs of, for example, older people as pedestrians. The overall aim of this thesis is to examine the implementation process in municipal planning, and effects of measures taken, to achieve barrier-free outdoor environments the year round. Older peoples’ perceptions as pedestrians in terms of usability, mobility, and perceived safety, as well as municipal employees’ views, contribute to the findings presented. A mixed-method approach is applied involving qualitative (interviews, focus group interviews, and participant observations) and quantitative (questionnaires) studies, which are conducted before and after measures to improve accessibility in both bare-ground and snow/ice conditions are implemented. An index, developed within this thesis, shows a large variation in the implementation process concerning accessibility among Swedish municipalities. Thus, there is still much to do to accomplish a society accessible to all citizens. Knowing which measures to prioritise will likely benefit the implementation process. This thesis shows only minor effects of the implemented measures though. Nevertheless, difficulties reported in walking due to physical barriers have in fact decreased. In conclusion, removal of physical barriers the year round have potential for encouraging walking in old age, especially among older people with functional limitations and mobility devices. A travel-chain perspective on accessibility is essential though involving removal of physical barriers from indoor to outdoor environments, from one transport mode to another, from public to residential areas. Older peoples’ needs as pedestrians are not completely fulfilled by current legislative directives on accessibility (BFS 2003:19 HIN1), which calls for a focus on other issues as well, e.g. problems with bicycles and cyclists on pavements and footpaths as well as the need for benches to rest on. In snow/ice conditions, it concerns improved ice prevention and snow removal, especially snow removal on detailed level. Safety/security-related issues are important as well; however, barrier-free environments are to be considered as a basic precondition for peoples’ ability to use an environment at all. In the end, this thesis has implications for further research and for policy/planning at different levels in society.
The aims of this thesis were to study the association between functional impairment due to pain, and activity expressed as walking speed (WS) and Timed Get up and-Go (TUG), and to examine the associations between functional impairment and social participation (SP) and quality of life (QoL). The thesis comprised four studies. In study I activity 3 years after trauma and stratified for pain was examined. For fractured, both with and without pain, higher WS was noted for subjects with the last fracture more than 3 years ago compared to subjects fractured less than 3 years ago. The median time for fractured in pain and a trauma more than 3 years ago walking 15m at a self selected speed was 14 s compared to 20 s (p = 0.04) for subjects in pain and fractured less than 3 years ago. Both fracture and pain independently explained levels of WS. In study II the association between functional impairment and SP and QoL was investigated. QoL included Life satisfaction index A (LSI-A) and SF-12 consisting of a mental component (MCS) and a physical component (PCS). Fractured with and without pain were compared to non-fractured controls and in 12 out of 21 activities fewer fractured in pain took part compared to controls. Regarding QoL, fractured in pain scored lower for MCS, PCS and LSI-A, compared to controls. In study III the association between WS, TUG and QoL and SP was examined. In a logistic regression model adjusting for confounders, significant associations remained between SP and WS, TUG where an increased probability of taking part increased with a faster performance. In study IV the extent of SP due to formal and/or informal care was examined. Adjusted odds ratios for SP using non support as a reference, showed that subjects with informal support did not have a lower probability for participating while subjects with informal and/or formal support had a significant lower probability for SP. In conclusion, fractured with and without pain a limitation in WS was observed up to three years after trauma suggesting that there is rehabilitation potential the first years after fracture. A health condition with fracture and a functional impairment due to pain, or a deterioration WS or TUG are associated with a restriction in SP and a lowered QoL. The results also substantiate the influence of informal support i.e. care given by relatives and friends have decisive influence to maintain SP and thereby an active lifestyle.
To improve population health, it is important to create environments that support activity, participation and health. One crucial aspect concerns the degree to which the built environment is accessible for all people including those with reduced functional capacity. The overarching objective of this thesis was to explore and further develop methodology for accessibility assessments based on the notion of person-environment fit. Type profiles that represent groups characterized by their combinations of functional limitations were explored as an approach to analyze accessibility problems at the group level. To support societal planning and decision procedures, basic simulated accessibility analyses were conducted as a method to identify different sets of housing improvement priorities that are applicable for groups with different functional capacity. Sixty-one core environmental barriers in terms of accessibility problem detection were identified. This represented a preliminary version of an accessibility screening tool, which can be efficient for research and policy interventions focusing on accessibility. Based on a conceptual analysis, techniques for statistically analyzing the variation of agreement data were explored. This approach can identify the most influential sources of disagreement. Finally, a typology of person-environment fit constellations was constructed, which will thereby facilitate an extension of the methodology for accessibility assessments that are applicable in different environmental arenas. The results of this thesis have implications for further research related to the development of tools and methods that can ultimately support societal efforts in achieving a built environment that is accessible for all citizens, regardless of functional capacity.
Traveller information designed to fulfil needs and expectations of individual travellers is a key factor in improving access for older people and people with disabilities to public transport. The overall aim of this thesis is to contribute to the knowledge of user and provider perspectives on the provision of traveller information for older people and people with disabilities in public transport with a focus on use and provision of such traveller information through online traveller information services. The research work is based on perceptions of older people and people with disabilities, together with experts’ views on the implementation process. Both qualitative methods (interviews, focus group interviews, group discussions, workshops) and quantitative methods (questionnaires) were used. The substantial influence on the travel of older people and people with disabilities of use of online traveller information services is the empowerment of those of the older travellers and travellers with disabilities that are anxious and insecure before a journey. Through better access of traveller information offered by online traveller information services these travellers can find what they need to build their confidence before a journey and subsequently be supported in their roles as travellers. That is, when they do travel in public transport they want to be able to do so safely and with confidence; they do not necessarily want to increase the number of journeys they undertake. Thus, theoretically the concept of motility has higher relevance for this particular group of travellers than the concept of mobility. The exploration of the traveller information content shows that even though the need to plan and prepare for a journey seems to be equally important for the whole group of older people and people with disabilities as it is for subgroups based on functional limitations, the importance and the intended use of the traveller information differ between groups as the focus shifts from comfort information on an aggregated level to an increasing importance of accessibility information for subgroups. Both the comfort information and the absolute information enable assessment of the effort required to carry through a journey. This is decisive for the choice to travel, but the traveller information focused on comfort relates more to the individual choice to travel while absolute traveller information enables the traveller to assess whether travel is possible at all. Finally, to be accessed the traveller information needed by older people and people with disabilities need to be implemented. The inertia of the implementation process was explored through conflicts of interest that can help forward barriers in the implementation process. The findings point to there being a verbal problem in policies, legislation and guidelines that leave room for interpretation of the necessity of implementation of measures like traveller information needed by older people and people with disabilities. Finally this thesis carries implications for further research within all three areas that have been researched.
Older people have more functional limitations than younger people and they form a segment of the population that is more dependent on mobility devices than other age groups. Since they spend most of their time at home, their dwelling is an important environmental arena for performing everyday activities. Barriers in the environment can limit or hinder activity performance. Therefore, older people are sensitive to the accessibility of the environment. To ensure housing accessibility, it is critical that professionals are provided with valid and reliable assessment instruments to identify accessibility problems before the planning of housing intervention strategies. It is also critical that housing standards addressing accessibility intended to accommodate people with functional limitations are valid in the sense that their definitions truly support accessibility. However, there is a paucity of valid and reliable assessment instruments targeting housing accessibility, and in-depth analysis of factors potentially impacting on reliability in complex assessment situations is remarkably absent. Moreover, the knowledge base informing the housing standards appears to be vague. We may therefore reasonably question the validity of the housing standards addressing accessibility. This thesis addresses housing accessibility methodology in general and the reliability of assessment and the validity of standards targeting older people with functional limitations and a dependence on mobility devices in particular. The overarching aim of the thesis was to develop and explore methods applicable for improving housing accessibility assessments and to explore feasible approaches to create housing standards that truly support accessibility and accommodate older people. A main methodological contribution of the present thesis is the development of the content-valid Nordic HE instrument which is deemed sufficiently reliable in Nordic countries, and the recommendations for in-depth examination of inter-rater agreement for the improvement of reliability. A second main contribution of the present thesis is that it explores the consequences of the housing standard definitions in terms of accessibility and provides estimates of the proportion of dwellings considered accessible and the proportion of persons defined as having accessibility problems. Collectively, these results have the potential to improve and influence research, practice and policy in a global context for the benefit of the health and well-being of older people with functional limitations. Moreover, the results provide new knowledge and invite reflections on central concepts and methodology relevant to psychometrics and research on person-environment fit.
Vanessa Stjernborg  
MSc Human Geography  

PhD defence: 11 April 2014  
Transport and Roads  
vanessa.stjernborg@mah.se  

Doctoral Thesis  
Outdoor Mobility, Place and Older People - Everyday Mobilities in later Life in a Swedish Neighbourhood.  
Department of Technology and Society,  
Faculty of Engineering, Lund University  

The overall aim of this thesis is to offer an understanding of everyday mobilities outdoors among older persons from a place- and context-dependent perspective. The emphasis is to take a gentle approach towards an overall perspective with consideration to physical aspects (like the home neighbourhood), social aspects (like social networks and social participation) and mental aspects (like place images, mental maps and fear of crime). The thesis builds on three different studies with a mixed method approach that have resulted in five papers. Two of the studies are qualitative and were conducted in two neighbourhoods in Malmö city, in southern Sweden. The first neighbourhood is a disadvantaged inner-city neighbourhood, which has been highly exposed in mass media. This ethnographical case study includes a critical discourse analysis of newspaper articles, observations, ‘travel-alongs’ and interviews with senior participants of a senior group in the neighbourhood. The study focuses on issues such as fear of crime, social participation and wellbeing in the light of everyday mobilities in later life. The second study, a case study, focuses on the everyday mobilities of older people in a suburb, with longitudinal interviews and time-geographical diaries. The third study is a quantitative study focusing on changes in outdoor mobility. This study is based on a sample of older people in the transition from a two-person household to a single-person household from a questionnaire that went out to households in both Skåne county and Östergötland county in Sweden. Results from the first study show that social participation and social networking in the neighbourhood have positive effects on everyday mobility and fostering positive effects on neighbourhood development. Thus, avoidance and protective behaviour among the seniors occur because of fear of crime, implying restrictions in everyday life mobility. However, social participation in the form of being a part of the senior group and knowing people in the neighbourhood seems to have a salutary effect on fear of crime and a commendatory effect on everyday life mobility. The results from study two show a pronounced dependence on car use. Representations of suburbia - as places of freedom, independence and mobility enabled by private cars - devolve into a harsh reality, i.e. disabling lock-in effects for people gradually losing locomotion, and experiencing diminishing mobility capital and social intercourse. Finally, in the third study the results suggest that society must put more effort into offering good walking conditions, since a) walking seems to be the most important mode of transport for outdoor mobility in this case and b) walking is valued almost as high as a car after becoming alone in the household regardless of whether the population in our study reported unchanged, decreased or increased mobility.
Many older people express strong preferences to remain in their own housing as long as possible. Due to declining health they may, however, become dependent on others for their daily care, eventually reaching a point where they consider relocation to a residential home. The overall aim of the dissertation is to reveal the process preceding older people’s potential relocation from ordinary housing to a residential home in a societal context, and to study how older people, their family members and care managers experience and describe the process individually and in relation to each other. The first article of the dissertation is based on older people’s perspective, the second on family members’ perspective, and the third on the care managers’ perspective. In the fourth article a theoretical model is used in order to focus on why the care managers tend to apply a restrictive approach in their occupational exercise. An analysis based on a holistic perspective is presented in the introductory chapter of the compilation thesis. To try to understand what happens when older people consider relocation from ordinary housing to a residential home, various theoretical approaches have been applied. Altogether 21 older people, 17 family members, and seven care managers have contributed to the empirical material, mainly in interviews. From a holistic perspective, attention is drawn to expressions of “consideration” as a prominent feature in the process when older people’s potential relocation to a residential home comes to the fore. As a result, different expressions of consideration reveal that those involved use the ideals of older people’s independence and self-determination in order to justify personal actions and attitudes. By consideration, nobody is prepared to take the full responsibility for the decision, and instead the responsibility for a potential relocation decision is located at somebody or something else. The ideals of an older person’s independence and self-determination are promoted, at the same time as the application of these ideals in reality becomes significantly limited, like in “paradoxes of consideration”.
This thesis elucidates the use of powered mobility devices in a Swedish context. The overall aim was to increase and deepen the knowledge on powered mobility device use in relation to participation and accessibility in different environments and among different user groups, with a specific focus on independence and autonomy. An additional aim was to contribute to the knowledge base regarding the optimization of use of such devices. The thesis is based on four studies in which different research approaches were applied through the combination of different types of data in order to interpret the complexity of powered mobility device use. Quantitative, qualitative and mixed methods were utilized. The first study was a prospective cohort study in which data was collected using structured interviews at baseline and two follow-ups. The second study was an exploratory multiple longitudinal case study. A focus-group methodology with a descriptive design was used in the third study. The fourth study was a cross-sectional study based on survey data collected from people with spinal cord injury. The main contribution of the studies that constitute the empirical basis of this thesis is that the purpose of providing people with powered mobility devices is mostly fulfilled in that such devices provide their users’ with greater opportunities for participation. Nevertheless, there are also problems in terms of accessibility in various environmental arenas that have an impact on mobility. An additional important contribution is that the results show that the experiences of users of powered mobility devices should be taken seriously as they convey different aspects of how the use of such devices could be optimized. In conclusion, this thesis contributes to our understanding of the use of powered mobility devices and has the potential to optimize independence in terms of mobility and participation among users of such devices. Finally, the results have practical implications for occupational therapy in the provision of powered mobility devices. Likewise, this new knowledge about the needs of powered mobility device users in terms of accessibility are of importance to politicians, professionals and other stakeholders engaged in housing provision and physical planning.
The overarching aim of this thesis was to contribute to the existing knowledge on the use of assistive devices in everyday life, by adding the perspective of very old single living people in a European context, namely Latvia and Sweden. The aim was to investigate the socio-demographics and environmental and health aspects that impact on device use in the two national contexts. A further aim was to explore the prerequisites for use according to different aspects of the physical and institutional environment. The thesis builds on four studies in which a variety of study designs have been employed. The data derived partly from a European project on home and health – the ENABLE-AGE Project – and additional data were collected for two of the studies. Quantitative data from the Latvian and Swedish sub-samples of the ENABLE-AGE Survey Study comprising well-established instruments and study-specific questionnaires designed to capture objective and subjective aspects of home and health were used (Study I, II, IV), and additional qualitative interview data were collected through semi-structured interviews in Latvia (Study III) and Sweden (Study II, III). Study I: In a Swedish subsample no differences were seen between users and non-users of assistive devices according to socio-demographic or environmental variables at baseline or follow-up. The significant differences seen were related to aspects of health. The number of users increased over the study period and barriers in the outdoor environment turned out to predict use of mobility devices. Study II: In a Swedish subsample of three very old men using mobility devices, it was shown that the social and physical environment impacted on device use. Well-designed devices facilitated device use, while poor street conditions, crowded public transports and bad weather hampered mobility device use. Study III: Both differences and similarities were shown between Latvia and Sweden regarding the organisation and operationalization of the national service delivery systems for assistive technology. The utilisation of professional competences and national financial circumstances affected very old people’s opportunities to be provided with assistive devices. Study IV: In Latvian and Swedish subsamples, national differences were seen in number and type of reported leisure activities outside the home. Differences were also seen for the number of activities reported between users and non-users of mobility devices in relation to their self-rated physical mobility. Conclusion: The use of assistive devices increases with age and supports very old people in everyday life activities, even though there are differences between Latvia and Sweden. In order to ensure equal opportunities for activity and participation for very old people across Europe, it is important to understand what lies behind personal and environmental prerequisites for the use of assistive devices within as well as between countries.
Introduction: Moving in very old age is considered to be a major life event and relocation and access to appropriate housing options is a hot topic in the public debate across Europe. For very old people, the decision-making process and aspects influencing relocation is not well studied. Occupational therapy interventions mainly focus on ageing-in-place solutions when aiming for independence and well-being for older people. Although theoretically, relocation can be seen as a major form of environmental adaptation that helps counter aspects of age-related functional decline. Aims: The aim was to expand and deepen the knowledge on relocation in very old age in two Western European countries (Sweden and Germany). With a focus on person-environment relations concerning housing and health, predictors and consequences of relocation were explored. Also, residential decision-making was explored with focus on how very old people reason about their home and everyday life in relation to relocation and ageing-in-place. Methods & Results: The thesis is based on the Swedish (studies I to IV) and German (studies III and IV) parts of the ENABLE-AGE Project. At baseline, the participants were 80-89 years old and lived alone in ordinary housing. In study I (N=384), Cox regression models showed dependence in cleaning but perceived functional independence when living in a one-family house predict a move within the ordinary housing stock. Dependence in cooking and cognitive deficits in combination with accessibility problems predicted a move to special housing. After relocation to another dwelling in the ordinary housing stock (N=29) the number of environmental barriers in the new dwelling were fewer than in the former (study II). Usability and accessibility were stable comparing former and new dwellings. Analyses of in-depth interviews of 80 participants in 2002 (study III) and 16 participants in 2003 and 2011 (study IV) revealed ambivalence between moving and ageing-in-place to arise along with increasing problems in everyday life. The findings supported the use of residential reasoning as a concept describing older peoples reasoning on relocation and ageing-in-place as one intertwined topic. Conclusions: The findings contribute to the knowledgebase on relocation in very old age, with practical implications for very old people and their families, occupational therapists and other professionals and for societal planning at large. The knowledge can be used as a first step in designing counselling services to help deal with very old people’s ambivalence and to guide in their decision-making processes. Further, having the potential to integrate theoretical perspectives from different disciplines to enhance our understanding on residential decision-making in old age, theoretical development on the concept residential reasoning is needed.
Physical activity is beneficial for the health of persons with disabilities but the levels of such activity are lower than for persons without disability. In addition the level of physical activity decreases with increasing age. For persons aging with a disability it may be a challenge to engage in physical activity, partly because of the disability and partly because of contextual barriers. One group of persons aging with a disability is those with late effects of polio. The latter are recommended being physically active with respect to their impairments and activity limitations but there is very limited knowledge regarding their engagement in physical activity and related factors.

The overall aim of this thesis was to increase knowledge about PA in ambulatory persons with late effects of polio by describing PA, assessing the relationships between PA and impairments, activity limitations, participation restrictions and life satisfaction, and furthermore by exploring perceptions of PA. The 81 participants had a confirmed history of acute poliomyelitis affecting the lower limbs, and were between 50 and 80 years of age. In the first study physical activity was analysed by self-report (The Physical Activity and Disability Survey) and by a pedometer. In the second and third study impairments, activity limitations and participation restrictions common in this population were assessed. The fourth study was qualitative and 15 participants were individually interviewed regarding their perception of physical activity and the personal and environmental factors related to physical activity. The results showed that the participants were physically active on average three hours per day, mostly in low-level intensity activities and walked on average 6212 steps per day. The amount of PA varied considerably between the participants. There was a positive association between physical activity and life satisfaction. Physical activity was associated with impairments (knee muscle strength and self-reported impairments), activity limitations and participation restrictions (gait performance, self-reported limitations in walking and fear of falling). The variance in physical activity was moderately explained by the assessed impairments, activity limitations and participation restrictions. Overall the participants had a positive perception of physical activity but multiple factors affected them in their effort to perform PA. The participants described aspects that were closely related to the late effects of polio, such as specific impairments, changes in physical activity over time, past experiences, and contextual barriers. Persons with late effects of polio want to be physically active but may need assistance in order to be able to create suitable strategies for minimizing the impact of their impairments, to prioritize and to change aspects of performance. These results could assist health care professionals in guiding this group to achieve or maintain an active and healthy lifestyle.
This thesis has contributed to the methodological development in the field of assistive technology and has generated new knowledge about the effectiveness and the service delivery process when powered mobility devices are provided to adult first time users in a Nordic context. Some of the results have been used to investigate the relationship between the three key elements of Donabedian’s conceptual model when scooters are provided to users from two Nordic countries, Denmark and Norway. As most of the results from the psychometric testing of the SATS and NOMO 1.0 were above the recommended levels, both instruments can be reliably administered in studies among adult users of powered mobility devices in Nordic context. The factor analysis of the need for assistance and frequency scales of the NOMO 1.0 identified unidimensionality for the first scale and multidimensionality for the other. However, further psychometric testing is required for the NOMO 1.0 regarding the validity. As for the SATS, the instrument needs to go through a basic investigation of its validity. There is a need to consider the wording of the items in order to avoid, for example, double-barrel questions. A factor analysis should be carried out in order to establish the dimensionality and to see if there is a need for item reduction. In other words, a revision of the instrument is needed. Concerning the NOMO 1.0, (further validity studies) a confirmatory factor analysis is needed. Reliability and validity studies are needed for the study-specific questionnaires used in the SATS study. All three instruments need to be psychometrically tested in other user groups of assistive devices than powered mobility devices and in other cultures than the Nordic countries. Supporting previous research, this thesis showed that the powered mobility device interventions increase mobility-related participation in daily life among adult users in a Nordic context. Mobility became easier for several aspects, and buying groceries and go for a walk/ride were carried out more frequently. Men, scooter users, and users with poor self-reported health seem to benefit the most from the interventions. Assessments and administrative work were accomplished in almost all the cases, while the other steps of the service delivery process were carried out to a various degree when scooters were provided to users in Denmark and Norway. More time was spent on assessments, administration and total time in the Danish sample. The user satisfaction with different aspects of the service delivery process was high. However, there was no association between time spent in the service delivery process and use satisfaction and effectiveness. The finding that there were differences in time spent on the service delivery process between samples from two countries with structural differences confirm the assumption that structure of the services predicts the time spent in the service delivery process. Different rules regulating the area seem to be an important explanation for the time differences. The expected association between the structure, the time spent in the service delivery process and the outcomes in terms of user satisfaction with the service delivery process and effectiveness was not found.
The aim of this thesis was to contribute to the understanding of aspects related to home, health and participation for community living people with disability and identify different groups with different needs for interventions. Study I used focus groups to explore aspects of importance for participation. Twenty-nine people with Parkinson’s Disease participated in nine focus groups. Studies II-III utilized baseline data from an ongoing study among people applying for housing adaptations in southern Swedish municipalities. Study II investigated personal, environmental, and activity-related factors linked to participation frequency and satisfaction among 128 housing adaptation clients. Study III investigated differences in participation frequency, participation satisfaction and self-rated health between groups of housing adaptation applicants. Study IV utilized interview data and study specific questions in longitudinal mixed-method design to explore experiences of participation before and after a housing adaptation. Study I revealed that participation was experienced in a variety of situations in a complex context of home and community. Study II showed that frequency of participation had a strong association with gender, cognitive impairments and dependence in ADL while satisfaction with participation had a strong association with age, usability aspects and self-rated health. Study III identified six heterogeneous groups, differing in terms of age, ADL dependence, functional limitations, cognitive impairments, concerns about falling and usability of the home, that also showed significant differences in participation and self-rated health. In Study IV, an overall theme of struggling with participation towards satisfaction with participation emerged and revealed how the participants experienced their participation on a continuum. The findings provide insights into how participation inside and outside the home, with others or alone is related to the person, the environment, and the performance of activities. This speaks to the importance of being observant of the different aspects of restrictions to participation for each individual, especially as disability often progresses over time.
The overall aim of this thesis is to explore how the societal challenge of removing environmental barriers in the outdoor environment has been met in Sweden and how removing environmental barriers can affect the user perception of the outdoor environment. The thesis comprises two studies, the Municipality Study and the User Study. The Municipality Study explores implementation of accessibility policy in municipal transport planning. The implementation process is explored through the eyes of municipal transport planners, with a mixed-method approach. The process of implementation of accessibility policy is explored in a longitudinal perspective. The user perception of the outdoor environment, the User Study, is explored through the eyes of older people. The study is based on a previously executed study, where an intervention was carried out in one neighbourhood in a middlesized town in Sweden. The User Study explores impact of an intervention on older people perception of the outdoor environment in a cross-sectional and longitudinal perspective. Results indicate that interventions in the outdoor environment facilitate walking for older people, even as they age. However, results also indicate that some municipalities are not working as actively as they should towards accessible outdoor environment. Some municipalities reduce their efforts as they perceive they have met the requirements of accessibility policy. Municipalities have reduced cooperation with interest organisations, which can only be considered as a regression in implementation of accessibility policy. This especially applies in light of results from the User Study. The user involvement in the User Study resulted in improved perception of the outdoor environment, even in a longitudinal perspective. Therefore, municipalities should cooperate with interest organisation in order to implement successful accessibility measures. Furthermore, municipal employees and politicians should understand that accessible outdoor environment will not be achieved with selective measures. Accessibility measures have to have good maintenance and be evaluated on regular basis. In conclusion, an environment designed to facilitate walking for people who are fragile, is an environment that is accessible for all. A person carrying luggage, a person with a pram, a person who is temporarily experiencing disability, but more importantly people who are experiencing long-term disability and limitations, all benefit from an accessible outdoor environment.
Stina Jonasson  
Reg. Physiotherapist  

**PhD defence:** 4 November 2016  
**Health Sciences**  
stina.jonasson@med.lu.se  

**Doctoral Thesis:**  
*Fear of falling in persons with Parkinson's disease.*  
Department of Health Sciences,  
Faculty of Medicine, Lund University.  
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 Fear of falling (FOF) is common in persons with Parkinson’s disease (PD) and may have large consequences on daily life, causing a sedentary lifestyle, social isolation and reduced quality of life. FOF is therefore an important aspect to consider for researchers as well as clinicians and the rehabilitation team. The overarching aim of this thesis was to increase the knowledge of how FOF can be assessed in persons with PD, as well as to expand and deepen the understanding of FOF in persons with PD in relation to explanatory factors and experiences. Four different FOF rating scales were analyzed in the first two studies. These were the Swedish version of the Falls Efficacy Scale (FES(S)), Falls Efficacy Scale-International (FES-I), Activities-specific Balance Confidence scale (ABC) and modified Survey of Activities and Fear of Falling in the Elderly (mSAFFE). The first study was a linking study in which the four FOF rating scales were linked to the International Classification of Functioning, Disability and Health (ICF). This study did not include any empirical data. The second study was a psychometric study, in which the four FOF rating scales were administered twice (test and retest) as a postal survey. This study included 102 participants (median age 74 years, median PD duration 5 years). The third study was a multivariable regression study, in which explanatory factors of FOF (conceptualized as concerns about falling) were explored, taking both PD-related disabilities, personal and environmental factors into consideration. This study included 241 participants (median age 70 years, median PD duration 8 years). The fourth study was a qualitative interview study which explored how persons with PD and FOF experienced their FOF. Interviews were conducted with twelve persons with PD (median age 70 years, median PD duration 9 years). The studies revealed that the vast majority of the items in the four FOF rating scales emphasized the ICF component of activities and participation. All four scales predominately focused on the chapter of mobility. This was especially the case for ABC, while the other scales were more diverse. The psychometric comparison revealed that ABC had markedly worse data completeness than the other scales, and FES(S) and ABC had more outliers when comparing the two test occasions. All four scales showed acceptable reliability, but FES-I was the only scale with a test-retest reliability that reached the suggested level for usage in individual comparisons. Several factors were significant (p < 0.05) explanatory factors of concerns about falling. Walking difficulties in everyday life were the strongest explanatory factor, followed by orthostatism, motor symptoms, age and fatigue. FOF affected the lives of the persons with PD and FOF in several ways. It was experienced as a disturbance in everyday life. FOF was a varying experience and different strategies were adopted to handle FOF. In conclusion, FES-I or mSAFFE are suggested for assessing FOF in people with PD. However, scale selection should consider the aspects of FOF that one wishes to address. Moreover, the results indicate that interventions targeting FOF need to be individually tailored for persons with PD and focus on several aspects, e.g., PD-related symptoms and disabilities, activities and environmental factors.
As a result of advances in healthcare and rehabilitation, many people with spinal cord injury (SCI) have lived several decades with their injury. Knowledge of living with long-term SCI into older age is limited, despite an increased focus on aging with SCI in research and clinical practice. The overarching aim of this thesis was to describe and understand the life situation of older adults with long-term SCI in southern Sweden, with a specific focus on secondary health conditions (SHCs), activity limitations, depressive symptoms, participation in leisure time physical activity (LTPA) and life satisfaction. This thesis is based on the first data collection of the Swedish Aging with Spinal Cord Injury Study (SASCIS), a longitudinal cohort study of persons aged 50 years or older and at least 10 years after SCI. Associations between variables were investigated using multivariable linear regression analyses. The 123 participants (36 women, 87 men) in the SASCIS had a mean age of 63 years and a mean time since injury of 24 years. Injury levels ranged from C1 to L5, with 62% traumatic injuries and 31% complete injuries. A large majority (88%) used mobility devices, 53% were living in a relationship and 35% were working full-time or part-time. Bowel-related and bladder-related problems were reported by 32% and 44%, respectively, and 44% reported spasticity. Two thirds experienced moderate to severe pain in everyday life. Activity limitations, (i.e., physical independence), were on average moderate. A higher level and more severe SCI and spasticity were significantly associated with more activity limitations, explaining 68% of the variance. A total of 5% were regarded as having probable depression and 29% had clinically relevant depressive symptoms. Sense of coherence (SOC), the coping strategy Acceptance, neuropathic pain and LTPA explained 53% of the variance in depressive symptoms. A stronger SOC was the strongest explanatory factor for fewer depressive symptoms. The on average strong SOC indicated favorable adjustment to living with SCI. Participation in LTPA was low and almost one third did not participate in any LTPA. Sociodemographics, injury characteristics and SHCs explained less than 14% of the variance in LTPA participation. The use of a powered mobility device exhibited the strongest association with less participation in LTPA. The participants rated their life satisfaction just above the midpoint between satisfied and dissatisfied with life. Sociodemographics, injury characteristics and SHCs explained 38% of the variance in life satisfaction, where having a partner was the strongest contributor to a high level of life satisfaction. In conclusion, older adults with long-term SCI in southern Sweden exhibit a relatively high level of physical independence, a low presence of probable depression, a strong SOC and are generally satisfied with their lives. Many do not reach the amount or intensity of LTPA to achieve fitness benefits, and more research is needed to identify modifiable factors that can enhance their participation in LTPA. In clinical practice, pain and depressive symptoms should be evaluated, and participation in LTPA assessed and encouraged. Measures that strengthen psychological resources, provide adequate pain management and encourage participation in LTPA may support mental health. The results serve as a starting point for an increased understanding of the life situation of older adults with long-term SCI in Sweden, and can be used to inform rehabilitation planning and provide routines for follow-up.
Licentiate Graduates  2007-2017
The thesis is part of a Swedish interdisciplinary research project targeting accessibility problems in public transport for people with Cognitive Functional Limitations (CFLs). A major goal for occupational therapy interventions and rehabilitation is to facilitate performance of desired activities in any domain in life, ultimately striving for societal participation. Access to and use of different modes of transport (car, motorbike, moped, bicycle, public transport, walking, Special Transport Service, STS) is of significant importance for gaining access to places outside the home. Public transport serves an important function, but for vulnerable groups of citizens, accessibility and usability problems affect the possibilities to perform activities beyond walking distance. To make public transport accessible and usable for all, the prerequisites and needs of vulnerable groups must be known and taken into account in future development. Stroke is a common diagnosis resulting in not only CFLs and physical functional limitations (PFLs) but also emotional effects. Thus people living in the community after stroke with sufficient mobility to be public transport users were in focus for this research. The two studies building up the thesis were based on a descriptive and explorative survey with a quantitative design, involving interviews, self-reports and professional assessments with 84 individuals 18-36 months post stroke and the spouses of a sub-sample (N=30). The aims were to study long-term functional limitations from different perspectives as well as changes in use of various modes of transport and possible relations between decreased/ceased use of public transport and PFLs or CFLs, depression, and social activity outside home. CFLs were frequent, whether professionally assessed, self-evaluated or spouse-reported. Self evaluations were mainly similar to the spouse-reports but expressed more CFLs in comparison to a part of the professional screening. Over one third of the participant who reported decreased/ceased use of public transport, also had significantly more CFLs, PFLs, depression and decreasing social activity, in comparison to those with unchanged or increased use. The use of own car or motorbike ceased post stroke, most often replaced by STS or travelling by private car or taxi as a passenger. Yet, more than one fourth were still frequent car drivers. The results emphasise the need for enhanced outdoor mobility intervention strategies in the sub-acute stroke phase, and the findings indicate that improvements of memory, speech, self-evaluated coping with new environments/situations, and writing, could be important for the use of public transport. Future research should target environmental aspects that support or hinder use of public transport in assisting the development towards improved outdoor mobility among persons with CFLs. In terms of practical implications, the results constitute an important knowledge base for development of more efficient rehabilitation programs as well as for public transport planning.
Jenny Rosenkvist
MSc Sociology

Licentiate defense: 16 June 2008
Transport and Roads
jenny.rosenkvist@hotmail.com

Licentiate thesis:
Challenging aspects of mobility in public outdoor environments and use of public transport: exploring the situation for persons living with cognitive disabilities.
Department of Technology and Society,
Faculty of Engineering, Lund University.

The aim of this thesis was to explore and gain deeper insight into and understanding of mobility in public environments for people with acquired cognitive functional limitations (target group of this thesis) and of reasons why some of them do not use public transport. Using an explorative approach, the target group’s mobility was firstly discussed by experts in focus group interviews. Secondly the reasons for not using public transport anymore after acquiring cognitive functional limitations was described by the target group themselves. The results of this thesis show that mobility and especially use of public transport is not an unproblematic activity for the target group. They face usability problems such as difficulties to manage the serial tasks, the complexity and dynamic in traffic environments. Further, other people’s acts and decisions as well as how the target group dealt with feelings, such as anxiety and fear, play a role for their mobility and use of public transport. Reasons for not using public transport could be that the target group did not consider public transport usable or it could be that they considered use of public transport as completely out of the question. Planning for mobility and usability in public transport for people with acquired cognitive functional limitations would mean to completely integrate a travel-chain perspective, to make sure that information is available on beforehand, to offer routes with calmer surroundings parallel with ordinary public transport used by for example commuters.
Current Graduate Students
Stroke survivors constitute a vulnerable group due to long-term disabilities that can lead to restrictions in activity and participation and affect health and well-being in a negative manner. Since transport possibilities enables activity and participation but many stroke survivors are prevented from driving a car and experience difficulties to travel by bus, an intervention focusing on increasing the ability to travel by bus are required. A self-management program is promising because it enables the participants to learn skills and generalize the knowledge to solve different types of problems. However, to establish if a program like that has any effects it requires reliable assessments. There is a need for development and piloting of a self-management program targeting use of public transportation after stroke, with special attention to the identification of factors that support successful recruitment.
Thanks to advancements in the acute stroke management most people survive a stroke. Still, many survivors experience long-term functional disabilities as well as restrictions in activity and social participation. Enabling stroke survivors to be active and participate in society as they age with their disabilities is an important task for the health sector and for society. To be able to implement effective interventions an improved understanding of factors and processes that hinder or promote activity and participation from a long-term perspective is needed. There is also a need for more precise methods to evaluate such aspects. Making use of quantitative and qualitative methodology this PhD-project aims to increase the knowledge about the long-term life situation of people ageing with stroke, with a specific focus on activity and participation in different areas of life. The studies are based on longitudinal data collected over a 10-year period with patients included in the Lund Stroke Register as well as in-depth interviews with a sub-sample of the long-term survivors. To clarify and refine analyzes, the ICF (International Classification of Functioning Disability and Health) has been used as a conceptual framework.
In Sweden about 5,000 individuals are living with a spinal cord injury (SCI). Globally no reliable prevalence is estimated, but the annual incidence is estimated to 40 to 80 cases per million population. Survival and longevity after a SCI have greatly improved thanks to improvement in acute treatment, rehabilitation and physiatric care. Due to such improvements after the second World War those currently ageing with a SCI are the first generation to do so. Premature ageing among individuals with functional limitations is indicated by research, that is, they age earlier than individuals without a functional limitation in the same age. This means that people ageing with a SCI may be confronted with age-related issues earlier than their peers. Ambulation, transfers and housework are activities in daily life reported as problematic when having a SCI, and these are closely related to the design of the home environment. In everyday life people with SCI experience difficulties at an earlier age due to functional limitations and environmental barriers, while practically no research-based results on such issues have been presented. Little is known on how the housing environment and the closest neighborhood hinder or support activity performance. The core of the theoretical framework for this thesis is Lawton’s ecological theory on ageing (ETA) and the notion of person-environment fit.
Home is fundamental to people’s well-being and as people grow older their housing needs and preferences change. Previous literature suggests that living in a home that is perceived as usable, meaningful, and familiar influences health and independence in daily activities. However, previous studies on perceived home and health dynamics involve very old individuals, that is, individuals in the fourth age where functioning and health have declined. In order to increase the knowledge on health trajectories related to home along the process of aging, research on aspects of health and aspects of home among older people in different age spans is needed. The importance to fill this knowledge gap is emphasized by the fact that the proportion of the population 65 years and older is drastically increasing, and that the vast majority of individuals belonging to this group are living in their own homes. Also, senior citizens want to age in place and the opportunity to do so is highlighted as an important factor in policies and programs with the aim to support health and well-being of older people. Given these gaps in knowledge and the importance of housing for health at old age, the main aim of this thesis is to generate knowledge on perceived aspects of home and the implications they have for aspects of health and well-being among people aged 67-70 years.
Parkinson's disease (PD) is a chronic progressive neurodegenerative disease that results in functional loss and disability due to motor symptoms (i.e., tremor, rigidity, bradykinesia and postural instability) and non-motor symptoms (e.g., fatigue, depression and cognitive dysfunction). The severity of PD is most commonly described by using the Hoehn and Yahr (HY) stages, which range from stage I to V, a higher level indicates greater disability. A fear of falling (FOF) is more common and pronounced in people with PD. They have also an increased risk of falling than others of the same age; the proportion of fallers ranged from 24 to 67 %, when using a 6-month recall period. It is also common that they experience near falls. Activity avoidance due to the perceived risk of falling (i.e. fall-related activity avoidance) may contribute to sedentary behavior and participation restrictions, a decline of physical abilities and, ultimately, in an increased risk of falls. As yet, there is limited knowledge regarding the association between fall-related activity avoidance and FOF as well as a history of falls in people with PD. To the best of our knowledge, no study has investigated how fall-related activity avoidance relates to a history of near falls and disease severity.
Jean Ryan
Urban Planner

Mid-way review: (not applicable)
Transport and Roads
jean.ryan@tft.lth.se

Work in progress
Mobility opportunities among older people in
Sweden’s large metropolitan regions: Exploring the role of public transport.
Department of Technology and Society,
Faculty of Engineering, Lund University

The aim of this project is to study potential and realised mobility among the young-old (within the age group 65-79) living in Sweden’s large metropolitan regions: Stockholm, Gothenburg and Malmö. The main focus is on mobility opportunities and actual trips that are supported by the public transport system, and factors which result in different kinds of use (and non-use) of the public transport system. The focus is not restricted to just geographical accessibility. Individual accessibility is also an inherent part of the project: can an individual travel when and where he/she would like? The most important concern as part of this work is the distribution of mobility opportunities: are there large differences with respect to potential and realised mobility between sub-groups within the larger group? This project mainly employs quantitative methods, alongside smaller qualitative elements. The quantitative studies include the analysis of travel survey data and geographical analysis.
Little is known about the most severely ill Parkinson patients (those in stages IV-V on the Hoehn and Yahr scale I-V), as this group is often excluded from research. Care for Late Stage Parkinsonism (CLaSP) is a European multicenter study ongoing since about two years at seven centers in six countries (Lund, Sweden one of them). The goal of the study is to survey the most severe Parkinson patients’ symptom profile; their motor- and non-motor symptoms, social needs and the burden that the disease causes from both patient and carer perspectives. The study aims to improve future care for patients and their carers in the late stages of the disease. My PhD work is mainly based on this study and the overall theme for my thesis and focus is on late stage Parkinson’s disease.