

## On the Possibilities of "Ageing Successfully" with Extensive Physical Impairments

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### Article abstract

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## On the Possibilities of "Ageing Successfully" with Extensive Physical Impairments

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Article hors thème • Open Topic Article

### Abstract

Based on qualitative interviews with Swedish women and men between the ages 65-72 who have been living with physical impairments for a long period of time, this article considers the opportunities and challenges of adopting a leisurely active and self-fulfilling lifestyle in later life if one uses a wheelchair and/or is relatively dependent upon other people's support. The participants' accounts point to the importance of considering how social and environmental contexts may influence the meanings and consequences of chronic illnesses and impairments for people of all ages. General developments in welfare, technical improvements, as well as a long line of reforms that include legislation on the adaptation of homes and the Act concerning Support and Service for Persons with Certain Functional Impairments (*Lag om stöd och service till vissa funktionshindrade*, LSS) are commented upon as changes that have contributed to the leisurely active lifestyle of the interviewees. Because it focuses on today's "young old disabled people" – women and men who have grown up and are growing old during an era of technological advances and developments in the area of disability policies – the article gives voice to a group of people who have been largely overlooked in gerontology and in the literature on the modern, active, "successfully ageing" senior citizen. In research on disability and in disability policy there are, similarly, few references to disabled seniors.

**Keywords :** disability, impairment, retirement, personal assistance, social and environmental contexts, successful ageing

### Résumé

Cet article a été réalisé à partir d'entrevues qualitatives auprès de femmes et d'hommes suédois(es) de 65 à 72 ans ayant des incapacités physiques depuis un long moment. Il examine les opportunités et les défis auxquels sont confrontées les personnes utilisant un fauteuil roulant pour se déplacer et/ou se trouvant en situation de relative dépendance quant au soutien apporté par les autres qui désirent adopter un mode de vie actif et stimulant. Lors des entrevues, les participants ont souligné l'importance de considérer l'influence du contexte social et environnemental sur le sens et les conséquences des maladies chroniques et des incapacités pour les personnes de tout âge. L'article présente et commente de quelles façons les plus récents développements en matière de protection sociale, de technologies et de réformes, y compris celles sur l'adaptation du domicile et la Loi concernant les services et le soutien apportés aux personnes ayant des limitations fonctionnelles significatives (*Lag om stöd och service till vissa funktionshindrade*, LSS), ont contribué selon les participants à l'adoption d'un mode de vie plus actif et stimulant. Parce que l'article s'intéresse aux « jeunes aînés ayant des incapacités » - c'est-à-dire aux femmes et aux hommes ayant grandi et vieillissant dans une ère de changements technologiques et d'évolution des politiques s'adressant aux personnes ayant des incapacités –, il donne la parole à des personnes ayant été le plus souvent ignorées par le champ de la gérontologie et par la littérature scientifique sur le vieillissement actif et réussi des citoyens aînés. De même, peu de place semble être accordée aux aînés ayant des incapacités dans le secteur de la recherche et des politiques dans le champ du handicap.

**Mots-clés :** handicap, incapacités, retraite, services de soutien, contexte social et environnemental, vieillissement réussi

## Introduction

In the writings of scholars in the field of ageing studies, what stands out as a prerequisite for a modern, engaged, self-fulfilling, leisurely active lifestyle in later life is relatively good state of health and functioning. For example, the British social philosopher and historian Peter Laslett (1989) argues that even if the preconditions for self-realization and pursuing of leisure activities characteristic of the so-called Third age are often greatest when one has passed retirement age, retirement as such does not warrant active and positive ageing. What Laslett describes as crucial, on the other hand, is a person's health and functional state. Similarly, characterizations of active, "successful ageing" have been closely related to the maintenance of high physical and cognitive function (Minkler & Fadem, 2002). Laying out their model of successful ageing, American geriatrician and physiologist John W. Rowe and social psychologist Robert L. Kahn (1998) highlight three hierarchically ordered features as necessary preconditions for successful ageing : voiding disease and disability; maintaining mental and physical function and continuing engagement with life. The paradigm of successful ageing that emerged from the work of Rowe and Kahn (1987, 1997, 1998) have had a great impact on gerontological thinking and research, leading to numerous intervention studies with the important aim of identifying and preventing functional losses among older people (Minkler & Fadem, 2002; Scheidt, Humpherys, & Yorgason, 1999).

Not everyone, however, has uncritically embraced the notions of successful and self-realizing ageing put forward by Laslett and his allies. Blaikie (1999), Minkler and Holstein (2005) and Öberg and Tornstam (2001) have, among others, argued that an active ageing ideal is likely to reinforce the stigma surrounding diseases and impairments in older ages and contribute to the marginalization of a large group of older people. According to Cohen (2005), comparisons between seniors with impairments and "successful agers" should for this reason be avoided altogether : "Those and others who have been precluded from the for-

mulas to successful aging by illness, trauma, or other cause of impairment, should not be contrasted to the *successful agers*, and even by implication characterized as failures" (p. 111, italics in original).

It might not be Cohen's intention, but even this kind of reasoning may lead to the conclusion that impairments naturally and completely render a leisurely, self-fulfilling lifestyle as out of the question. An active and "successfully ageing" person with extensive impairments emerges as impossibility, an image reinforced by a complete lack of visible impairments or tools such as wheelchairs, walkers or canes in advertising and in media presentations of the modern, recreationally active senior citizen.

However, does an active and engaged lifestyle as a retiree necessarily require a relatively good state of health and functioning? Or, alternatively, could it be that there are ways to live a self-realizing life even for a senior who uses a wheelchair and/or is dependent on others for help with such things as dressing and using the toilet?

Based on qualitative interviews with Swedish women and men 65-72 years of age who have been living with physical impairments for a minimum of 30 years, the aim of this article is to challenge and problematize writings in ageing studies that presents a good state of functioning as a prerequisite of active, "successful ageing". Unlike many of the contributions to the debate on the relationship between health and function and active ageing, not only the challenges, but also the *possibilities* of "ageing successfully" with chronic illnesses and impairments will be considered. By highlighting bodily *and* social dimensions that contribute in shaping the interviewees' lifestyles, the article also points to the relevance of acknowledging human functioning and disability as a multidimensional, biopsychosocial (Üstün, 2003) phenomenon.

According to Laslett (1989), the emergence of healthy older people spending many active years in the Third Age is a new, modern phenomenon arising from a combination of in-



creased longevity, compulsory retirement and pension systems. However, while the idea that societal changes has led to changed experiences of ageing is widespread among scholars in the field of ageing studies, few (e.g. Minkler & Fadem, 2002; Minkler & Holstein, 2005) seem to have paid attention to the transformations in the meaning and consequences of impairments in later life which are indicated in this article. Because it focuses on today's "young old disabled people" – women and men who have grown up and are growing old during an era of technological advances and developments in the area of disability policies – the article gives voice to a group of people who are seldom, if ever, mentioned in gerontology and in the literature on the modern, active senior citizen. In research on disability and in disability policy there are likewise few (e.g., Jeppsson Grassman, 2003; Harrison & Stuijbergen, 2005; Zarb & Oliver, 1993; Pentland et al., 2002; Sheets, 2005; Walker & Walker, 1998) references to disabled seniors. No previous empirical research focusing on the lifestyles of individuals in this situation have been found.

### Method and empirical material

The article is based on empirical material collected as part of a qualitative interview study whose aim was to explore the meaning of social and chronological ageing for people who have lived with physical impairments over a long period of time, in a Swedish context (Larsson, 2009). Individuals around 65 years of age who had lived with a physical impairment for a minimum of 30 years were recruited through various disabled persons' associations, the national insurance office and a municipal ombudsman for disabled people.

The 20 persons who participated in the study were between 56 and 72 years of age (born 1932-1949) at the time of the interview. Six (aged 56-67) were working full - or part-time, two (62 and 64 years of age) were on early retirement pension or its equivalent and 12 (aged 65-72) were – like most Swedes who have passed their 65<sup>th</sup> birthday – on retirement

pension.<sup>1</sup> *This present article* is based on the interviews with these latter 12 individuals, seven women and five men aged 65-72, who were on retirement pension. According to self-reports, the period in which the participants in this subset had lived with a physical impairment ranged from 30 to 68 years. At the time of the interview, seven of them received personal assistance in accordance with the Act on Support and Services for Certain Disabled Persons (*Lag om stöd och service till vissa funktionshindrade - LSS*) or the Assistance Benefit Act (*Lag om assistansersättning – LASS*), which indicates that they were judged to have major and lasting physical impairments and required extensive support and service. All 12 were dependent upon some form of mobility support (cane, walker, or wheelchair) more or less all the time; nine primarily used a wheelchair. The diagnoses reported were the following : polio (three), multiple sclerosis (MS) (five had at one time been diagnosed with MS, but two of these presented the diagnosis as uncertain or ambiguous), cerebral palsy (two), spinal injuries (one), stomach and intestinal diseases (one). One respondent reported another, more uncommon diagnosis and one reported two different diagnoses. Their educational and professional backgrounds were varied.

In the study as a whole, a *life course perspective* (Giele & Elder, 1998; Plummer, 2001) was used as a methodological orientation. Using a life course perspective in the methodological sense involves actively building a time dimension into the research design and analysis. Some approaches are retrospective, where people, often using qualitative interviews, may recreate or reflect on their lives. This tradition, in which the study belongs, in turn includes a variety of biographical approaches and methods of analysis (Chamberlayne, Bornat &

<sup>1</sup> All Swedish residents are entitled to a state-financed guaranteed minimum pension from the age of 65, which is the standard retirement age in Sweden. All workers in Sweden are entitled to income pension, which one earns during productive working life. In addition, many employers make extra monthly payments to a so-called occupational pension, which is based on collective agreements. Available to : <http://www.sweden.se/eng/Home/Society/Pensions/>, downloaded Feb. 23, 2011

Wengraf 2000). The approach applied is to use life stories as a *resource* to contribute to knowledge and understanding of aspects of social life (Bertaux, 1990; Coffey & Atkinson, 1996; Plummer, 2001).

Carrying out the interviews with this approach meant that all participants were encouraged to talk freely about their lives, both in the past and in the present. The interviews began with the participant being asked to give a brief description of her or his life. Additionally, an interview guide was used that included questions about the participants' everyday lives with disabilities at different life phases (childhood, youth, adulthood, today, the future) and their experiences of different types of services such as home help services, personal assistance and municipal transport services and of age limits within the public support system. Furthermore, a specific question concerning subjective age ("How old do you feel?") was included.

The interviewer/author in a flexible way asked the questions in the guide that the participant did not answer in her or his narrative and posed follow-up questions. The latter were aimed at encouraging the participant to describe and reflect on changes he/she had experienced over time with respect to his/her own life with disabilities (e.g. "Have you experienced any changes concerning X during your life?"), to make sure that the participant's statement was correctly understood or to further explore a theme raised in the interview. In practice, all but one of the 20 interviews took the shape of a life story largely driven by the participant. This interview, with one of the 12 participants who were on retirement pension, departed from the pattern and was largely driven by the interviewer in accordance with the structure of the interview guide. The more open approach in the other interviews was not applicable in that case since the participant's ability to talk was declining and it was only through the help of the personal assistant present that the interviewer/author could grasp the answers to the questions posed.

The location of the interviews was decided in consultation with the participants, as with the decision of whether an additional person would be present during the interviews and to what extent this other person would participate. In the case of the 12 individuals discussed in this article, the interviews took place at the participants' homes. In seven of the 12 interviews, an additional person (personal assistant, spouse or common-law wife) was in the room for some time as the interview took place; in two of these cases, the other person (a personal assistant) was present throughout the interview. As in all other interviews, the participants' statements and experiences was the focus of the interviewer/author. If anything, the presence of the additional persons has to be considered as an asset. At least one of the interviews would certainly not have been possible to carry out with the same quality without the personal assistant facilitating the communication.

The interviews lasted between one hour and 30 minutes to three hours (the majority around 2,5 hours) and were recorded on minidisc with the consent of the participants. In connection to each interview, observer notes were made concerning aspects such as technical aids and home equipment. The interviewer/author transcribed all the interviews verbatim. In this process, all names of persons were changed to protect confidentiality.

The analysis of the interview data followed the procedures of a directed approach to content analysis (Hsieh & Shannon, 2005) such that previous theoretical discussions and empirical findings concerning the implications of ageing for people living with disabilities guided the formulation of research aims and were used in the process of analysis. The analysis can also be described as *abductive* as it involved moving back and forth between the empirical material and social scientific explanations and concepts (Blaikie, 2000; Mason, 2002). While the strengths of a directed approach to content analysis include supporting and extending existing theory and research findings as well as making it explicit that the researcher is unlikely to be working from a naïve perspective, it also has some inherent limitations. One is that the



researcher might be more liable to find evidence that is supportive rather than un-supportive of theory (Hsieh & Shannon, 2005). In order to lessen this tendency, the analysis did not only incorporate themes in the interviews that supported previous research, but also included themes that stood out as contradictory or unanticipated in relation to the theoretical and empirical starting point of the study. In addition, part of the process of analysis was that other researchers within a larger project about ageing with disability, in which the study belongs, examined the interpretations made (see Fay, 1996).

The analysis progressed in several steps and started while conducting the interviews (see Coffey & Atkinson, 1996) by making initial analytical notes about themes in the individual interviews that appeared relevant, based on the focus of the analysis. After all the interviews were conducted, the transcribed interviews and observer notes were perused repeated times in order to sort the data and to clarify themes. The overall starting point was to identify all the changes over time in respect to a life with disabilities that had occurred in recent years (as expressed by the participants) – as well as to identify themes that appeared as contradictory or unanticipated. The themes relating to change were analyzed in order to determine their relevance to social and chronological ageing, and to identify in which ways they did so. In this analytical work, the theoretical discussions and empirical studies concerning the implications of ageing for people living with disabilities, which had also been the starting point of the study (e.g., Harrison & Stuifbergen, 2005; Jeppsson Grassman, 2003; Pentland et al., 2002; Sheets, 2005; Walker & Walker, 1998; Zarb & Oliver, 1993), was used as methodological tools. Subsequently a wider range of discussions and empirical findings were taken into account to further analyze the themes in question, as well as the unexpected themes generated. That is, research concerning the implications of social and chronological ageing "in general" (e.g., Hockey & James, 2003; Laslett, 1989; Neugarten & Hagestad, 1976; Tunaley, Walsh & Nicolson, 1999), of acquiring an impairment or chronic illness at different ages

(e.g., Bury, 1982) and of living with impairments over a long period (eg., Williams, 2000), including bodily, physiological aspects (Mosqueda, 2004), were considered in the analysis. The analysis also involved splitting and renaming themes and going back to the original data and so forth (see Coffey & Atkinson, 1996).

In its entirety the analysis ended up with a broad spectrum of results, supportive of the research that had been taken into account since the planning of the study, as well as contradictory and unexpected in relation to this starting point. The empirical material, principally the unexpected themes generated during the analysis, turned out to be particularly useful to challenge theoretical discussions within the fields of medical sociology and gerontology through the use of negative cases (see Plummer, 2001).

The point of departure for this present article is one of the unexpected themes that emerged during the early stages of analysis that subsequently appeared as useful in challenging and problematizing academic writings in ageing studies that presents a good state of functioning as a prerequisite of active, "successful ageing". The theme in question is the accounts of leisurely active lifestyles presented by the interviewees who had reached the standard retirement age in Sweden and were on retirement pension. While all of the 20 participants in the study as a whole appeared to live active lives, six by working full- or part time, it was those 12 retired participants' accounts that stood out as particularly striking and particularly useful, due to the fact that many of the theories and discussions on active, "successful ageing" implicitly or explicitly focus on retired people (e.g. Laslett, 1989).

#### *- Seniors with personal assistance*

It is important to stress that the 12 participants discussed in this article are not to be considered as representative of Swedes aged 65-72 with physical impairments, in that the majority (seven of the 12) have personal assistance in accordance with LSS or LASS. In 2005, the

year in which most of the interviews were conducted, there were 1253 individuals in Sweden, 65 years or older, receiving personal assistance according to LASS (Swedish Social Insurance Agency, 2009a). 286 individuals were receiving personal assistance according to LSS (National Board of Health and Welfare, 2006). That same year 135 000 individuals, 65 years or older, were receiving home help services and 100 400 were staying in sheltered housing (National Board of Health and Welfare, 2007).

LSS is a rights law supplementing other legislation. Its aim is "to promote equality in living conditions and full participation in the life of the community" (Act 1993:387: section 5) for people with considerable and permanent functional impairments. Support may take the form of personal assistance, counselling, housing with special services or relief provision for the parents of children with impairments. Personal assistance refers to "personally designed support that is provided by a limited number of persons for anyone who owing to major and lasting functional impairments needs assistance with her or his personal hygiene, meals, dressing and undressing, communicating with others or other help that requires extensive knowledge about the person with a functional impairment (basic needs)" (Act 1993:387 : section 9a). A person who needs personal assistance for her or his basic needs for more than 20 hours a week may be entitled to assistance benefit. The right to this benefit is set out in the Assistance Benefit Act, LASS. Personal assistance according to LSS or LASS is free of charge to the individual. The LSS/LASS law came into force in 1994 and experience has shown that it has a major impact on the living conditions of the individual qualified for help under the Act (Szebehely & Trydegård, 2007).

The seven interviewees who had personal assistance, aged 65 -72, belong to the first cohort of Swedish citizens with the legal right, according to LSS and LASS, to keep their assistance after 65 years of age. This right to keep assistance after 65 was introduced in 2001. However, the conditions were that personal assistance had to have been granted before the age of 65, and the amount of assistance accorded

may not be increased after the 65th birthday. The relatively high number of participants aged 65 or older with personal assistance in the study is explained by one of the research questions that dealt with individual consequences of losing the right to increase the amount of assistance after 65 years of age, despite increasing needs. For that reason, the selection process involved searching for interview subjects in this situation.

## Results

In this section, similarities between the 12 retired participants' lifestyles and academic accounts on healthy, leisurely active, "successful ageing" will be illustrated, followed by a passage highlighting the prerequisites and obstacles to an active lifestyle with physical impairments in later life that appeared in the interviews. To provide an in-depth understanding of the phenomenon in question, some of the participants and their situation will be focused on and presented in some detail.

### *- Leisurely active seniors with physical impairments*

When the 12 individuals, aged 65-72, who are on retirement pension relate what they have been up to lately, what they are planning to do in the near future, or are asked to talk about an ordinary week and a normal day, the image of rather, or very recreationally active, committed individuals emerges. The women and men in question describe how they go to the theatre and concerts, are involved in artistic activities, take part in language studies, sports and gymnastics, and travel both within and outside Sweden. Several take an active part in society through volunteer work in various levels (international, national and municipal) and within various associations aimed at improving the living conditions of disabled people. Some are active in providing supervision for their personal assistants and in handling elements of the administration connected with their assistance. They appear, in other words, as continually engaged in life in a way typical of a "successfully ageing" senior citizen (see Rowe & Kahn, 1998).



The current lifestyle for the participants largely seem to be a matter of devoting their free time to activities that they to some extent have been engaged in even earlier, when they were still on early retirement pension or were working. As Margareta (aged 66) who left work when she was in her fifties puts it : "much of what I thought was kind of hobby stuff before, I pursue in a somewhat different way now". Some express that the activities that they are engaged in today are the kind that they probably would have devoted their careers to if the possibility had existed. Among those who expresses this is Inger (aged 67) who was diagnosed with polio as a child. Inger relates that she applied and became accepted to an art college when she was a young woman. At that time, however, the educational institution was located at the fourth floor in a building without a lift, which made it impossible for her, as a wheelchair user, to begin her studies. Today Inger, with the support of her personal assistants, devotes a good portion of her time to artistic activities of various forms. Likewise, other participants express how developments in technical aids have created an opportunity for them, despite increased impairment, to engage in sports in ways that were impossible when they were younger. Hence, the dimensions of self-fulfilment that is characteristic of the Third Age (Laslett, 1989) can also be part of being a senior with impairments.

Another striking example that points to this is the story of Ann-Marie (aged 65), who was diagnosed with MS at the age of 20. She is an active member of an international art association. Through a monthly scholarship, a more established artist supports her in her artistic development for a few hours every Wednesday. As Ann-Marie has lost the ability to move her arms and legs, she uses her mouth when she paints. Aside from being one of the participants engaged in artistic activities and gymnastics, Ann-Marie is also among those who appear to be an experienced traveller. In recent years, she has visited Denmark, Majorca, the Canary Islands and Iceland. During the interview, Ann-Marie expresses her future travel plans like this :

On the topic of travelling, I probably won't travel abroad anymore. I've had enough of that. Although, sometimes I could think that I haven't discovered all of Iceland yet. I should go to the northern part too. But no, it probably wouldn't be. I'll keep myself to Sweden from now on. And you know what; recently I had this idea to adjust Lennart's car so that we can turn one of the seats and I can have a wheelchair in there. In that way we can go on shorter trips alone. So that's our small project right now.

Lennart, who is referred to in the interview extract above, works as Ann-Marie's personal assistant and has for many years assisted her with tasks from brushing away strands of hair from her face to personal hygiene, meals and dressing. However, it is Ann-Marie herself, through a specially designed computer, who administers the assistance and plans the assistants' schedules.

Another participant is Bertil (aged 70) who has been retired about as long as he has used a wheelchair, that is, since he was approximately 50 years old. Bertil was diagnosed with MS when he was 40, but he questions the accuracy of the diagnosis. A few years ago, he was also diagnosed with diabetes. Unlike Ann-Marie and Inger, Bertil does not have personal assistance. According to his own judgment, he is not currently in need of extensive support. He has a security alarm (in case I fall or something, which happens sometimes) and daily telephone contact with the municipal home-help service. In addition to this he has arranged service on a private basis to have a person come every two weeks to help him with cleaning and "petty jobs". The nature of the petty jobs depends on Bertil's current needs. Bertil's home is adapted for wheelchair use. For example, the sink can be lowered to a height that makes it possible to wash the dishes sitting down and Bertil's bed is designed so that he can get in and out of it without help from another person. In his electric wheelchair, the *Permobil*, Bertil moves about indoors as well as outdoors. The height of the *Permobil* can be



raised or lowered, which Bertil reports to be an advantage when he does his shopping and has to reach the higher shelves. Asked about the relationship between his "feel age" and chronological age, Bertil answers :

[I feel] much younger than I am actually, because I have the advantage of having always been very active and have always wanted to do something. And that, I think, is something pretty good. To sit and stare into a wall is the worst thing that I can think of. I don't want to end up in any of those institutions. I've seen those places; they sit in their wheelchairs and sleep. What the hell are they waiting for? No, I want to be able to do things until I die and just fall together. And because of that I probably feel a bit younger. [Especially] after a trip like the one I did just now...

As indicated by the participants' stories quoted above, not only do the interviews challenge earlier discussions about the Third Age and "successful ageing" by conveying a picture of retired people with extensive physical impairments as adopting a leisurely active lifestyle. The interviews also call into question the arguments that a relatively good health and functional state is a prerequisite of being able to "feel young" or "not old" (see MacFarlane, 2004; Öberg & Tornstam, 2001). In a quantitative survey study conducted by Öberg and Tornstam (2001), a vast majority of the 1250 20- to 85-year old Swedish respondents reported lower subjective ages than their chronological ages. In light of this result, most of the participants in the study appear as statistically typical by expressing a sense of "feeling relatively young" when asked about their subjective age. In expressing this, some refer to their lifestyle. Bertil is one of these. In the interview extract above, the trip that Bertil refers to is a cruise to Finland with former colleagues, which he has just returned from the day before the interview. This trip is presented as an example of his active life. Bertil appears to be an active person in general. During the interview, which took place in May, he says that he plans to go

on a three-week sailing camp in another part of the country in the beginning of summer. He has been to the same camp for six summers in a row. Bertil says that he began with sailing when he was a bit over 60 years old as a less risky alternative to his former hobby, gliding. Included too in Bertil's future travel plans is a trip to New York. Furthermore, he is engaged in gymnastics, and he devotes his time to various computer-activities. A few hours each day is dedicated to work in front of the computer. Besides writing a memoir, he spends time "engaging a bit in shares" at the computer, although he emphasizes that it is a matter of small-scale share speculation. He also regularly visits a computer centre for people 55 and over, where he expands his knowledge in computers. To sum up, by his engaged and leisurely active lifestyle, Bertil appears to be a rather typical "successfully ageing Third ager". As previously indicated, he is no exception among the participants.

According to the British disability researcher Priestley (2006), the narratives of successful and active ageing adopted by older people and their pressure groups to assert and sustain more positive identities in later life "are premised on a view of successful ageing that has no place for impairment and disability. Ageing with disability is implicitly defined as "unsuccessful" ageing and adopting a positive identity of ageing means distancing oneself from a disabled identity as long as possible" (p. 88). In contrast, not only does Bertil appear as an active and "youthful" senior citizen; he does not seem forced to distance himself from a disabled identity to adopt a "successfully ageing" identity either. In fact, he is an active member of two different disability associations. The sailing camp that he participates in is organized by one of these associations. During the interview, Bertil also tells about his involvement in various collective efforts to improve the living conditions for disabled people in his hometown.



*- Prerequisites of – and obstacles to – a leisurely active lifestyle with physical impairments in later life*

In the passage above, some prerequisites to the 12 retired participants' lifestyles have been touched on. The extent to which the women and men in question are engaged in recreational activities are dependent in varying degrees on such things as technical aids and support services which provide for more than just the satisfaction of basic needs.

For those seven that have personal assistance, this support stands out as very important or critical for the achievement of the lifestyle they have. They talk about the LSS/LASS law and personal assistance as "the best thing that ever happened" to them and "heaven-sent". When life with personal assistance is compared to life with earlier forms of support and care such as municipal home help services, the possibility to influence the choice of assistants, flexibility and greater control over ones' everyday life are among the benefits highlighted. Some expressed that assistance makes it possible to "manage oneself", which can be seen as an indication that it is possible to be relatively dependent on other people, yet perceive oneself as autonomous.

It is also clearly expressed during the interviews that the opportunities to live a leisurely active life with physical impairments in Sweden might still be improved. For those who do not own a car or do not have access to public transportation adapted to wheelchair users, the possibilities to participate in activities outside the home are dependent on how the municipal transport service is organized, for instance the amount of trips one is entitled to per year. A participant living with a gastrointestinal illness reports difficulty in finding suitable toilets and getting a **Disabled Parking** Permit. Those who use wheelchairs also recall problems finding adapted toilets and report limited access in some settings. One pointed to high kerbs that risk one "falling on one's head" when crossing the street. Another described public transports as a "danger to one's life" and several mentioned difficulties finding suitable hotel accom-

modation. One participant said that she gave up flying after her electric wheelchair broke on two consecutive flights.

In the interview, Bertil showed in a tangible way that a leisurely active lifestyle with impairments in present-day Sweden might still include certain problems, pointing to three large bruises on his forehead and cheeks. During the cruise to Finland, Bertil fell over in the boat cabin. He is upset that the cruise company's definition of a disability-adapted cabin did not match his expectations at all. In particular, there was no security alarm in the cabin. Thus, Bertil had no choice but to lie on the cabin floor for several hours before receiving help to get back into the wheelchair. Bertil is also among the interviewed wheelchair users who speak of stairways as barriers to involvement in recreational activities. Before Bertil moved to the town where he currently lives, he was a dedicated bridge player. Once settled in the new town, he called around to various bridge clubs in order to continue his hobby, but realized in the end that he had to give it up because all bridge clubs were either located upstairs, or in a basement room one floor down. "Stairways should be removed!" Bertil exclaims in the interview.

The participants also express that their daily lives require time-consuming organizing and planning. Users of municipal transport services have to book their trips in advance and wheelchair users prepare their visits to theatres and restaurants by a first inquiring by telephone if it is possible for them to enter the premises at all.

Not all the conditions for a recreationally active lifestyle expressed during the interviews were social or environmental in the sense that they depend on external aspects such as accessibility and design of support and services. In some cases, it rather seems to be the individual's state of health and functioning that constitute a barrier to engagement in certain activities – or in fact, in other respects, to fully appropriate a self-realizing, active lifestyle. For example, implicit in the image of what it means to take part in recreational activities is social interaction. An unspoken assumption is that an

active senior citizen does not feel lonely. However, for Christer (aged 65), access to social interaction is not a self-evident part of his daily life.

Among the 12 participants, Christer stands out as particularly recreationally active. Getting an interview with him was not easy. It was not that Christer was reluctant, but he was unsure whether it was possible to fit the interview among his other activities. When we finally met, after a couple of rebookings, Christer said that he used to plan the coming week by going through the newspaper's entertainment - and cultural supplement every Friday. He describes himself as a frequent visitor to theatres and concerts, with a broad musical interest that includes blues, jazz and classical music. He also volunteers as a kind of "entertainment and leisure consultant" (the author's expression) for an association for visually impaired people in which he was previously employed. Through his good knowledge of what goes on in town, he helps other members of the association to get involved in cultural events such as soup theatres and lunch concerts. Besides this, Christer is also a member of a variety of associations. Asked about which associations these are, Christer takes out a thick bundle of membership cards from his wallet. The bundle includes membership cards for music -, disability - and retirees' associations. He says that he is not particularly interested in the disability - and retirees' associations' ordinary activities, but participates when there is an arrangement that attracts him, such as parties and musical events.

However, during the interview it also became evident that Christer's daily life is darkened by the fact that he is on his way to losing the ability to communicate with other people entirely. Despite his active lifestyle, he is, as he puts it, bound to "become a hermit". Due to an unusual illness, Christer's ability to see, move and talk has been gradually declining since childhood. At the time of the interview, he could only tell the difference between darkness and light and needed a wheelchair and support from another person to move about. It was only through the help from one of his personal as-

sistants that the interviewer/author could grasp Christer's answers to the questions posed.

Birgitta (aged 68), who uses a walker outdoors, considers that her impairment did not appear as a barrier until her four children left home and both she and her husband were retired. Before that, it would have been difficult to engage in recreational activities anyway, even without impairments :

When the children lived at home and everything – it had not been so easy then anyway. I don't think so. But then it's clear that nowadays we would have been able to do much. There are just certain things that one can't do. Like my husband has been to the mountains and went hiking with some friends. That would have been great fun. Just going out into the woods and pick berries, to be able to go out and do such things, or ride a bike – he bikes a lot too. Recently he was biking in Denmark. Those are the things one could have done. I would have been able to come with him. Those are the kind of things one misses.

One of the participants who was a wheelchair user said that riding a four-wheeled motorcycle in the mountains might nowadays be a possibility for those who cannot walk, "but it is not quite the same thing" as he put it.

Impairments may not only prevent engagement in some activities. That the time left over for various activities may be limited due to one's health and functional state is also expressed during the interviews. To move, eat, shop, cook, dress and manage personal hygiene may take a relatively long time, which in turn limits the time left to engage in other activities. Paradoxically, to some of the participants this seemed to result in having to be particularly active. Or as Bertil put it : "because everything is done so slowly I have to be really busy all the time to catch up".

So far, all prerequisites – and barriers – to an engaged and leisurely active lifestyle with



physical impairments commented on in this passage appear to be independent of age. For example, the organization of special services, stairways as well as extra time needed for dressing and eating are likely to affect an individual's opportunities to engage in recreational activities irrespective of her or his age being 12, 40 or 70. However, several of the interview subjects also spoke about a radically reduced income in connection with their 65th birthday. That is, there was a financial change linked to the transition from early retirement pension to retirement pension at the age of 65. Among those who feel this change are 65-year-olds Ann-Marie and Christer.

In the interviews, the participants were not asked to provide any detailed information about their economical situation, but in the light of their accounts and housing standard their financial conditions appear to be varied. One or two of the 12 women and men seemed to live in relatively modest circumstances and several expressed that they are used to economizing scarce resources. Some reflected on the possibility of moving to cheaper housing in order to manage on retirement pension. That their place of residence is specially adapted to their state of function makes this decision complicated. Concerning recreational activities, the transition to a retirement pensioner did not seem to involve any lifestyle changes at the time of the interview. For some of the participants, however, it is likely that the financial consequences of a relatively short working life will eventually amount to reduced opportunities to engage in certain types of activities. Apart from the fact that, in present-day Sweden, a relatively short working life results in a particularly low retirement pension (Försäkringskassan, 2009), living with impairments often includes specific costs (Zarb & Oliver, 1993). In other words, retirement tends to increase already existing economical inequalities (Calasanti & Slevin, 2001).

## Discussion

The analysis presented in this article illuminates how individuals ageing with impairments are likely to face specific barriers in an aspiration for a leisurely and self-fulfilling lifestyle.

Among these are bodily and financial constraints and buildings primarily designed for walking. However, based on the participants' descriptions of their everyday lives, the article also shows that it is reasonable to surmise that a senior with extensive impairments can achieve a fairly engaged, self-realizing and recreational active lifestyle – *if the necessary environmental, economical and supportive conditions exist*. Unlike Laslett's and others' representations of an active and "successful" senior citizen, the study conducted shows that some people live in countries that can provide a relatively high potential to live with extensive physical impairments and at the same time take an active part in social life. The empirical examples presented also point to the relevance of acknowledging not only the bodily dimensions, but also the life course dynamics and social dimensions of disability in academic and political discussions dealing with the meanings and consequences of impairments in later life (see Sheidt, Humphreys, & Yorgason, 1999). That is, dimensions that can be found in conceptual models and frameworks that synthesizes what is true and useful in the medical model (that views disability as a problem of the person, directly caused by disease or other health condition) and the social and "Scandinavian" model (that views disability as a problem created by an unaccommodating social environment) (Shakespeare, 2006; Üstün and al., 2003, p. 568). One out of several examples of such an existing multidimensional, biopsychosocial, framework is WHO's International Classification of Functioning Disability and Health (ICF).

An important part of the developments that make the participants' lifestyles possible has been the disabled people's movement (Ekensteen, 2003; Peterson, Ekensteen, & Rydén, 2006). Members of "the collected disability movement" (SOU 1992:52) were, for example, represented in the government investigation (SOU 1990 : 19; SOU 1991 : 46; SOU 1992 : 52) preceding the introduction of the system of personal assistance in 1994. Scholars in the disability field have also been important actors in shaping Swedish disability policies and researchers and policymakers have frequently taken a protagonist stance and stressed the

importance of disabled people becoming equal citizens (Jönson & author, 2009). By focusing on aspects of the social or physical environment that prohibit disabled people to live their lives "as others", emphasis in the last decades has shifted away from the "imperfections" of the individual to the broader society and to questions on how to make the environment accessible.

Still, in Sweden as in other countries, engagement in critical thinking on disability is rare in official discussions on ageing policies as well as in gerontology. Rather than focusing on environmental and societal failures to remove barriers, disability in ageing discourse is, even today, frequently viewed through the medical model lens. That is, ageing discourse continues to espouse a perspective that stresses the inabilities of the person and tends to overlook the environmental and societal limitations that diminish a disabled person's opportunities to participate in society and enjoy life. On the other hand, in actions against disability discrimination and in disability studies, there are few references to older disabled people (Kennedy & Minkler 1998; Priestley 2003). Although developments in rights for disabled people have brought benefit to many, including people who have passed their 65th birthday, the progress has favoured young adults. Sweden is, in other words, not unique in that older people with extensive impairments do not have the same rights to special support as younger people with impairments do (see Kane & Kane, 2005; Kennedy & Minkler, 1998; Putnam, 2002). As been argued in an earlier article (Jönson & author, 2009) this "ageism" can be understood partly as the result of a successful endeavour to provide disabled people of younger ages with rights that are typical of non disabled citizens. In this struggle, what is just and equal have been defined in relation to citizens of similar ages : children, youth and adults of "active ages". To some extent the exclusion of older people can be understood as the inadvertent result of a struggle against other forms of prejudice; that is, as a struggle against "ableism". The tendency to separate disability from ageing and older people in disability theory and policy can also be explained by the cen-

trality of workforce participation in these areas. "Crucial 'non-wage-earning' populations – children, homemakers, and the elderly – are therefore acknowledged only in passing in most prominent critical analyses of disability policy, despite the fact that they make up the bulk of the disabled population, at least in industrial and postindustrial societies" as Kennedy and Minkler (1998, p. 758) point out.

Just as it is easy to find explanations as to why later life and older disabled people are neglected in the field of disability, the rather one-eyed focus on health and function among scholars like Laslett (1989) – that is to say, anti-ageists striving for redefinition of older people and of post-working life (Gilleard & Higgs, 2002) – is not hard to understand. Due to economic-, medical- and cultural advances, senior citizens in countries like Sweden today are, in general, more healthy and vital than earlier generations (Wiggins et al., 2004). Hence, the possibility to fight ageism and the "inevitable decline" perspective that dominates so much of ageing research (Swindell, 1993) through other research which aims to normalize older people and provide more "updated" and positive images of ageing and retirement on the basis of functional ability among seniors, comes handy (Jönson, 2001; Jönson & author, 2009). Another side of this strategy, however, is that it reinforces a rather one-sided, individualised and personal tragedy view of disablement.

What is unique about the men and women in the article at hand and about their stories and lifestyles is that they manage to do something that anti-ageists and disability activists so far largely have failed in doing. That is, they provide "updated" and positive images of older people *with impairments* and point to the necessity of creating a society adapted to people with and without impairments *of all ages*. In this way, they could be considered as pioneers. "Successfully ageing" healthy older people spending many active years in the Third Age may appear as a new, modern phenomenon (cf. Laslett, 1989). However, seniors with extensive impairments living fairly recreationally active lives supported by technical aids and



personal assistance stands out as even newer and more modern.

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