



## WG2 Case study profile

<b>WG2 Thematic Group</b>	<b>WG2.1a. Older people and people with disabilities. The restructuring of governance</b>
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<b>Name(s) of proposer</b>	Tine Rostgaard
<b>Institution</b>	Aalborg University
<b>Title of case study</b>	Transitions between disability and ageing
<b>Country/region/place investigated</b>	Denmark; Aalborg, Copenhagen and Roskilde local authorities
<b>Social service sector(s) investigated</b> <i>(Erase non relevant ones)</i> <ul style="list-style-type: none"> <li>• Older people</li> <li>• People with disabilities</li> </ul>	<p>Our societies are ageing, so that the share and number of elderly in society is increasing over the next decades. We know that elderly can remain functionally able-bodied even into very old age, however, the prolonged longevity is likely to result in an increase in the sheer number of people who must live with a disability and who need help and assistance (Lafortune et al, 2007). At the same time, people with disabilities also live longer - and well into old age - due to advances in medicine, technology and social conditions.</p> <p>Research into disability has often concentrated on the disability among persons aged 18-65 years of age, from the perspective that different obligations and entitlements separate these from persons 65+. It is well known that the risk of becoming disabled increases by 1-2 percent from the age of 60+, but little is known about the persons with a disability who pass the old age limit of 65 years of age or about elderly who acquire a disability after the age of 65 years.</p> <p>This raises the question of how disability and old age is united as a phenomenological, legal and social concept, in regards to social rights and in regards to the development of individual needs, but also in regards to the socio-economic resources in the near future - all questions which are in focus in this project.</p>
<b>Category of case study ('what' is investigated)</b> <i>(Erase non relevant ones)</i> <ul style="list-style-type: none"> <li>• Subsector/policy/programme (meso-level)</li> <li>• Project/initiative/experience (micro-level)</li> <li>• Actor(s)</li> <li>• Place (s)</li> </ul>	<p>National policy</p> <p>Local social and health care sectors</p> <p>Individuals (older people and people with disabilities)</p>
<b>Time frame considered</b> <i>(from when to when)</i>	2000-presently
<b>Five 'perspectives'</b> <i>(Erase non relevant ones)</i> <ul style="list-style-type: none"> <li>• Cost efficiency/quality/user satisfaction</li> <li>• Governance</li> </ul>	The research project indirectly addresses the cost efficiency and quality of the services provided for each user group (older people and people with disabilities), when considering them as two separate groups
<b>Three processes in restructuring + crisis</b>	The project involves local governments with different practises in separating the administrative structures of handling older people and people with disabilities. Two local authorities have integrated

<p><i>(Erase non relevant ones)</i></p> <ul style="list-style-type: none"> <li>• Cuts/rationalization/management reforms (NPM, others)</li> <li>• <i>Vertical</i> subsidiarity (administrative re-arrangements between <i>government</i> levels)</li> </ul>	<p>administrative practises, and the third has seperated, but is considered to integrate.</p> <p>The project also takes into account how developments in needs and power in the two groups may have shifted focus and the allocation of economic ressources in later years</p>
<p><b>Specific questions/focus</b></p>	<p>The research project will look at the demographic development over the coming years for people with disabilities who are ageing and for older people who acquire a disability. We will investigate what challenges this demographic change pose for the welfare state, e.g. when social rights for people with disabilities change in the transition into old age, but also in regards to the transition from being old to being disabled. Which individual, social and legal definitions are used to distinguish between disability and 'ordinary' frailty in old age, and do elderly and persons with disabilities hold different expectations, social rights and obligations? And finally, how are transitions between disability and old age experienced and lived by the individual?</p> <p>In the project we will accordingly contrast two transitions between disability and old age:</p> <ol style="list-style-type: none"> <li>1. A person with a disability who enters into old age</li> <li>2. A person who in old age develops a disability</li> </ol> <p>The project will contribute with new theoretical and empirical evidence about transitions between disability and old age, which can be used in the planning of political interventions and in the implementation of welfare policies at state and local level, and in this way create a better coherence between policies of disability and old age.</p>
<p><b>Local Stakeholder Network (LSN)</b></p>	<p>No (but we involve three local authorities and will be presented the results to them afterwards)</p>

## Disability and old age - A socio-political contradiction?

### Project aims

Ageing societies is a global concern. We know that the number and proportion of elderly in the population will continue to increase in the next decades. Despite that recent research shows that older people can greatly preserve their functional capacity, the fact that we live longer will in all likelihood result in an increasing number of people who in their old age live with a disability and need assistance (Lafortune et al, 2007). At the same time, the medical, technological and social development ensures that more people with disabilities are living longer and thus acquire the status of being 'old'. However, ageing people and people with a disability may not have the same entitlements in old age as the social legislation considers them as two separate groups.

Research on disability has so far in Denmark been limited to the age limits of 18 and 65 on the grounds that are subject to differing laws for children 18 to 65 year olds and older. We know that the risk of becoming disabled increases from one per thousand per year before the age of ten to a few percent per year for 60 years of age. But we do not know much about people with disabilities who pass the age of 65 and comes under a new law, or about older person who acquire what could be considered a regular disability.

This raises the question of how disability and aging unites as a phenomenological, legal and social concept, in relation to social rights and in relation to the development of individual needs, but also in relation to the need for setting of planning ahead in terms of resources in the coming years - all issues that are focus of this research project.

The project looks at demographic trends over the past decades for people with disabilities who are aging and older people who acquire a disability in Denmark. We will identify the challenges that this demographic change pose for the functioning of the welfare state, e.g. how and whether social rights change once you turn 65, but also in transition from being merely 'old' to having a functional ability that would otherwise – and if you were below 65 – be defined as a disability. What individual, social and legal definitions are used to distinguish between disability and old age related loss of functional ability, and there are differences in the social expectations, as well as social rights and obligations for a person with a disability as opposed to an old person? And finally, what are the daily lived experiences of the transition between disability to old age and from old age to disability for the individual?

In th project we compare the two transitions between disability and aging:

1. A person with a disability who ages (65+)
2. A person who in old age develops a disability

The project will lead to new theoretical and practical knowledge about people with disabilities and older persons living situation and everyday terms that can be used in the planning and implementation of welfare policies in municipalities and to achieve

consistency in the social legislation. The target group of the project is thus both politicians, practitioners and researchers.

### **Background**

Developments in aging has been the subject of much global attention in recent years. The changing demographic composition of the population is due to the fact that we live longer, but also due to falling fertility rates, and that our health systems have become more efficient.

In the EU, it is estimated so that the life expectancy for men by 2060 will increase by an average of 9 years, from the current 76 years to 85 years. Thus, men will to some degree have caught up with women, although women are still expected to live longer, from 82 years in 2008 to 89 years in 2060. The Danish development is expected to be very similar to the average of the EU for the women in this period, with a change in life expectancy from 81 years to 88 years, while the change in Danish men's expected life span is also positive with a change from 76 years to 84 years, but still somewhat from women's. The proportion of older people 65 + in relation to the population of working age will thus increase from 15.5% in 2008 to 25% in 2060 in Denmark (European Commission, 2008).

From a welfare perspective, it is imperative to be able to estimate the future need for health care and social care services, not least for the 65+ as this group of the population will as mentioned increase. In Denmark, the proportion of people 65+ with functional limitation declined over the past 20 years. Where 41% of people over 65 years in Denmark in 1987 reported having at least one physical or sensory related disabilities, only 30% in 2005 (Ekholm et al., 2006).

International studies of older people's health and functional shows that although the proportion of people with disabilities has fallen, aging of society is likely to lead to an increasing number of elderly in need of assistance and care (Lafortune et al, 2007). And it is quite evident that the risk of having a disability increases with age: Where only 20% of 65-74 year olds in 2006 reported having at least one disability, it rises to 38% for the 75-84 olds and 64% for people over 84 years (Ekholm et al., 2006).

The demographic development, which thus represents both an aging of society and an extended life expectancy for people with disabilities, raises the issue of how to organise welfare and allocate resources to the groups of people who have a disability and who are ageing. There is a growing understanding of the need to take a holistic perspective on disability and aging, combining political, administrative and research traditions in the two areas.

Several international organizations have stated the need to look broadly at how aging and disability will impact our future societies, for example, the Council of Europe recommends member states to ensure the elderly and people with disabilities equal rights to social services and equal legal rights (Council of Europe, 2009) and WHO in their research program 'Active aging' identified the need to look at disability in a lifetime perspective (WHO, 2010).

The organisation of social policy and social services in particular aimed at older people and people with a disability, however, is in many countries, including Denmark, divided into different sectors and with different services available. For example. A person with disability can in Denmark be entitled to 15 hours of attendance per month (SEL § 97), while no similar right is available for a person 65+, regardless of this person has the same functional ability. People between 18 and 65 years with a disability have according to SEL § 100 the right compensation for extra costs, while no similar option for a person 65+. Similarly, many senior centers only offer activities aimed at persons without major functional disabilities.

The separation between the elderly and disabled is also reflected in the research conducted in both Denmark and other Nordic countries. Disability researchers have primarily focused on citizenship for people with disabilities, and the key research themes have in this field acted on discrimination, empowerment and autonomy (Gustavsson et al, 2005).

Research on aging has on the other hand focused on the older persons as care recipients and the organization of the public tender care for the elderly, especially with emphasis on staff working conditions (Szebehely, 2005). However, there is a need to also do research that cuts across disciplines, if we are to address the complexity that will arise with the aging society. A research perspective that looks across aging and disability will lead to theoretical innovation, new ways to ask enquire, but also to better understand the differences and similarities between people with disabilities and older people's lives and everyday terms.

### **Analytical framework**

The reason for this division of disability and aging are many. There are both structural and cultural differences between disability and aging, but there are also similarities. One may basically say that both can be defined by a labor / welfare division, where both persons with a disability and older persons are categories that are not defined in relation to productivity at the labour market, which is otherwise for most people is the entrance to social entitlements. The twentieth century development of welfare states has resulted in a separation of many groups from the labor market, including the elderly and disabled. This has been done through the introduction of public pensions and disability pensions. One may say that both disability and old age are parallel structures, both regarded as independent and non-adult social categories qua non-participation in the labor market (Priestly, 2003).

There are cultural similarities in the way, old age and disability are perceived, in regards to being dependant and being different (otherness), but also in relation to notions of disengagement and isolation, which has been supported by past policies that have resulted in segregation and institutionalization of disabled and elderly (Ibid).

However, the structural and cultural differences are also evident: old age is surrounded by a sense of normality as this is a phase of life which most people experience. Loss of functional ability is – although most research shows that this takes place later and later in life – a not unexpected phenomenon in later life. Bodily and mental changes are considered as a natural part of old age, and which ageing

people are expected to face and adapt to. Older people, who have experienced a life time of ups and downs, are even expected to possess better resources for adapting and accepting the bodily and mental changes that occurs in old age (Pound, Gomperte and Ebrahim, 1998).

On the other hand, the image of successful and active ageing which is the preferred image of old age presented also by many organisations representing the old, provides a new image of ageing. Here, the emphasis is on the active life and how you may in old age create a new identity for yourself, as you are less constrained by structural circumstances. Instead, one may opt for what ever old age one may want and is expected increasingly to "choose" not to be old (Biggs, 1997). Bodily and mental weakness in this way becomes a consequence of the (wrong) way of living in previous life phases, rather than an irreversible and unavoidable component in the phase of later life.

As Priestly (2003) notes, the promotion of successful and active ageing, however, also means the desire to distance oneself from the image of the 'weak elderly', and thus marks a distance to the disability-related issues of old age. In a similar manner, many older people find it hard to identify with campaigns for people with disabilities, also as these often focus on the 'normalisation' of younger phases of life, such as campaigning for better opportunities to take up education and work. This may help marginalizing and excluding the growing proportion of the old who have an actual disability.

But there are also more fundamental differences: In recent times, many (young) people with disabilities have started considering disability as an identity contributing component. Following the social model, which is the prevailing today, disability is not considered to be a question of individual way of living, but as a form of societal oppression, creating barriers and excluding people with disabilities. In this way, the strategies of organizations representing elderly and disabled people respectively has been to make demands for citizenship and recognition based on strategies which in fact distance the two groups from each other.

The question is therefore how we may come to see disability and ageing within the same perspective: to what degree is there commonness in identity and development of need for people with a disability who are ageing and for older people who gain a disability? Do they have the same social rights, goals and make the same demands to the welfare state? Does the social legislation create differences that are unfair to the individual? And how does the individual confront and overcome transitions between disability and ageing?

### **Research questions**

The project focuses on the consequences of ageing among older people and disability have for the welfare state and for the individual. The research questions are the following:

1. Concept: How may disability and aging be understood and defined as a legal, social and individual life concept? What distinctions are made between being

disabled and old, and does this distinction change, as one ages?

2. Implications of demographic trends and the need for care and service: what is the demographic development in the number of persons with a disability now and in the future and what will their needs and resources be in the future?

3. Challenges to the Welfare State: What existing social rights and obligations exist for people with a disability and people who are old, and what expectations do older people and people with a disability have for the welfare state now and in the future?

4. Everyday practice: How are transitions between disability and ageing observed and lived?

### **The project's subprojects and data**

The project consists of 4 parts, each of which examines key issues for understanding the transitions between disability and aging. The object is both people with disabilities who get older and older people who develop disabilities.

We initially examine the conceptual framework for understanding disability and old age as a legal and social but also as an everyday concept. This part of the project will have a legal and political science perspective by examining how disability and old age are understood and defined in legislation and social policy. We will also take a phenomenological perspective, i.e. we are taking our starting point in the subject's understanding and experiences, by examining older people and people with disabilities and their thoughts about identity and status. Data consists of a review of legal texts and manuals, and interviews with key political and organizational actors, as well as older people and people with disabilities. These interviews will be used throughout the project.

The project then examines demographic trends in disability and aging. Based on SFI longitudinal survey data, Ældredatabasen, we examine how the number of older people with disabilities has developed over the past decade, and we make a forecast of the development in the near future, on the basis of data on middle-aged people with disabilities. This part of the project will also look at the resources and needs of older people and people with disabilities, through analysis of amongst other functional ability, loneliness, hobbies and social network, and will provide a model for how resources and needs will look like for the future of older people with disabilities.

We then present the existing social rights and obligations for disabled and elderly, and investigate the expectations of the future older persons with disabilities for their old age in relation to social services. Data consists of a review of Social Services, as well as studies of local practice, in three local municipalities. The municipal studies look at how the social services unfolds in practice, and also look at how the transition from disability to old age /old age to disability takes place, and what social services are offered. Here, data consist of vignette studies, which accounts for municipal policies and practices. Vignettes are short stories that in this project will provide details about people in different social situations. Municipalities may then unfold how the local socio-political effort would look like in this situation. In addition, the interview data that have been collected in the project's initial phase is included to explain the expectations of people with disabilities to the municipal social services.

Finally, we study everyday practice for individuals with disabilities and older people. Here, interview data collected in the initial phase is included. Interview topics that are covered here will be about the organisation of daily life and the experience of the transition from disability to old age /old age to disability.

### **Status**

At present the vignette studies are being conducted and will be ready in late June. The demographic study is also being conducted. Interviews with managers and social workers have been conducted in all three municipalities. Also, interviews with chairpersons from the local councils representing older people and people with a disability respectively have been conducted.

### **Preliminary results**

#### *Conceptualisation of disability and ageing*

From the interviews with managers and social workers it appears as the term 'disability' is not a commonly used term to define and identify the group in question, and this is regardless whether the person is below or above 65 years. Instead, functional ability is the preferred term to use when a person's limited physical or mental capabilities are to be defined. This means that it is possible to discuss and evaluate functional ability across age and regardless of actual disability. As one social worker expresses it they see older people who quite clearly have a disability but also see young people who have age-related somatic problems.

On the other hand, all the municipalities use the terms disability (handicap) and old age (ældre) for naming the different administrative sections in charge of the two user groups. When applying for services, many forms are also using the concept of disability, also when service users are above 65 years of age.

#### *Organisation*

In two of the municipalities there are no sectoral divide between disability and old age, while in the third and the biggest, different administrative sectors deal with old age and disability, i.e. in most cases citizens are moved to the old age section once they turn 65+. Persons who are believed to require more care can remain with the sector dealing with disability also after the age of 65 years. The service level may however not be identical. One example is the laundry service which a user had previously received help with in her home from the home helper. After the transition to the 'old age sector', this service was not longer offered, as an external laundry service was used instead and the user then complained.

#### *Social rights*

In the social legislation a number of entitlements cease once one turns 65, such as the right to receive compensation for extra costs for transport or other costs related to functional limitation, or the right to 15 hours monthly for a person to accompany you.



Other social services can continue into old age such as the personal assistant (BPA) but someone over the age of 65 cannot apply for this service.

### *Representation*

Both older people and people with a disability are represented in local policy making through the elder council (Ældrerådet) and the Disability council (Handicaprådet), composed by local citizens elected to sit in these council. The councils must each be consulted on every policy making that may in principle affect older people and people with a disability.

From the interviews with the chairpersons of the councils it is clear that although the councils meet up once annually they cooperate only to a limited degree, have very different interests and take different stands in most matters, such as the approach to welfare technology. Here, one chairperson from an elder council expressed her concern for the lack of human contact resulting from the introduction of robots, which she found was not a concern for the council representing people with a disability who found that the major issue was the increasing independence that the robot could provide. Only few issues are common concerns, such as mobility and accessibility in the local area. Generally, the interviews with chairpersons of the councils confirm that they find that they represent a group of citizens which have only little in common. As an example one chairperson of a disability council declined to be interviewed as he believed that old age was beyond their field of interest.

Whereas older people have one major and quite influential interest group (Ældresagen), the organisations representing people with disabilities seem perhaps more fragmented.

### *Needs*

Although functional ability is the basis for the assessment of need regardless of age and although most case workers state that they do not take age into account when assessing need, the age related needs definition is nevertheless practised. One example is the assessment of hearing impairment, where a certain loss of hearing is expected as one ages and something which may not trigger the offer of a hearing aid. For a person 10 years younger, the same loss of hearing would on the other hand be regarded as unusual and therefore give entitlement to a hearing aid.

### *Adaption and coping*

Several case workers point out the fundamental difference in when a disability is acquired, not only in terms of chronological age but also in terms of the number of years that a person can become accustomed to the loss of functional ability. They point out that a young person acquiring a loss of functional ability often will find it easier to adapt and cope with this, whereas this is more difficult in old age, even though one may expect that a certain functional limitation will occur due to old age.

Rather than being focussed on the actual disability and diagnosis that the person may have from previously, many case workers explain that they rather take a starting point in how the person copes.

One case worker points at the difference of being old (gammel) and elderly (ældre), where elderly has a more positive connotation, as is it connotes a dynamic process and not the final life phase.

Another case worker finds that he especially associates people who are born with a disability as belonging to the group of disabled, whereas a person who later in life gains a functional limitation he less associated with having a disability.

### *Reablement*

Current policy practice in old age care in Denmark has within the last 5 years become reablement. 'Active' help and assistance is provided instead of 'passive'. This means that instead of offering care and assistance, the assessor should in cooperation with the older person, consider whether systematic training could help him/her to re-gain the functional ability, to a degree where the person would not need help. Also older people already receiving services are in many municipalities now re-assessed for active care. In most cases the training takes place as a 10-12 weeks intensive intervention. Following this, the older person is re-assessed. If there is still functional limitations, the person will receive services such as home help. In some municipalities, if the older person declines the offer for training, no services are given.

Several case workers explain that there is a certain expectation that age automatically entitles to services, not least the cleaning services in home help. In contrast to many other countries, the home help service is still free of charge in Denmark.

Whereas reablement is today more a more a common practice in the services for older people, people with disabilities are less likely to be met with the requirement or offer of training to regain functional ability. The resources set of for training for people with disabilities also seem more limited.

### *Image and deserving care*

The case workers are also aware that there is potentially more media awareness if they decline an application for services from an older person than someone with a disability.

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