

JYU DISSERTATIONS 845

Salla Era

Reimagining Boundaries

Policies, Concepts and Everyday Life at
the Intersection of Disability and Old Age



UNIVERSITY OF JYVÄSKYLÄ
FACULTY OF HUMANITIES AND
SOCIAL SCIENCES

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ABSTRACT

Era, Salla

Reimagining boundaries: policies, concepts and everyday life at the intersection of disability and old age

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Populations are ageing around the world. Disabilities are more prevalent at older ages, but often older persons with disabilities remain excluded from disability policies and services in many countries. This dissertation explores the intersection of ageing and disability in policy, research and everyday life. The theoretical underpinnings of the research will be developed particularly through the lens of critical and feminist disability studies, while also drawing on perspectives from care ethics.

The research is qualitative. Article I uses policy documents related to the reform of the Disability Services Act as material. Article II is a selective literature review of international research on ageing and disability. Article III draws on written accounts collected from older persons with disabilities.

The results of the study show that there is no clear and common understanding of disability in ageing. In policy documents, disabilities in old age were not always seen as disabilities, and the origin of the impairment often determined whether or not it was considered to justify disability services. In addition, international research conceptualised disability in diverse ways. In research on ageing, disability was understood in terms of an individual's impairments and functional abilities, whereas in disability studies, disability was defined as a broader sociomaterial phenomenon. The written accounts show that how, in what way, where and when help and support are provided was important in everyday life. The authors had different perceptions of dependency and independence, reflecting the concept of independence in disability activism, but also the ideal of self-sufficiency. On the one hand, asking for help was described as difficult while, on the other hand, accessing public services was also seen as challenging due to unclear applications and services.

This dissertation shows that there is conceptual ambiguity at the intersection of ageing and disability, both in services and in research. I suggest that policies need to critically consider the grounds and conceptualisations on which they are built, and what the intended and unintended implications of the set boundaries are.

Keywords: disability, ageing, policy, concepts

TIIVISTELMÄ (ABSTRACT IN FINNISH)

Era, Salla

Rajoja uudelleen kuvittelemassa: Politiikat, käsitteet ja arki vammaisuuden ja vanhuuden risteyksessä

Jyväskylä: Jyväskylän yliopisto, 2024, 97 p.

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Väestö ikääntyy ympäri maailman. Vammaisuus ja toimintarajoitteisuus on yleisempää korkeassa iässä, mutta usein silti ikääntyneet toimintarajoitteiset henkilöt ovat monessa maassa jääneet vammaispolitiikkojen ja -palveluiden ulkopuolelle. Tässä väitöskirjassa tarkastellaan ikääntymisen ja vammaisuuden risteämistä niin politiikoissa, kansainvälisessä tutkimuksessa kuin arkielämässä. Tutkimuksen teoreettinen pohja rakentuu erityisesti kriittisen ja feministisen vammaistutkimuksen kautta, hyödyntäen myös hoivaetiikan näkökulmia.

Tutkimuksessa käsitellään aihetta laadullisesti. Artikkelissa I aineistona on käytetty vammaispalvelulain uudistukseen liittyviä politiikkadokumentteja. Artikkelit II ja III on valikoiva kirjallisuuskatsaus kansainvälisestä ikääntymisestä ja vammaisuuteen liittyvästä tutkimuksesta. Artikkelissa III on hyödynnetty toimintarajoitteisilta ikääntyneiltä henkilöiltä kerättyä kirjoitusaineistoa.

Tutkimuksen tulokset osoittavat, että vammaisuudesta ikääntyessä ei ole selkeää ja yhteistä ymmärrystä. Politiikkadokumenteissa ikääntyessä tulleita vammoja ei aina nähty vammaisuutena, ja toimintarajoitteisuuden alkuperä usein määrätti oikeuttamista vammaispalveluihin. Lisäksi kansainvälisessä tutkimuksessa vammaisuutta käsitteellistettiin eri tavoin. Ikääntymisen tutkimuksessa vammaisuus ymmärrettiin yksilön toimintakyvyn kautta, kun taas vammaistutkimuksessa vammaisuus määrittyi laajempaan sosiomateriaalisena ilmiönä. Kirjoitusaineiston perusteella arkielämässä merkitystä oli sillä, miten, millä tavoin, mistä ja milloin apua ja tukea saadaan. Kirjoittajilla oli erilaisia jäsenyyksiä riippuvaisuudesta ja itsenäisestä elämästä, jotka heijastelivat vammaispolitiikan itsenäisyyskäsitteitä, mutta myös yksin pärjäämisen ideaalia. Avun pyytämistä kuvattiin vaikeana, ja toisaalta myös julkisten palveluiden hakeminen näyttäytyi haastavana epäselvien hakemusten ja palveluiden takia.

Väitöskirja osoittaa, että ikääntymisen ja vammaisuuden risteyskohtaan liittyy käsitteellistä epäselvyyttä niin palveluissa kuin tutkimuksessakin. Ehdotan, että politiikoissa on kriittisesti tarkasteltava rajanvetojen perusteita ja niitä ohjanneita käsitteellistyksiä sekä niiden seurauksia.

Avainsanat: vammaisuus, ikääntyminen, politiikka, käsitteet

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Käylä and Tampere, Autumn 2024
Salla Era

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- I Era, S. (2021). Equality according to whom? Debating an age-related restriction in the upcoming disability legislation reform in Finland. *Journal of Aging Studies*, 58, 100953.
- II Era, S., Katsui, H., & Kröger, T. (2024). From conceptual gaps to policy dialogue: Conceptual approaches to disability and old age in ageing research and disability studies. *Social Policy and Society*, 1-17.
- III Era, S., & Kröger, T. (2024). Being independently dependent: Experiences at the intersection of disability and old age in Finland. In Katsui, H., & Laitinen, M.T. (Eds.). *Disability, Happiness and the Welfare State: Finland and the Nordic Model* (1st ed.). Routledge, 48-67.

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1 INTRODUCTION

Disability and old age intertwine in many different ways conceptually, and there's confusion about what constitutes disability – especially related to policies. This confusion at the nexus of disability and old age can then trickle down to the everyday lives of older persons with disabilities. In this dissertation, I ask the following: *how do disability and old age intersect in (1) policies, (2) concepts, and (3) everyday lives of older persons with disabilities?* This dissertation consists of three articles and this summary. Each article focuses on one part of this question: the first article views the question in the policy context, the second from the conceptual perspective and the third from the viewpoint of older persons with disabilities. Even though each of them regards mainly one part of the question, all articles contribute to the broader considerations of the question. A few motivations guide the research questions.

RQ1: How do disability and old age intersect in policies?

The population is ageing both globally and in Finland. In Finland, the number of people aged 75 and over is predicted to double from 2010 to 2040 (Statistics Finland, 2024). At the same time, persons with disabilities live longer lives: due to advances in health and medicine, many people with illnesses or conditions that previously would have been fatal are now surviving into old age (Kelley-Moore, 2010, p. 99). However, population ageing does not inevitably lead to an increase in the number of people with disabilities, but the change is linked to social structures. For example, some conditions such as polio are 'phasing out' while some are 'phasing in', like spinal cord injuries that previously could have been fatal (Kelley-Moore, 2010, p. 101). Nevertheless, the number of older persons with disabilities is predicted to grow (WHO & World Bank, 2011, p. 35). It is essential to study and review the policies in this nexus, since in the future, the population of persons with disabilities will be older than before.

Disability policies often overlook older people (Jönson & Taghizadeh Larsson, 2009), even though disability is more prevalent in older age. According to the World Report on Disability (WHO & World Bank, 2011, pp. 28–30),

estimates of disability prevalence worldwide range from 15.6 per cent to 19.4 per cent. The prevalence rates for people over the age of 60 are much higher, ranging from 38.1 per cent to 46.1 per cent (WHO & World Bank, 2011, pp. 28–30). For example, in Germany, people over the age of 65 make up 54.3 per cent of the population of persons with disabilities (WHO & World Bank, 2011, p. 35). However, estimating disability is challenging, since disability is defined and measured in various ways in different parts of the world.

In Finland, too, the population of persons with disabilities is ageing, which is reflected in the demographic change in disability service users. With the exception of transportation services, the share of people over the age of 65 among disability service users has increased over the last decade. For example, among personal assistance users, the share of people aged 65 and over has grown from 20 per cent to 37 per cent between 2010 and 2022 (Sotkanet, n.d.). In the six largest cities in Finland – Helsinki, Espoo, Vantaa, Turku, Oulu and Tampere – about 60 per cent of disability service users are aged 65 and over (Kuusikko, 2022, p. 27).

Many countries have established some way of restricting older people's use of disability services (Jönson & Taghizadeh Larsson, 2009; Leahy, 2018), and the same has been extensively discussed in the context of a reform of disability legislation in Finland. Policies at the intersection of disability and ageing have been criticised as being unequal (Jönson & Taghizadeh Larsson, 2009), unnecessarily siloed (Leahy, 2018) and in need of rethinking (Naue & Kroll, 2010). Excluding older people with disabilities from disability services steers them to services for older people that are often very different in their scope and content. Instead of organising services in different siloes, many have suggested bridging these two service strands in order to better support older persons with disabilities (Bickenbach et al., 2012; Naue & Kroll, 2010; Priestley & Rabiee, 2001).

Both ageing and disability policies are built on different assumptions and principles: for example, disability policies often follow the groundwork of the disability movement, relying upon more social understandings of disability and the diversity of humanity, whereas ageing policies are argued to have a more medicalised view (Naue & Kroll, 2010, p. 3). Hence, it makes a difference which policy field the person 'falls' into – or whether they fall in between.

RQ2: How do disability and old age intersect in concepts?

In this policy context, the definition of disability is of utmost importance: who is considered a disabled person? How we understand disability influences how we respond to disability but also how people make sense of their own disability. Disability in general has been understood in many different ways throughout the years, for example, as a personal tragedy, oppression or a result of parents' moral flaws (Vehmas, 2004). When the academic discipline of disability studies began to form, disability as a concept started to focus more on the social conditions and the barriers faced by people with impairments. The disability movement demanded social change: in order for disabled people to achieve equal rights and participation in society, barriers need to be removed.

Disability in old age is not understood similarly to younger ages. Often, older persons with disabilities are not understood as 'disabled' per se, but rather 'just old' (Priestley, 2014). Especially *disability with ageing* seems to be left undertheorized and therefore ambiguous within either policy field (Leahy, 2018). Age-related disabilities are often seen as 'normal' ageing and not disrupting the normative life course (Kelley-Moore, 2010; Priestley & Rabiee, 2001), compared to disability in childhood or adulthood where it would be considered a biographical disruption, to borrow Bury's (1982) words on chronic illness. In addition, the disabled identity in old age is a complex phenomenon, dependent on social conditions (Kelley-Moore et al., 2006; Leahy, 2023). The development of a disability-rooted identity is less likely with late-onset impairments (Kelley-Moore et al., 2006). These conceptual issues may contribute to excluding older people from disability services: older persons with disabilities are not considered 'disabled' in the same way as younger people with disabilities are (Leahy, 2018; Priestley & Rabiee, 2001, 2002).

RQ3: How do disability and old age intersect in the everyday lives of older persons with disabilities?

There is still only limited knowledge of the experiences of older persons with disabilities in Finland, though important research has been done in recent years and is being done at the moment. For example, studies have been made on the policy level regarding dementia (Hoppania et al., 2017) but also from the viewpoints of deaf people with dementia (Rantapää, 2024) as well as the retirement transitions of persons ageing with intellectual disabilities (Granö et al., 2023). Collecting the experiences of older persons with disabilities will provide knowledge of what is important from the viewpoint of the people these policies are meant to support.

This dissertation focuses on the intersection of disability and ageing or old age. In this research, the intersection refers to a broad field that discusses ageing and disability together, not only to disability in old age. I see research on the intersection as a multidimensional sphere: it includes both the studies on older persons with disabilities and the comparisons between the domains of disability and ageing. First, research on older persons with disabilities provides micro-level insights: experiences of ageing with disabilities, the complexity of the concept of disability in old age, and the policies regarding older persons with disabilities. From this perspective, this dissertation focuses on the experiences of older persons with disabilities as well as policies and services in this micro-level intersection. Second, the intersection of disability and old age also includes comparisons of policies, research or conceptual underpinnings of ageing and disability, or ambitions in disability and old age activism, respectively (see, for example, Priestley & Rabiee, 2002). From this viewpoint, this dissertation provides macro-level insights on the conceptual foundations of ageing research and disability studies and helps to further understand the concept of disability in old age. Thus, this dissertation studies the everyday life and policies regarding

older persons with disabilities, but it also compares disability concepts in ageing research and disability studies.

I use the term 'older person with disabilities' when I mean an older person with impairments that together with surrounding barriers result in difficulties in everyday life – in accordance with the Nordic relational approach to disability (Gustavsson et al., 2005). I use 'disabilities' in the plural to acknowledge that there can be multiple restrictions due to impairments and/or the environment. I acknowledge the social model approach in which disability is separate from impairment and it is the environment disables persons with impairments. However, I draw from critical realist perspectives on disability to stay mindful of people's experiences as to what the disabling factor is and the bodily restrictions one may have (Watson, 2019). The aim of this dissertation is to increase knowledge on the experiences of older persons with disabilities and related policies in Finland, but also to develop the theoretical and conceptual formulation of disability in a broader sense, as well.

This summary is structured in the following way. First, I introduce the policy context in which this dissertation is situated. The main focus of this dissertation is on Finnish disability policy, which is heavily influenced by international policy documents, such as the United Nations Convention on the Rights of Persons with Disabilities of the United Nations (CRPD). The international context is introduced to show that many national developments have not taken place in a vacuum but are in constant connection with developments elsewhere in the world. Next, the national context is presented by comparing Finland's disability services and services for older people. They are similar in many ways, but some essential differences exist. After that, I review the situation of older persons with disabilities currently in the service system, as they are a major user group in disability services.

Second, following the policy context, the different disability conceptualisations are reviewed both generally and regarding old age, as they are often understood variously. The disability conceptualisations presented in the section are closely linked to other theoretical underpinnings of this dissertation, which are introduced in the following section.

In the next part, I present the data and methods of this dissertation. Each of the three articles have their own research questions, data and methods, even though thematic content analysis has been used in each of them. In addition, I review my own researcher position as well as the limitations of the study in the section. After data and methods, the results of the articles are presented, with each article in its own sub-section. Each article answers one part of the general research question of the dissertation.

After the results, the main findings are discussed from pragmatic and ontological viewpoints. In the discussion section, I also consider the ways the findings could contribute to policies, and what kind of future research it could motivate. Finally, the conclusion reviews the contributions of this research to theory as well as practice.

2 POLICY CONTEXT: FINLAND

2.1 International entanglements

Disability policies in many Western countries have developed along the same lines, with a strong influence from the disability rights movement. This subsection focuses on the disability rights movement and current policies as they have guided and continue to guide Finnish disability policy today.

One of the cornerstones of the disability rights movement is Independent Living (IL). The origins of the idea can be traced back to the US in the 1970s, where students led by Ed Roberts, often called ‘the father of the Independent Living Movement’, studying at the University of California, Berkeley fought to employ personal assistants to enable accommodation in dorms with other students instead of separate hospital wings (Pearson, 2012). The key idea of Independent Living was – and is – that disabled people should have the same choice and control in their lives as any other citizen. It does not mean self-sufficiency, but rather enabling independence through *chosen* support how, when and where the person needs it (Brisenden, 1986).

Inspired by the success of the pioneers, other students sought similar support, and it finally led to the establishment of the first Centre for Independent Living in Berkeley in 1972 (Pearson, 2012, p. 241). Its goal was to promote integration by organising support services for disabled people, based mostly on the personal assistance model that was tested and proved to be working. Soon after, CILs spread throughout the country (Dejong, 1979) and to Europe, leading also to the establishment of the European Network of Independent Living (ENIL) in 1989 (ENIL, 2022). In the Nordic countries, centres of Independent Living were established not long after the original one in Berkeley. In Sweden, for example, STIL was founded in 1984 by Adolf Ratzka. In Finland, CILs work under Kynnys ry (the Threshold organisation), which is a broader disability rights organisation founded in 1973, on the initiative of Kalle Könkkölä.

At the same time as the IL movement began in the US, disability rights movements were active in Europe as well. The social model of disability, one of

the most influential ideas guiding disability studies and policies, was formulated in the UK. The foundations of disability organisations were laid already in the 1960s with Disabled Income Group (DIG), after which came the Union of Physically Impaired Against Segregation (UPIAS) and the Disability Alliance at the beginning of the 1970s (Finkelstein, 2001). While disability rights were negotiated everywhere, in the UK, UPIAS together with the Disability Alliance made the revolutionary distinction between impairment and disability – impairment being the individual condition and disability the barriers the society imposes on top of those impairments (UPIAS/Disability Alliance, 1976). That distinction formed the basis of the social model of disability (Oliver, 1990) that has influenced disability policies worldwide.

While the (materialist) social model gained support in the UK, parallel debates around disability approaches existed in other countries. For example, in the US, the focus has been more on the cultural and social construction of disability and the minority model, for instance, in Mitchell and Snyder (2020). In the Nordic countries, the relational approach to disability has been prominent (Gustavsson et al., 2005). Even though it contains some variations, the relational approach to disability emphasises the need to recognise the relationship between the individual condition and the contextual factors (Gustavsson et al., 2005, p. 34). Disability models are more thoroughly discussed in section 3.1.

As disability rights gained visibility all over the world, disability policies progressed. The United Nations declared the year 1981 as the International Year of Disabled People, which marked a recognition of national governments' responsibility in ensuring disability rights (Barnes, 2012), leading to the World Programme of Action Concerning Disabled Persons adopted in 1982, and then to the United Nations Decade of Disabled Persons in 1983–1992 (Woodburn, 2013, p. 79). The year 1981 also marks the establishment of Disabled People's International (DPI), an international human-rights network consisting of national organisations of disabled people, that has had a major influence in pushing disability rights to the international policy agenda. The development started with 250 disability activists from around the world, including UPIAS and Independent Living activists from North America and other parts of the world, gathering at the Rehabilitation International Congress with non-disabled rehabilitation and charity experts in 1980 in Winnipeg, Canada (Hurst, 2005, p. 66). A year later in Singapore, the DPI was formed. In the following years, DPI advanced disability rights in the European Union, the UN and WHO. For example, DPI demanded that WHO change its International Classification of Impairment, Disability and Handicap (ICIDH) that had been used widely to assess and classify disability, and this resulted in the new International Classification of Functioning, Disability and Health (ICF).

The UN General Assembly adopted Standard Rules on the Equalization of Opportunities of Persons with Disabilities in 1993, which further demonstrated the interest of international legal regulations to ensure disability rights (Sabatello, 2013, p. 15). The development finally led to the establishment of the CRPD in 2006. Drafting of the Convention was a joint effort and included civil society in

the work (Woodburn, 2013, p. 81). One overarching theme in the Convention is enforcing the participation of persons with disabilities in developing, implementing and monitoring policies and legislation, which is visible in the drafting of the CRPD itself, but also in its provisions (Sabatello, 2013, p. 23).

The CRPD has marked a change in how disability is approached worldwide. The approach to disability in the Convention is social and relational (Sabatello, 2013), and it has been interpreted to resemble both the (non-radical) social model (Harpur, 2012) and the biopsychosocial model (Leahy, 2018). According to the UN, it incorporates a human-rights-based approach to disability (HRBA) (United Nations, 2014). The CRPD was established to secure human rights for disabled people, and it provides structures to monitor the national implementation. Finland signed the Convention in 2006, but it was ratified only in 2016 after changes to the national legislation.

The CRPD comprises 50 Articles that concern cross-cutting rights, different kinds of human rights of persons with disabilities and guidance on the implementation and monitoring of the convention on a national level. Even though the CRPD articles can be considered to apply to disabled people of all ages, Mastin and Priesley (2011, p. 172) note that older persons are left somewhat invisible in it. A few articles include sentences regarding older persons, for example, on health care and the prevention of impairment in Article 25, but no specific articles target the intersectional rights of older persons with disabilities similarly as do the ones for children (Article 6) and women (Article 7) (Mastin & Priestley, 2011). However, the CRPD provides a tool to secure the rights of also older persons with disabilities that are still underrecognised in many countries, as also noted by the former Special Rapporteur on the Rights of Persons with Disabilities (Devandas-Aguilar, 2019).

Despite the establishment of the CRPD and many other positive developments in disability rights in recent decades, much work for disability rights and in disability activism remains to be done. Many current developments have negatively impacted the lives of disabled people: Bergths et al. (2020, p. 3) highlight, for example, '[t]he onslaught of neoliberalism, austerity measures and cuts, impact of climate change, protracted conflicts and ongoing refugee crisis, rise of far right and populist movements'. Technology and social media have also created new forms of activism that are easily accessible (for those with language and technological skills, for example). Bergths et al. (2020) note that the history of disability activism concerns mostly the Global North, but new African, Asian and Latin models of disability have started to be developed, and additionally, there have been calls for stronger and more radical models of disability to protect rights and focus on disability justice.

2.2 Disability services: from institutions to Independent Living

In Finland, the trajectories of disability services and services for older people had developed along the same path until the turn of the 20th century, when the group of 'paupers' started to be recognised as different groups with different needs (Jaakkola et al., 1994, p. 117). Before that, in addition to family care, poor relief was the main form of support for people in need (Kröger, 1997; Satka, 1996). Older people and persons with disabilities (as well as people with mental illnesses and children without guardians, for example) were cared for as poor relief, including poorhouses that were gradually turned into municipal homes (Markkola, 2008; Paasivaara, 2002; Topo, 2011). Poor relief at the turn of the 20th century was paternalistic in nature and primarily sought to regulate the morale of the population and restrict the civil rights of the people it was helping (Kröger, 1997). Since the 1950s, municipal homes became places of living and caring for older people and social services developed to include various types of support (Paasivaara, 2002; Topo, 2011).

Disability legislation started to form in the mid-1900s in Finland. The Second World War had left many people impaired, and a new interest in disability issues arose. Since then, there have been two distinct paths of persons with intellectual disabilities and those with physical disabilities (Saloviita, 2005). Accordingly, there have been two separate laws that concern persons with disabilities: one concerning persons with intellectual disabilities and the other mainly physically impaired people. The latter started as the Social Welfare for Invalids Act in 1946. It aimed to rehabilitate especially war veterans and other 'potentially employable' persons for working life, while it left older as well as 'asocial' disabled people out of its scope (Leppälä, 2016). The former, the Act on Mental Retardation from 1958, guided the development of services for persons with intellectual disabilities, and divided Finland into 15 special care districts, with each having their own central institution (Miettinen & Teittinen, 2014). Even though most persons with intellectual disabilities still lived with their family (Tarvainen, 1966, pp. 66-67), the number of people in these institutions continued to increase until the mid-1980s (Miettinen & Teittinen, 2014). Institutionalisation was not specific to Finland, but also happened elsewhere in the Western world (Mietola et al., 2013). These large institutions were criticised from the beginning. For example, the so-called normalisation principle opposed institutions and introduced the aim that persons with intellectual disabilities should be able to live a similar life compared to their peers in the same age group (Miettinen & Teittinen, 2014; Nirje, 1970, 1976).

The United States was the first in furthering deinstitutionalisation at the end of the 1970s, while Finland was still building institutions (Mietola et al., 2013, p. 9). In the Nordic countries, Sweden was at the forefront in developing community care and reducing the number of people in institutions already in the 1970s, while the number of people in institutions was its highest in the mid-1980s in Finland (Tøssebro et al., 2012, p. 3). In the mid-1990s, Norway was the first to

close all its institutions (Tøssebro et al., 2012). In Finland, the Act on Special Care for the Mentally Handicapped (519/1977) replaced the Act on Mental Retardation and it marked a move away from large institutions to community-based solutions and mainstream social and health care, reflecting the normalisation principle (Miettinen & Teittinen, 2014, pp. 64–65). The national aim has been that no person with intellectual disabilities would live in an institution by the end of 2020 (STM, 2012). Though still not zero, the number of persons with intellectual disabilities in institutions has dropped from 2,516 in 1999 (STAKES, 2001, p. 74) to 403 in 2021 (Finnish Institute of Health and Welfare, 2022). The 1977 Act remains in force, with some modifications, for example, to self-determination in 2016.

The Social Welfare for Invalids Act of 1946 reflected the idea of rehabilitation for persons with disabilities (Saloviita, 2005). The aim of the Act was to rehabilitate persons with (physical) disabilities to become active (working) members of mainstream society, for example by providing vocational training. However, not all persons with disabilities were included in these support measures, and disability organisations demanded more inclusive legislation (Leppälä, 2016). During the 1970s, changes were made to the Act to introduce more rehabilitative measures not based on economic expectations and the inclusion of impairment groups on a broader spectrum, even though it was not replaced until 1987 by the new Disability Services Act (387/1987) (Leppälä, 2016).

Following an expansion of disability activism in Western countries, and after the UN International Year of Disabled Persons in 1982, the approach to disability started to shift from needs based to rights based (Leppälä, 2016). The UN Decade of Disabled Persons in 1983–1992 further strengthened the aim for equality and participation in disability services (Saloviita, 2005). In the Nordic countries, an interactional approach to disability developed that saw disability as an interaction between a person and the environment, or a mismatch (Leppälä, 2016). As in the Nordic countries, and in the Western world in general, the Finnish discussion demanded the end of segregated services and promoted inclusion.

The normalisation principle guided the development of disability legislation in Finland, similarly to other Nordic countries. The principle accelerated deinstitutionalisation, even though at first, it was used to improve conditions in institutions (Tøssebro et al., 2012). ‘Phase two’ of normalisation brought a shift away from institutions and closer to general services, both on the levels of legislation and the level of government responsible for organising the services. For example, Denmark abolished special legislation for persons with intellectual disabilities in 1976, and Norway followed in 1991. Sweden enforced rights-based legislation (Tøssebro et al., 2012, p. 136). Finland did the same, as the new Disability Services Act of 1987 included ‘subjective’ rights to services. Subjective rights mean enforceable legal rights to services that cannot be denied if the criteria for eligibility are met, regardless of, for example, budget restrictions.

The new Act aimed to steer away from the diagnosis-based scope of the Social Welfare for the Invalids Act, and included services that were targeted to a

broader spectrum of persons with disabilities (Leppälä, 2016). It did not exclude intellectual disabilities, either, even though with the existence of two separate Acts, acquiring services according to the Disability Services Act had proved to be difficult for persons with intellectual disabilities (Saloviita, 2005). Services included, for example, transportation, service housing, interpretation, assistive devices and personal assistance to enable participation in society, regardless of whether or not the person would aim for the open labour market. The emphasis shifted from rehabilitation to equality and human rights (Saloviita, 2005). In 2009, the rights were expanded, as previously discretionary personal assistance was also added under the coverage of subjective rights, while services took another step towards independent living and living in the community.

The role of disability activists and organisations has been major in pushing the legislative changes forward. From its establishment, Kynnys ry has been at the forefront of advocating for improvement. For example, the personal assistance system was on the agenda from the late 1970s, and through persistent advocacy, it was first integrated into disability services in 1988. As mentioned, in 2009 personal assistance was secured by subjective rights, following, for example, a demonstration that closed the biggest street in the capital city Helsinki organised by the *Rammatt pantterit* (Crip panthers) – an activist group inside Kynnys ry (Laitinen & Saraste, 2014). Disability activism in Finland has also been active outside Kynnys ry, for example, there are a number of impairment-specific disabled people's organisations (DPOs) in Finland.

At the moment, there are still two Acts regarding persons with disabilities: the Act on Persons with Intellectual Disabilities (519/1977) and the Disability Services Act (387/1987). However, they have been under reformation for over a decade, and the original goal has been to merge these two Acts so that, in the future, there would be only one act that would concern all persons with disabilities. In addition to merging the Acts, there has been a need to refine the contents of the disability services and also the scope of application of the act regarding whom it concerns. For this dissertation, the discussion regarding the exclusion of older persons from disability services has been a point of interest. This is discussed further in section 2.5.

2.3 Services for older people: transforming long-term care

Older people with disabilities can be entitled to both disability services and services for older people, even though the intersection can be complex. Older persons' services have developed on a different path, with a focus on care rather than rehabilitation and participation, even though recent years have seen at least a symbolic aim for increasing participation in these services (see, for example, Hoppania, 2015).

As persons with disabilities, along with many other residents, moved away from municipal homes by the 1950s, these started to become places of living for older people. From the 1950s onwards, poor relief was gradually replaced by a

new service-type social care, even though poor relief had already shifted towards more diverse ways of support (Anttonen, 2009, p. 60). With the expansion of the Finnish welfare state from the 1960s onwards, care for older people started to develop as a new type of public service.

Municipal home help has been characterised as the first real social service for older people (Rauhala, 1996, p. 118). It had been supported by the state from the 1950s, and was enforced in 1966: it was a reform that marked the inclusion of the principle of universalism into social services (Anttonen & Sipilä, 2000, p. 116). The urbanisation of the agrarian Finnish society further accelerated the need for public social services. In the 1970s, the abolishment of the legal responsibility of adult children to care for their parents – in the 1950s, over a half of people aged 65 and over lived with their children (Nihtilä & Martikainen, 2004, p. 136) – enforced the rationale to develop alternative types of care.

Paasivaara (2002, p. 62) has named the period from 1940s to 1970s as the ‘great transformation’ of care for older people. During that period, the traditions of poor relief were eradicated, and public care services were developed in the spirit of universalism. The Finnish welfare state expanded, and public institutional care increased. The responsibility shifted from families to the state. The period from the 1970s to the 1990s was a time of ‘welfare state services for older people’ (Paasivaara, 2002, p. 86), when Finland was at its peak in the provision of social care services for older people, including home help (Karsio, 2024, p. 26; Kröger & Leinonen, 2012). It was also a time of institutional care (Paasivaara, 2002; Topo, 2011), similar to what was happening in disability services at the time. After the 1990s, the expansion of the Finnish welfare state ended (Karsio, 2024, p. 26) and services for older people took a turn towards a more mixed model of managing social and health care (Topo, 2011, p. 884).

The 1990s saw a change in how services for older people were organised. Various legislative reforms and the decentralisation of power to municipalities made the outsourcing of social services to non-profit and private providers possible (Karsio, 2024, p. 27). After the recession of the 1990s, care services did not recover to their previous level, and the development from the 1990s onwards has been characterised by austerity and welfare cuts (Kröger, 2019, p. 6). The marketisation of care has been notable from the 1990s onwards, as in the beginning of the decade there was practically no for-profit care providers, whereas in 2018, already around 30 percent of all personnel were working in for-profit organisations (Karsio, 2024, p. 35). The marketisation of care may have brought savings from public services but created a two-tier system where the low-income population uses public services, whereas people with high income could use their own money to buy care (Mathew Puthenparambil et al., 2017).

Similarly to disability services, the 1990s started a period of deinstitutionalisation in older people’s services (Karsio, 2024, p. 27). Where disability policies followed the principles of normalisation, ageing policies adopted the principle of ‘ageing in place’, according to which older persons should have the right to stay at their current home as long as possible and receive necessary care services there (Vasara, 2015). The aim of ‘staying at home’ was in

concert with the goal of deinstitutionalisation. However, although the objective was to abolish institutional care, it was replaced by a new type of service housing. It was different in that it was defined officially as a 'home', where cost structure was different from institutional care: rent, care, and other services are charged separately whereas in institutional care everything was included in one fee (Hoppania et al., 2016, p. 53). Similarly, home care services were transformed. Kröger and Leinonen (2012) describe the process in home care as 'transformation by stealth', because no official decisions or major legislative changes were made to actively reform the services, even though many legislative changes made the subtle shift possible (Karsio, 2024). In publicly funded home care, the coverage decreased to include only the frailest old people, while buying services from private providers was increasingly supported by, for example, tax deductions and vouchers (Kröger & Leinonen, 2012). The home help that was once characterised as the first real social service for older people (Rauhala, 1996) became increasingly medicalised and integrated with home nursing (Kröger & Leinonen, 2012). A similar shift has been seen in older persons' services more generally (Rintala, 2004). As in home care, the coverage of residential care services has also been decreasing in recent years, whereas informal care increased during the 2000s (Karsio, 2024, pp. 29–30).

The growing number of older people in need of care has raised concerns of the cost of care and has, as Kröger (2019) calls it, resulted in 'demographic panic'. At the same time, there have been worries about the quality of care during the time of increasing costs that has been taken up in media from time to time (Hoppania, 2015, p. 86). During the 2000s, civic activism and recognition of problems in care for older people spurred initiatives to improve the situation, but it did not result in any legislative changes until 2012 with the introduction of the new Act on Supporting the Functional Capacity of the Older Population and on Social and Health Care Services for Older Persons (980/2012, henceforth Older Persons' Services Act) after grave deficiencies concerning care for older people came to light and forced the government to react (Hoppania, 2015, p. 90).

Even though the aim of the new legislation was to ensure sufficient services for older people and secure their right to care, it provided no subjective rights (Hoppania, 2015, p. 120). According to Hoppania (2015, p. 164), the hegemonic discourse in debates about the Act was that deficiencies arose from insufficient regulation, and not from insufficient resources. What was new about the Act was that it regarded participation in local decision-making (§ 11), the timeline for the provision of social services (§ 18), possibility for cohabitation for couples (§ 14) and the reporting of an older persons' needs (§ 25) (Hoppania et al., 2017). However, it has been criticised for not providing any practical guidelines for the realisation of its articles, as many provisions are expressed merely as principles (Hoppania et al., 2017, pp. 230–231).

Whereas the Disability Services Act states services that persons with disabilities can acquire, services for older people are organised according to the Social Welfare Act (1301/2014). Karsio and Anttonen (2013, p. 88) divide care for older people into three parts: (1) home care services and support services

(including transportation, meals-on-wheels, shopping assistance, for example), (2) residential care and (3) support for informal care. These parts still remain. However, these services are not secured by subjective rights.

2.4 Disability services and services for older people: miles apart?

Similar developments happened both in disability services and services for older people. Deinstitutionalisation, decentralisation, marketisation and the change from citizen to consumer have marked recent decades, affecting both service fields. Deinstitutionalisation progressed faster in disability services that aimed at zero residents in institutions by the end of 2020, even though this objective did not hold. In older persons' services, there were around 2,500 people living in institutions in 2021 (Finnish Institute of Health and Welfare, 2022), and institutional social care for older people is supposed to be abolished by the beginning of 2028 (Older Persons' Services Act 980/2012, statute 876/2022). However, institutional care for older persons had already started to be replaced by service housing or intensive service housing. The most significant change in the shift from institutional care to (intensive) service housing has been argued to be the cost structure in which older persons end up paying more (Hoppania et al., 2016, p. 53).

Even though there are many similarities in the trajectories of disability services and services for older people, some differences exist. One major difference is that most disability services are secured by subjective rights, while older persons' services are not. Older persons' services received its own legislation only in 2012, which was supposed to secure high quality services for older people and increase their participation in decision-making, but these guarantees were not secured by subjective rights, in contrast to disability legislation. Disability legislation further enforced rights, as a subjective right to personal assistance was added in the Disability Services Act in 2009. In other words, disability services are more secured than older persons' services.

Another difference is between health and social care. Even though institutional care has been decreasing both in disability services and older persons' services, services for older people have been increasingly medicalised (see e.g. Kröger & Leinonen 2012 about home care). Where disability services have aimed to enforce participation in social life, home-based care services for older people have seen a decrease in social care practices that would prevent social isolation (Kröger & Leinonen, 2012). Home support services like cleaning and shopping have nearly disappeared from municipal provisions, as home care has become increasingly medicalised (Kröger, 2019, pp. 9–10). Home-based services for older people have transformed from a wholesome service combining social and health care to covering only basic needs. Older people have been reported to experience care poverty even in the most basic needs (Kröger et al., 2019). In this respect, disability policies have moved in a different direction than

old age policies – even though the shift to more medicalised services has not been intended, but rather happened due to insufficient resources.

Both fields have experienced a shift to emphasise independence and the rights of the service users. For example, in the disability legislation reform, a major discussion has revolved around supported decision-making so that it would be possible for people with intellectual disabilities to participate in decisions concerning their lives. A person has a subjective right to supported decision-making in the new Disability Services Act (675/2023). The Older Persons' Services Act (980/2012) aimed to strengthen older persons' chances to influence and decide on their own services, but it does not mention possibilities for support in decision-making. In addition, there are no subjective rights to secure the possibility to participate in decision-making.

One major change affecting both services is the general social and health care reform in Finland. At the beginning of 2023, the provision of all social and health care was transferred from municipalities to brand-new welfare service counties. The aim of the reform was to increase regional equality and narrow health and well-being disparities between social groups of people (STM, 2024). It remains to be seen how this reform will affect services for older people and people with disabilities at the grassroots level.

2.5 Intersection of disability and ageing in Finnish social policy: overlaps and restrictions

Most of the disability services in Finland do not have age limits, and disabled people of any age can be entitled to disability services if they meet the criteria. At the moment, the criteria of the Disability Services Act (380/1987, § 2) stand: 'For the purposes of this Act, a disabled person means a person who, due to an injury or illness, has special long-term difficulties in carrying out ordinary activities of life.'¹ However, there are different criteria regarding different services: for example, personal assistance – a legal right to which was added to the Act in 2009 – is available for severely disabled persons, who are 'in need of assistance from another person necessarily and repeatedly due to a long-term or progressive impairment or illness in order to perform the activities referred to in subsection 1 [daily activities, studies, work, hobbies, societal participation, maintaining social interaction] and the need for assistance is not mainly due to illnesses and functional limitations related to ageing' (§ 8c). Personal assistance is, at the moment, the only disability service in the Disability Services Act that has an age-related restriction. As no specific chronological age limit is mentioned, the restriction is open to interpretations of what is and is not age-related illness or

¹ All translations in this section are made by the author, following the Finnish wording as accurately as possible. The Finnish term 'tavanomainen' has been translated as 'ordinary' or 'usual', even though in English, the closest term could be 'normal'. However, I chose not to use the term, since although the meaning of 'tavanomainen' is quite similar to 'normal', it does not have as negative an undertone as 'normal' has.

impairment. Confusions related to the application of the Act have had to be clarified in higher governing and legal bodies (e.g. Korkein hallinto-oikeus, 2012, p. 60).

Age-related restrictions in disability services are not unique to Finland, as they are also recognised elsewhere (Breda & Schoenmaekers, 2006; e.g. Jönson & Taghizadeh Larsson, 2009; Leahy, 2018; Mastin & Priestley, 2011). For example, in Sweden, personal assistance is available for people under the age of 65. One can keep the service after turning 65, but not increase it (Jönson & Taghizadeh Larsson, 2009). Similarly, in Ireland, public policies for people with disabilities and older people are separate, traditionally using an age limit of 65 to distinguish service user groups (Leahy, 2018).

Nevertheless, older people are a major user group in disability services. In Finland, over a half of all disability service users are over the age of 65, and especially transportation services (62% in the year 2022) and home modifications (58%) are used by older people (Sotkanet, n.d.). Less used are interpretation services (39%), personal assistance (37%) and service housing (35%). Figure 1 shows the change in the proportion of older people in disability services in 2010–2022. A slight decrease is visible in transportation services, whereas the share of older people has increased in other services.

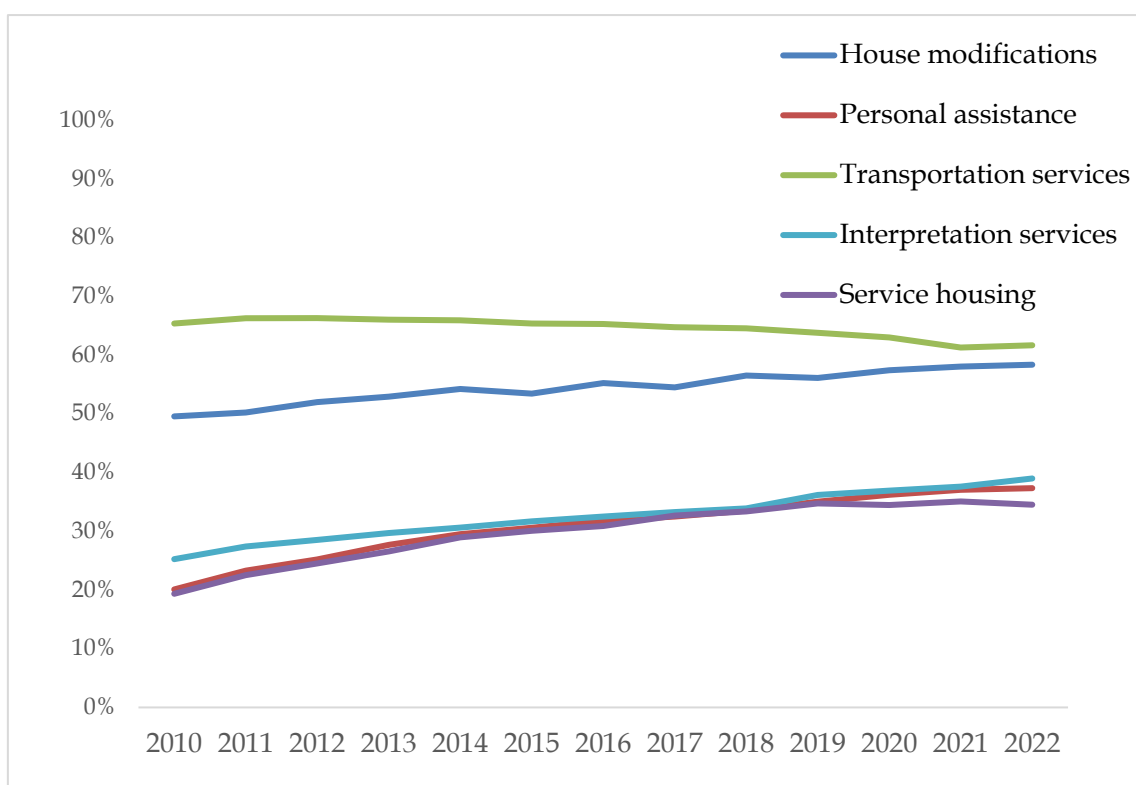


Figure 1. The share of people over 65 among the users of disability services in Finland 2010–2022 (Sotkanet, n.d.).

The Act that secures disability services is being reformed. It has been in the making for nearly a decade, and it was finalised in 2023. The new act concerning

disability services is planned to come into force at the beginning of 2025. An age-related restriction has been suggested to it on many occasions and in many different forms.

In 2017, a draft proposal for the Act suggested excluding from all disability services ‘older person[s], whose need for help or support is mainly due to illnesses or impairments which have started, increased or worsened with age, or which is due to age-related deterioration’ (STM, 2017a). After a comment round, the restriction was lifted in the government proposal in 2018, but it could not be voted on in the Parliament before the next government was formed. The new government continued the reform, and in a draft proposal in 2022, an age-related restriction was again introduced.

In the government proposal given to the Parliament in 2022, the suggested age-related restriction was similar to the one in 2017 as it included persons whose ‘need for help, support or care is mainly due to other factors than an illness that occurs in old age and is typical for old people, or general deterioration or frailty due to old age’ (HE 191/2022, § 2). However, the Constitutional Law Committee of the Parliament stated that the age-related restriction was problematic from the viewpoint of the CRPD and there are no sufficient acceptable grounds for the proposed age-related restriction (PeVL 79/2022) and hence, the restriction was lifted. In the modified proposal that was given to the Parliament at the beginning of 2023, the scope of application of the Act stated that a person could be eligible for disability services if they do not get required individual services according to any other law. The proposal was accepted, and it was planned to come into force in October 2023. However, the new government that was formed in the summer of 2023 postponed its implementation in order to further clarify the scope of application of the Act. In the spring 2024, a proposal for the Act was introduced for comments, and the age-related restriction was modified to include those disabled persons whose ‘necessary needs for assistance and support differ from usual needs at the persons’ stage of life’ (HE 122/2024, § 2). At the moment, the planned time of implementation is January 2025.

3 THEORETICAL FOUNDATIONS

In this chapter, I introduce the theoretical foundations on which my research stands. First, I present different conceptualisations of disability, both generally and in relation to old age. The conceptualisation of disability leans heavily on the sub-fields of disability studies, as well as their philosophical roots. After conceptualising disability, I introduce the broader theoretical underpinnings that stem from feminist and critical strands in disability studies, but also draw ideas from care ethics.

3.1 Conceptualising disability

Disability in old age can mean different things depending on the field. Ageing research and policy have traditionally viewed disability medically, rooted in the gerontological field, whereas disability research leans more on social approaches (Monahan & Wolf, 2014). The conceptualisation of disability matters in terms of policies: the way we understand disability dictates the responses to disability (Smart, 2009). For a medical understanding of disability, the right response is to focus on the impairment and the individual, whereas for a more social understanding, the emphasis is on how the environment could better accommodate disabled people and the responsibility for change lies with society (Smart, 2009).

The major disability-defining field, disability studies, is a widespread and diverse field, and definitions of disability are varied. Different subfields understand disability differently according to different ontological premises, but they may not align completely; for example, critical disability studies can include, but is not limited to, both the postconventional (Shildrick, 2012) and critical realist views of disability (Shakespeare, 2014; Vehmas & Watson, 2014) that underpin this dissertation.

Next, I briefly review what kind of understandings of disability exist in general, but also in the context of ageing. At the same time, I clarify how disability is conceptualised in this research.

3.1.1 Disability in general

The conceptualisation of disability has evolved from a tragedy and an individual medical problem towards more social approaches. It has been understood as a punishment of God, a tragedy of the family, a problem to be cured by praying or a broad range of medical interventions (Vehmas, 2005). With other social rights movements, the disability rights movement gained momentum in the 1970s and the understanding of disability started to change through the activism of persons with disabilities themselves.

Disability is often defined in terms of disability models, which can be broadly divided into two strands: individual and social models (Vehmas, 2004). However, today, disability studies has distanced itself from medical and individual models, and theoretisation focuses on different types of socially oriented models that understand disability as a broader phenomenon than a persons' medical and individual condition.

Today, perhaps the most influential model of disability remains *the social model of disability*, which was developed by Mike Oliver (1990) based on the social interpretation of disability, the latter of which was formulated by the disability activist group UPIAS together with the Disability Alliance in the 1970s. In *The Fundamental Principles of Disability*, they wrote: 'In our view it is society which disables physically impaired people. Disability is something imposed on top of our impairments by the way we are unnecessarily isolated and excluded from full participation in society' (UPIAS/Disability Alliance, 1976, p. 14).

The aim of the social interpretation of disability was to contest the traditional individual framing of disability. It claimed that disability is something that is imposed on top of impairments, and thus made the distinction between disability and impairment that continues to be the cornerstone of the social model of disability. Mike Oliver formulated this idea into the social model of disability that was adopted by, or rather became, the building blocks of, the academic discipline of disability studies in the UK. The social model has been treated as a complete theory of disability, even though Oliver later wrote that creating a whole theory of disability was not his intention, but rather a tool for necessary political change towards how disability is perceived in society (Oliver, 2013). In his commentary, he argues that the social model 'took on a life of its own' (Oliver, 2013, p. 1024) and many critiques target aspects of the model that were not intended in his original formulation. In Oliver's view, disability models are 'ways of translating ideas into practice' (Oliver, 2004, p. 20).

Even though the social model has been influential in generating permanent political change, it has attracted criticism as well. Oliver (2009) notes criticism from within the disability rights movement and scholarship that he takes up. For example, the model has been viewed as disregarding the body and experiences of living with impairments along with pain and suffering that cannot be taken

away by removing barriers (Crow, 1996; French, 1993; Morris, 1991a). Another strand of criticism claims that multiple identities have not been recognised by the model (Shakespeare & Watson, 2001), nor other oppressions like sexism, for example (Morris, 1991a).

To develop the social model, Thomas (2004) added 'impairment effects' to bring the body back into the picture and discuss difficulties of the impairments, but still to support the core ideas of the model. She terms this the relational social model of disability. Shakespeare and Watson (2021, p. 23) critique this model by suggesting that the impairment/disability division is not helpful to begin with, as it would be extremely difficult to make distinctions between the social and the medical in the complex experiences. Another critique targets the idea that impairment would be separate from disability in the sense that disability is socially created but impairment is not: Kafer (2013, p. 7) argues that both are dependent on a specific time and space and are thus socially constructed, calling this the political/relational model of disability.

As mentioned, the social model shares similarities to models developed in different cultural locations, or rather that there are many other social approaches to disability. In the US, for example, disability is often considered a minority identity (Siebers, 2008, p. 4), whereas relational or interactional models in the Nordic countries regard disability as a mismatch between the individual and the environment (Tøssebro, 2004; Traustadottir, 2009). This approach has sometimes been referred to as the Nordic (relational) model of disability (Goodley, 2014), and it is relevant for Finnish disability policies. However, Traustadottir (2009) notes that the Nordic approaches are not a theory, but rather a family of ideas locating the problem in the environment and the social context, similarly to the British social model, though it does not make distinctions between impairment and disability as the social models does (Traustadottir, 2009). According to this approach, disability is contextual, relative and relational (Tøssebro, 2004). It is contextual in that it depends on the situation and context whether a condition is disabling. Deafness, for example, would not result in a disability in a signing environment. The relativity of disability comes close to social constructionist perspectives, as disability depends on how it is defined in the current time and place. An example of this is how boundaries of intellectual disability have shifted throughout the years (Traustadottir, 2009). The Nordic model also has variations emphasising different aspects of it. For example, Gustavsson (2004) recognises five variations, of which three are more constructionist while the other two share the basic realist understanding of disability. The Nordic relational approach is important both for this dissertation and in the context of Finland.

Shakespeare and Watson (2021) note that disability studies in the US originated from different roots than it did in the UK and the Nordic countries. In the US, disability studies is more likely to be located in the arts and humanities, whereas in the UK and the Nordic countries, the 'home' of disability studies lies in social sciences, especially social policy and sociology. In North America, disability studies has been more interdisciplinary, drawing from other fields such as critical race, feminist and queer theory, and the conceptualisation of disability

tends to lean more on the cultural production of disability rather than its material aspects (Shakespeare & Watson, 2021, p. 20).

The CRPD utilised the social model of disability in its formulation. Its approach to disability has been argued to represent a non-radical social model (Harpur, 2012) or the biopsychosocial model (Leahy, 2018), for example. According to Degener (2017), it codifies a human rights model of disability that goes beyond the social model. In general, the convention adopts a human-rights-based approach that steers away from the previous disability models, but especially the medical model (United Nations, 2014).

Even though the approach in the CRPD was inspired by the social model, it more focuses on the recognition of disabled people as rights-holders and the States' duty to secure those rights. Therefore, it is not a specific model to define disability, but rather an approach to guide the responses to disability – as Lawson and Beckett (2021) argue. In their view, social model would provide more guidance on the ontology of disability, even though Oliver (2009, 2013) himself argues that the social model of disability should be seen more as a tool to improve people's lives rather than a full social theory of disability. According to Shakespeare and Watson (2021, p. 32), the CRPD works well as a 'moral compass', but they argue that rights-based approaches are individualistic, as they focus on a person and the personal rights they can demand to be respected.

According to Leahy (2021), scholars in the ageing-disability nexus often adhere to or utilise the biopsychosocial (BPS) model of disability. The BPS model is not just a model of disability, but rather a broader model of human functioning. It is the model of the International Classification of Functioning, Disability and Health (ICF) of the World Health Organisation (WHO), and widely used worldwide. Some scholars (Goodley, 2014, p. 17) conflate the Nordic relational model to the BPS model, or the ICF approach, as they both take into consideration the relations and intertwining of bodies and environments. The BPS model was developed as the biopsychosocial model of disease in the 1970s in the medical field by Engel (1977) to contrast with the biomedical model. Engel wanted to take a broader approach to understand the emotional and social aspects of illness as well. The model, however, was adopted widely and is also applied outside medicine. The biopsychosocial model of disability, or the ICF model, has been criticised for taking its starting point in biology, and applying psychogenic explanations to physical conditions (Kennedy, 2017) or as Shakespeare, Watson and Alghaib (2017) put it, 'blaming the victim, all over again'. It has also been argued to be used in a way that enforces the medical model (Chou & Kröger, 2017).

While disability models are important on a practical level, they rely on different ontological grounds. These ontological grounds are often also connected to different strands of disability studies. For example, the social model has been connected, on the one hand, to a materialist understanding of disability and, on the other hand, to a social constructionist view. In both views, disability is dependent on different cultures and environments and different times. Shakespeare (2014, p. 12) locates the British social model in the material sphere

and notes that, with a materialist view, disability is rooted in material social forces and very concrete barriers, whereas the social constructionist view regards more abstract aspects such as ideas, cultures and discourses. He associates the social constructionist views with cultural disability studies that emphasise the cultural aspects of disability, identity and representation issues, for example (Shakespeare, 2014, p. 47).

Shakespeare (2014, p. 72) situates relational and interactional models, along with the ICF model, in critical realist frameworks. In his view, the critical realist framework offers a wider range of perspectives – including feminist ethics of care, on which I lean as well – on disability compared to both social constructionist cultural disability studies and the materialist ‘strong social model’. Shakespeare and Watson (2021, p. 33) promote the critical realist approach (together with Amartya Sen’s and further, Martha Nussbaum’s capability theory) to ‘recognise mechanisms underlying experiences’, in a way that combines experiences of living with impairments in different settings and analysing disabling barriers. Even though the Nordic relational approaches are many, and connected to various ontological roots, this thesis utilises the critical realist perspectives associated with the relational approach (Gustavsson et al., 2005).

In addition to critical realist perspectives, this dissertation utilises a postconventional view. According to Shildrick (2009), the postconventional approach to disability is broadly aligned with critical disability studies. She notes: ‘[i]n the postconventional approach, all categories are slippery, fluid, heterogeneous, deeply intersectional, and thus resistant to definition’ (2009, p. 4). Therefore, defining disability according to the postconventional approach is difficult, as it steers away from a traditional disability/ability binary. The postconventional approach recognises that boundaries are neither permanent nor fixed. Similarly, crip theorist Alison Kafer (2013, p. 10) writes about disability as an assemblage (borrowing from Jasbir Puar) in which categories like disability are not simple entities but rather are formed in different encounters between bodies, actions and events, and are hence relational and fluid. Crip theory was first developed in the US and was heavily influenced by cultural disability studies (Karlsson & Rydström, 2023) that focus on the cultural production of disability (Bolt, 2019). Crip theory or crip studies are interwoven with feminist disability studies as well as queer studies that similarly aim to question the status quo and the ‘natural order of things’ (McRuer, 2006). As such, the approach in this dissertation comes close to crip theory, but still adheres to the broader feminist and critical disability studies perspectives that also inform crip theory. However, the presented models and conceptualisations of disability only scratch the surface, as there are countless ways of understanding disability. Here, the presented ones were chosen for the purposes of this research and as a consequence, many important approaches remain outside of the scope of this study.

3.1.2 Disability in old age

According to Leahy (2021), definitions of disability in old age differ from definitions of disability in general in that there are two concepts (and conceptual grounds) at work: one of disability and that of old age or ageing. The discourse of disability in ageing relies on the medical understandings of growing old whereas in disability studies, the conceptual ground is built upon more social models (Monahan & Wolf, 2014).

Disability is discussed in ageing studies often in dichotomous terms: healthy/active/successful ageing versus non-healthy and unsuccessful ageing, where the emphasis in policies is on healthy ageing (Naue & Kroll, 2010). The originators of the concept of successful ageing, Rowe and Kahn, included three conditions for ageing successfully. One should have low probability of disease-related disability, high cognitive and physical functional capacity, and active engagement in life (Rowe & Kahn, 1997, p. 433). In the late 1990s, their aim was to contest gerontology's focus on the pathological versus nonpathological and the 'deficit' model of ageing, and broaden the understanding of what constitutes successful ageing (Rowe & Kahn, 1997; Timonen, 2016, p. 33). Throughout the years, the concept has received criticism from both disability studies (e.g. Gibbons, 2016) and ageing research (e.g. Timonen, 2016). From the disability studies viewpoint, the concept can be considered to be ableist as it defines successfulness as the absence of disability (Gibbons, 2016). Timonen (2016, pp. 13-33) recognises multiple problems in the concept, such as that it does not account for societal and environmental conditions, but is instead based on the experiences of privileged groups.

Even though successful ageing as such has rarely been used in policymaking, it has made its mark on the more policy-oriented concept of active ageing (Timonen, 2016, p. 35). Healthy and active ageing have been emphasised policy goals at the international (Timonen, 2016; WHO, 2002) as well as the national level (STM, 2020). The UN has declared 2021-2030 the Decade of Healthy Ageing, with the vision of which 'is a world in which all people live long and healthy lives' (WHO, 2023, p. 2).

The aforementioned approaches to ageing emphasise health and are useful in contesting the stereotypical view of older people as frail and dependent (Larsson & Jönson, 2018, p. 370). This tendency to counter ageism by emphasising successful/active/healthy ageing has however been criticised to result in another prejudice, ableism, as it 'communicates the message that societal status is gained through health and functional ability' (Larsson & Jönson, 2018, p. 371). In other words, disability in gerontological terms is often used to describe an 'undesirable condition that, at best, should be limited in scope and compressed in time' (Kahana & Kahana, 2017, p. 5).

Even though social scientific sub-fields of gerontology have a vast engagement with societal and environmental issues, biomedical definitions of disability still dominate even the social scientific field (Leahy, 2021, p. 22). Social gerontology has theorised old age in terms of the active third age and the fourth age, the latter of which is associated with frailty and health decline (Gilleard &

Higgs, 2010, 2015; Higgs & Gilleard, 2014; Laslett, 1987). Disability in old age, especially disability that started in later life, is often linked to frailty and the fourth age in ageing research, and is therefore often viewed negatively and through a medical lens (Leahy, 2021, pp. 50–51).

At the same time when the policy emphasis and the goal are on active and healthy ageing, disability in older age is perceived as 'normal' and a natural part of the ageing process (Leahy, 2018; Priestley, 2006, 2014). Although disability in younger ages is considered disruptive, in old age, it is viewed differently. Therefore, older persons with disabilities may be seen as 'just old' rather than 'disabled', which contributes to the exclusion of older persons from disability policies and research (Leahy, 2018; Priestley, 2014).

Using a disability studies lens, disability in old age has been researched in terms of equality and discrimination in policies (e.g. Jönson & Taghizadeh Larsson, 2009; Mastin & Priestley, 2011), life course (Jeppsson Grassman, 2013; Priestley, 2003) and the intersection of ableism and ageism (Gibbons, 2016), for example. The ontology of disability in old age has yet gained less attention. When defining disability in old age, research has used the terms ageing with disability (AwD) and disability with ageing (DwA) or ageing into disability to refer to two separate types of growing old: growing old with an early-onset disability or growing old while acquiring disabilities in old age (Verbrugge & Yang, 2002).

The different experiences of AwD and DwA have often been studied in separate fields with different terms and, hence, also the conceptualisation of disability in old age can vary according to the field (Molton & Ordway, 2019). Molton and Ordway (2019) note that disability with old age is studied in ageing research, whereas long-term disability in old age (or, in Verbrugge and Yang's terms, ageing with disability) is studied in research on long-term disability, or disability studies. Disability in older age has, however, been largely invisible in debates in disability studies (Leahy, 2021, p. 8; Priestley, 2006, p. 136). In ageing research, disability in old age is often regarded in terms of impairment and functionality (Naue & Kroll, 2010), and discussed in more medical terms than disability in other ages (Larsson & Jönson, 2018; Mastin & Priestley, 2011; Naue & Kroll, 2010; Priestley, 2006).

However, since disability in old age has not been theorised as disability in the same way as in other ages but rather as something that happens with old age, the disability studies frameworks have not been that much applied to older persons with disabilities. As disability in old age is seen mostly in functional and medical terms, the research also uses medical, functional and individual frameworks rather than sociomaterial ones. Paradoxically, older persons with disabilities are not considered 'disabled' but they are not 'abled' either. Although activeness in old age is celebrated, impairment is already associated with old age. Old age may be considered a time of decline and disengagement (Cumming & Henry, 1961), and therefore older disabled people are not expected to participate in society anymore. This assumption leads to accepting the exclusion of older persons from disability discourses, since impairment is equated with old age and therefore 'normal ageing' and a normal life course.

3.2 Critical feminist disability studies and care ethics

The conceptualisation of disability in old age, and its difficulty, is at the heart of this dissertation. In this research, disability is recognised as a complex concept and thus, a strict, all-encompassing definition is not what this study strives for. This section aims, however, to clarify the research fields and theoretical assumptions this dissertation leans on. This dissertation utilises critical and feminist disability studies, but also draws from feminist and critical care ethics that in some instances come close to the beforementioned.

Disability studies and activism grew with other civil rights movements, and in the 1980s, contributions from scholars focusing on disability and feminism began to increase (Bê, 2019). According to Garland-Thomson (2002), disability studies has done a lot of 'wheel reinventing' without noticing that feminist theory has been doing similar work for some time. In her view, disability studies could benefit from feminist theory, as feminist theory could benefit from disability studies perspectives.

Early feminist disability scholars argued that feminism lacked awareness of disability and inhibited ableist ideas in combating stereotypes of women. For example, Fine and Asch (1988, p. 4) note: '[p]erceiving disabled women as childlike, helpless, and victimized, non-disabled feminists have severed them from the sisterhood in an effort to advance more powerful, competent, and appealing female icons'. The stereotype of the dependent disabled person was forceful, even though the disability movement contested it and began to reframe the definition of independence. Here, the emancipatory models of disability, most notably the social model of disability, have been beneficial in contesting the stereotype by exposing the ableist ideas and misconceptions about being disabled (Bê, 2019, p. 364).

Scholars have pointed out specific challenges faced by disabled women as well as the relative disadvantage compared to disabled men and, hence, the need to acknowledge gender differences (Begum, 1992, p. 72). In addition, both the feminist movement and the disabled people's movement were argued to lack acknowledgement of disabled women's viewpoints (Deegan & Brooks, 1985; Fine & Asch, 1981, p. 242; Morris, 1991b). For example, Morris (1991b, pp. 28-29) argued that in feminist discussions on carers, women needing physical assistance are not generally included in the category of 'women' who care for 'dependent people'. Critically integrating feminist perspectives into disability frameworks, feminist disability studies, as Garland-Thomson (2005) calls it, started to form.

Scholars from both feminist disability studies and critical disability studies argue that disability is a universal experience that touches every family in some way, and if one lives long enough, everyone (Garland-Thomson, 2002; Shildrick, 2012). Being able-bodied is thus only temporary (McRuer, 2013). However, Shildrick (2012, p. 34) critiques this notion as it also is rooted in the disability/ability binary – as if one would simply cross the border from able-bodied to disabled. According to her, in reality, there is no simple distinction

between different forms of embodiment and perhaps one reason for disability being so feared is that the boundaries of disability are permeable and common. According to Garland-Thomson (2002, p. 336), 'disability is the most human of experiences'.

Shildrick (2012) presents a critique of the social (constructionist) model that emphasises the disabling environmental structures. According to her, it is not enough to create formal structures to eliminate the discrimination and exclusion of disabled people. It is important to understand the underlying values, attitudes and subconscious prejudices and learn why we fear disability and different embodiment. According to Shildrick (2012), there may be improvements in policies to ensure a more equal society, but often the changes do not disturb the disabled/nondisabled binary, as the changes happen in a certain normative context. In a similar vein, she argues, we are all part of the same 'sociocultural imaginary' and therefore responsible for rethinking it, regardless of our own individual embodiment (Shildrick, 2012, p. 36). Shildrick (2012, p. 36) urges disability studies to question whether demanding rights in the existing system is adequate – 'as though the problem was no more than one of material exclusion'.

Disability can only be understood in relation to ability and the idea of ability needs to be critically considered (Goodley, 2014). Garland-Thomson (2002) argues, similarly to Shildrick (2012), that the disability/ability system is not a natural state of being but rather a culturally constructed binary, one based not on biology but ideology. The system legitimises unequal distribution of resources and power and deems disabled people to be second-class citizens. Shildrick (2012, p. 34) writes from a postconventionalist viewpoint that all categories are 'slippery, unfixed, permeable, deeply intersectional, intrinsically hybrid and resistant to definition', and that the disability/ability binary is open to deconstruction. Critical thought recognises that the categories of disabled and nondisabled are not fixed (and problematises the whole notion of categorical clarity), but rather that all being is intersectional and there are multiple differences between all people that influence life (Shildrick, 2012).

This dissertation also employs ideas from (critical) care ethics that have a similar kind of undertones as critical and feminist disability studies. Care ethics or ethics of care is a moral theory that can be traced back to 1980 to Sara Ruddick's early work on 'maternal thinking' to recognise the distinctive thinking behind the practice of mothering in order to preserve life (Held, 2006; Ruddick, 1980). Carol Gilligan further developed the notion in the field of psychological theory, recognising moral reasoning aimed to enhance and preserve relationships (Fitzgerald, 2021; Gilligan, 1982). One key component of care ethics has been relationality and the interconnectedness of people, but also its appreciation of care as a value and practice (Held, 2006; Tronto, 1998). However, disability studies have had a difficult relationship with the concept of care (Kelly, 2013; Kröger, 2009). Disability activists and scholars have criticised the concept of care for portraying persons with disabilities as dependent and powerless. For example, according to Morris (1997, p. 54), '[p]eople who are said to need caring for are assumed to be unable to exert choice and control'. Choice and control, as

discussed in section 3.2.2, are the cornerstones of the Independent Living ideology in the disability movement.

This dissertation utilises care ethics critically within a disability framework. Research with a similar approach has been published earlier. Kröger (2009) identified similarities and opportunities of mutual learning between disability studies and care research and argues that there is a possibility for common ground. Morris (2001), even though at first critical, later suggested a version of ethics of care that would integrate disability perspectives and promote human rights in care. In a similar vein, Kelly (2013) argues for ‘accessible care’ that recognises the complex nature of care and the tensions that exist between different definitions of care, including care as oppression. Fitzgerald (2021) argues that instead of traditional care ethics, we need critical care ethics in understanding and organising long-term care. According to Fitzgerald, the critical difference between care ethics and its critical counterpart is that care ethics often sees all care as valuable and morally right, whereas critical care ethics delves deeper into how care is formed in socio-cultural-political contexts. The socio-ontological premise is the same: humans are interdependent and relational beings.

The main concepts of this research stem from the theoretical landscape of the mentioned research fields. Critical disability studies, as disability studies more generally, is interested in notions of equality and discrimination, along with the study of ableism. The concepts of independence, dependency and interdependence used in this research are important aspects in both care ethics and critical disability studies. These concepts align with Shildrick’s (2012) notions of the need to build formal structures in order to eliminate disability discrimination, but also to question the reasons behind fearing and rejecting disability. Regarding the latter, I employ ontological notions of human life and the concepts of in(ter)dependence that lie behind policies as well as the ‘sociocultural imaginary’ (Shildrick, 2012).

3.2.1 Equality and discrimination

Questions of equality and discrimination are fundamental to disability studies, or, as Goodley et al. (2019, p. 973) note, ‘[t]o contemplate disability is to scrutinise inequality’. In this dissertation, equality is studied concerning older persons with disabilities in disability policy in Finland. This section reviews equality in general, and then focuses on how equality has been examined in the context of disability and the nexus of disability and old age.

Equality has many conceptualisations and meanings, and it is not a simple idea that all would agree on (Baker et al., 2004, p. 21). In this research, I understand equality as what Baker et al. (2004, p. 23) would call basic equality: ‘[basic equality is] the idea that at some very basic level all human beings have equal worth and importance and are therefore equally worthy of concern and respect’. Human rights rely heavily on this assumption. However, this idea does not suffice when talking about disability equality: this abstract idea of equality is probably something we would all agree on, but it does not challenge inequalities

in people's everyday lives. What needs closer attention with regards to this dissertation is the reference group: equality compared to whom?

The question of 'compared to whom' is of utmost importance for disability rights. Older persons with disabilities are often in an unequal position compared to younger disabled people (Jönson & Taghizadeh Larsson, 2009; Larsson & Jönson, 2018; Mastin & Priestley, 2011). For younger persons with disabilities, comparisons are often to their non-disabled age peers, whereas for older persons, the comparisons tend to be internal - in reference to other service users, for example (Jönson & Harnett, 2016; Jönson & Norberg, 2023). In addition, disability in older age is considered 'normal'; hence, older persons are not considered disabled in the same way as younger people are (Priestley, 2006, 2014). The normality of disability in old age may have contributed to disability policies and activism excluding older persons (Hoppania et al., 2017; Jönson & Taghizadeh Larsson, 2009, Mastin & Priestley, 2011).

One underlying principle in Nordic disability policies is the normalisation principle (Tøssebro et al., 2012). According to the normalisation principle, originally related to people with intellectual disabilities, disabled people should be able to live a 'normal life' like their age peers (Nirje, 1970, 1976; Wolfensberger et al., 1972). However, this has been criticised for enforcing normative lifestyles and stereotyping groups (Jönson & Taghizadeh Larsson, 2009; Walker & Walker, 1998). Using the normalisation principle in a critical way, Jönson and Harnett (2016) have formulated an equal rights framework that could be used to claim rights in long-term care for older people. Jönson and Harnett argue that in older persons' services there is a tendency to make internal comparisons: comparing to other service users. In disability services, in contrast, comparisons are made externally: aiming for similar rights and justice that the 'ordinary citizen' has (Jönson & Harnett, 2016, p. 802). According to the equal rights framework, instead of using internal references, such as other care users, external references similar to disability policies would better ensure human rights for older people.

Both disability and ageing activists have attempted to make distinctions between disability and old age: ageing studies and activism to fight the negative stereotype that all older people are frail and passive, disability studies and activism to note that disabled people are not frail nor passive (as is associated with old age). However, both have happened at the expense of older disabled people, who are the 'unwanted stereotype' in each. According to Jönson and Taghizadeh Larsson (2009), one part of the institutional ageism inherent in disability policies can be a result of a longstanding fight against another prejudice, ableism.

According to Campbell (2001, p. 44), ableism is '[a] network of beliefs, processes and practices that produces a particular kind of self and body (the corporeal standard) that is projected as the perfect, species-typical and therefore essential and fully human. Disability then is cast as a diminished state of being human'. In other words, ableism is the assumption of ability, that is, favouring nondisabled people. Ableism holds close alliances to disablism, which means discrimination based on disability. In Campbell's words (2009, p. 4), '[d]isablism

is a set of assumptions (conscious or unconscious) and practices that promote the differential or unequal treatment of people because of actual or presumed disabilities'. Campbell (2009) argues that it is necessary to turn the focus from disability to a more in-depth examination of ableism.

Ableism plays a key role when discussing the dis/ability nexus, as Goodley (2014) would call it, also in relation to ageing. Gibbons (2016) argues that there is both ableism and ageism in the intersection of disability and old age. She introduces a concept of compulsory youthfulness that follows the lines of compulsory able-bodiedness by McRuer (2010), or compulsory heterosexuality in queer theory (Rich, 1980). The theory of compulsory youthfulness explores the intersections of ageism and ableism that create the societal assumption or expectation of staying youthful and nondisabled throughout the life course (Gibbons, 2016).

Kafer (2013) notes that ableism and the cultural ideas of normality affect not only disabled people, but everyone. She criticises the social model's distinction of impairment and disability from this point: if this distinction serves as a base for theorisation of disability, it makes it difficult to see how ideas of disability and able-bodiedness affect everyone. For example, she notes that anxiety about ageing can be a sign of compulsory able-bodiedness or -mindedness and the cultural ideals and norms of the body's form and function.

Just as normality and 'normal life' have been criticised as the ultimate goals in life, the ideal of independence has been questioned in both disability studies and care ethics. Feminist care ethics has instead talked about interdependence in a similar vein as independence in disability studies: independence can be achieved relationally, and no one is truly and absolutely independent. However, the view of independence and dependency differs between the two.

3.2.2 In(ter)dependence

Dependency is theorised in care ethics as well as critical disability studies. Disability studies has theorised that independence can be relational, but it has been criticised for continuing to hold independence as the ultimate goal of human life that everyone should strive for. Hence, dependency becomes something that should be avoided as much as possible (Kittay, 2011). In feminist care ethics, theorising of dependency recognises that we are all interdependent, but that we do need to talk about dependency to recognise different power relations in, for example, care relationships. The concept of independence, and by extension independent living, has different meanings depending on the field. The concept is at the core of disability research, policies and activism, as well as ageing policies. Independence is essential to the very concept of disability and, therefore, it is a key concept to examine at the intersection of disability and old age.

Disabled people have historically been regarded as dependent, similarly to older people and children, for example. Especially in the Western world, independence is the norm, and everyone strives to be as independent as possible. Disabled people, then, have been 'isolated through a stigma that is linked to

dependency and the need for care' (Kittay, 2007, p. 3). To break this stigma of dependency, the disability rights movement, and especially the IL movement, started to advocate for support to live independently. Within the IL movement, independence 'does not mean doing things physically alone. It means being able to make independent decisions. It is a mind process not contingent upon a normal body' (Heumann, 1977; quoted in Kittay 2007). In other words, the IL movement contested the idea that disabled people would be dependent by default and in need of care. Instead, the IL movement advocated for rights to be included in education, work, and society more generally.

Even though IL sees that independence can be achieved relationally, critics argue that the aim is to participate in a neoliberal world that values self-sufficiency and productivity, and that dependency is something to be feared. Kittay (2007, p. 4) argues that this may lead to disabled people adhering to questionable practices that 'mimic those of privileged groups who have taken for granted caring work, relegating it to unpaid or the worst paid labor'. She continues, '[f]or "independence" as the aim of a movement to include disabled people as full citizens of the human community only perpetuates the pernicious effects of the fiction that we can be independent' (Kittay, 2007, p. 5).

In contrast, the core of care ethics lies in the exact concepts the disability movement wanted to move away from: care and dependency. Feminist care ethics analyses caring as a practice but also as a broader feature in human life (Tronto, 1998) and dependency as an inherent feature of being human. Interdependence is a concept to describe the interconnectedness of everyone, and it is tightly linked with care: we are dependent on each other and each of us are and have been dependent on someone's care. Kittay (2011, p. 53) notes that care ethics has been criticized for being only suitable for private or informal spheres rather than challenging structures as the social model does, but argues, along with Held (2006) and Tronto (1998), for example, that care ethics would be suited and should be considered in the public realm as well.

In many ways, interdependence from care ethics and independence as understood in disability studies follow the same lines (Kröger, 2009): no one is truly and completely independent, and independence can be achieved through help. However, they have originated from different roots. The disability movement wanted to contest the thought that disabled people are always and necessarily dependent. The view of disability as an individual condition did not require that the structures change for disabled people to be able to work, for example, but rather the thought of disabled people as objects of care. As the disability movement started to form and demand rights, there needed to be structures that would allow disabled people to participate in society. It was necessary to contest the idea that all disabled people are dependent and in need of care, which forms the roots of disability activism and studies distancing themselves from the concepts of dependency and care. Another critical note is the power imbalance and inequalities resulting from that: on one hand, it can lead to oppression, and on the other, to paternalism – both of which are familiar to disabled people. The ideas of dependency and care have been the sources of

oppression that the disability movement arose to eradicate. It makes sense to steer away from the concept of dependency and aim for independence.

For care ethics, care and dependency are of interest, and something to be embraced rather than rejected. Interdependence notes that all people are interconnected and dependent on others, and independence and dependency shift throughout the life course. Interdependence can also be an argument for care: everyone needs care at some point in their lives, since dependency is part of being a human. Independence is relational in the sense that no one can avoid dependency: as Kittay (2007, pp. 4–5) argues, independence is fiction. The main aims and the roots of the concepts may be different, but a common understanding exists that human beings are connected and dependent on each other in many ways and support (be it care or assistance) is needed for humans to flourish. Kittay (2007, p. 6) argues for the de-stigmatisation of dependency with the help of care ethics as it would ‘serve both the disability community and the larger community better than an emphasis on independence’. In a similar vein, Hughes et al. (2005) argue that disability activists and feminists should find common ground in an ethics of care founded upon embodied interdependence.

In this research, the terms independence, interdependence and dependency are sometimes combined into one term: in(ter)dependence. This term recognises the complexity of the concepts and discussions around dependency and independence: people are interconnected, but dependency and independence fluctuate and form different kinds of combinations. This dissertation regards people as interdependent or interconnected, rather than considering one group as dependent and another as independent. However, as Kittay (2011) notes, the concept of dependency is necessary in order to discuss, for example, power imbalances and oppressive practices in care.

3.3 Summary of the theoretical foundations

This dissertation is positioned within Nordic critical feminist disability studies. Disability research in the Nordic countries has been closely connected to the welfare state and important policy developments and principles, such as the normalisation principle. Similarly, this research is closely connected to disability policy in Finland. In addition, this study utilises the relational approach to disability, but recognises the complexity of disability research where ‘no one theory, approach, method or model can bring all the answers’ (Traustadóttir, 2004, p. 19). Disability in old age, in many aspects, continues to be theorised within medical and individual approaches, and this dissertation aims to use a broader framework, invoking features from critical and feminist disability studies and care ethics. The ontological foundation for this dissertation follows mainly critical realist perspectives, but borrows ideas from the postconventional approach as well. The intention of this dissertation is not to develop theory by using disability as an ‘object of curiosity’, a concern that Goodley et al. (2019) express regarding the increasing interest in disability theories. This dissertation

aims to develop policies as well as theories that could better recognise older persons with disabilities: the focus is on promoting equality and the ways in which theory and research can contribute to this goal.

Equality and discrimination include aspects of ableism and further, normality. In many countries, disability policies overlook older persons, and one reason for this exclusion has been suggested to be the naturalness of disability in old age. Equality is achieved through comparisons which for older persons are different than for younger people, and normality and intersecting ageism and ableism persist in the background. This dissertation aims to question normality and, from that viewpoint, discuss inequality in disability policy. Equality works as a starting point for examining complex webs of ableism and ageism in the intersection of disability and old age.

One starting point in my dissertation is the tension between independence and dependency that I see as intrinsic to the very question of being a human. Persons with disabilities have been treated as dependent objects of care, which gives reason for the rejection of the whole concept of care within disability studies and activism. The Independent Living movement has contested this concept of dependency and introduced independence as a relational concept, similar to interdependence in care ethics. However, ageing policies have leaned on ideals of healthy and active ageing according to which disability (and with it, dependency) is to be avoided as much as possible. In disability frameworks, one can be 'independently dependent' (Barnes & Mercer, 2006) but in the ageing sphere the binary of independent versus dependent seems to persist. Nevertheless, this dissertation employs a critical view of the emphasis on independence in the IL ideology. The concept of in(ter)dependence is used to further develop the understanding of living at this intersection, but also of disability in general.

4 METHODOLOGY

In the articles included in this dissertation, various sources of data and multiple methods were used to analyse the topic from different viewpoints in order to obtain as wide of an understanding as possible. However, each article utilises the qualitative approach. Table 1 presents the data, methods and analytical tools used in the articles.

Table 1. Methodological information on the articles

Article	Article I:	Article II:	Article III:
	Debating an age-related restriction in the upcoming disability legislation reform in Finland	From conceptual gaps to policy dialogue: Conceptual approaches to disability and old age in ageing research and disability studies	Being independently dependent: Experiences at the intersection of disability and old age in Finland
Analytical tools	Justification theory Equality	Conceptual approaches to disability	In(ter)dependence
Data	Comments on the disability services legislation draft proposal in 2017, especially the parts discussing age-related restriction	Ageing research and disability studies literature <i>(Ageing & Society and Disability & Society)</i>	Written accounts of older persons with disabilities
Research methods	Problem-driven content analysis (Krippendorff, 2019)	Selective literature review	Reflexive content analysis (Braun & Clarke, 2006, 2016, 2019)

Article I focused on the disability legislation reform in Finland. In it, public comments on the draft proposal for a new disability services act in 2017 were analysed. The justification theory of Boltanski and Thevenot (1999) as well as the concept of equality were used as analytical tools. Krippendorff's (2019) problem-driven content analysis was used as an analysis method. Article II, co-written with Hisayo Katsui and Teppo Kröger, examined conceptual approaches to disability in ageing research and disability studies. We utilised a selective literature review, as we analysed only two journals. However, the analysis was conducted in a systematic manner. Article III, co-written with Teppo Kröger, concentrated on experiences of living with disability in old age. The experiences were collected through an open call for letters, and the data was analysed using Braun and Clarke's (2006, 2016, 2019) reflexive content analysis.

Article I was single authored, while Articles II and III were co-authored. In Article II, all authors contributed to the formulation of the research problem and reviewed and commented on various versions of the manuscript. In addition, Hisayo Katsui contributed to data analysis and the writing of the draft. In Article III, Teppo Kröger contributed to the conceptualisation of the manuscript and to the review, comments and editing of the drafts.

4.1 Analysing policy documents

For the first article, policy documents related to the disability legislation reform in Finland were used. Other kinds of background material were utilised for the study, including the government bill, a previous report of the law preparation, other supplementary material related to the bill, and meeting minutes of the parliament. However, in the end, the analysis focused on the comments given to a draft for the government proposal for a new act regarding disability services in 2017 (STM, 2017a).

A rationale and a detailed rationale for the draft Act were attached to the draft proposal of 2017. The draft Act that could be found within the draft proposal, and the age-related restriction was presented in § 2.3. The sub-section states that the Act would not be applied to an older person, 'whose physical, cognitive, mental or social functional capacity is impaired due to illnesses or injuries that have begun, increased or worsened with high age or due to degeneration related to high age'. In the other sub-sections of § 2 in the Disability Services draft Act, more general definitions of disability and organisation responsibilities are provided.

All the documents were presented in the call for comments that was open from 17 May to 17 July 2017. Altogether, 123 actors were requested to provide a comment on the draft proposal. Those actors included ministries, governmental authorities, municipalities, political parties and non-governmental organisations (NGO). In addition, the Ministry of Social Affairs and Health published a public call for comments to acquire comments from other actors that wished to contribute. After the call was closed, the ministry published a summary of

statements that depicted a broad picture of what was said in the comments. According to the summary, 162 comments were received. The largest proportion of all the commenters were NGOs (41%), with municipalities (11%) being the second largest group (STM, 2017b). However, there were only 159 comments available online. I analysed the written comments concerning the age-related restriction, which was mentioned in 97 of the 159 comments.

In the 97 comments, there were 161 argument units, as the comments contained multiple arguments. The comments were in Finnish or Swedish, and for the article, the quotations were translated from the original languages to English by the author.

The comments were publicly given and freely available on the website of the Ministry of Social Affairs and Health (STM, n.d.). The comments were delivered on a questionnaire form that included multiple choice questions as well as open questions. The questionnaire included 41 questions, of which four concerned the age-related restriction. Table 2 presents the multiple-choice questions that concerned the coverage of the Act and their answer options, as well as the open question – Question 8 – which were analysed for this article. In addition, Question 41 was included since it provided the commenters with an open space to write clarifications and additional comments on the questionnaire. Some commenters used the space to elaborate more on the age-related restriction, and therefore the answers were relevant to my analysis.

Table 2. Questions regarding the coverage of the Act in the questionnaire form for comments on the draft proposal for the new disability legislation²

Question	Answer options
5. On the basis of § 2, is it clear in which situations the special Act is applied?	Yes No No opinion
6. In the 3rd sub-section of § 2, a restriction to the coverage is provided. Is the restriction clear?	Yes No No opinion
7. Is the restriction necessary?	Yes No No opinion
8. Other notions about the content of § 2.	[Open space]
41. What else would you like to bring up concerning the draft proposal?	[Open space]

(Source: STM, n.d.)

The comment forms were then downloaded from the website for analysis, and they amounted to 2,321 pages. After that, the written comments regarding the

² Translated from Finnish by the author.

age-related restriction were extracted, which added up to 29 pages with font size 8 and 1.0 spacing. Only the written comments that discussed the age-related restriction were included, while submissions that commented only on other aspects of the draft proposal were excluded. Table 3 shows the total number of submissions retrieved from the website and the number of comments included in the analysis.

The commenters had to identify their position, that is, whether they are, for example, governmental authorities or NGOs. In the categorisation in the research article, the commenters own identification was mostly used, but within the NGOs, disabled people’s organisations (DPOs) were categorised separately. This categorisation was made because this legislation reform specifically concerns their members, and therefore their answers may differ significantly from, for example, NGOs of persons who work with disabled people (physiotherapists etc.). The categorisation of the commenters is presented in Table 3.

Table 3. Background information of the comments given to the draft proposal for the new disability legislation in 2017

Commenter	Submissions retrieved from the website	Written comments included in the analysis
Municipality	18	16
Joint municipal authority for a special care district	8	7
Other joint municipal authority	9	6
A ministry	6	3
Governmental or other public authority	16	7
NGO	64	40
DPO	29	22
Other types of NGO	35	18
Disability service user	6	0
Other private person	7	5
Other commenter	25	13
Total	159	97

As I myself categorised and therefore interpreted which NGOs represented disabled people (i.e., which are DPOs), and as they themselves could not express their identification on this matter, my interpretation can be contested. Some may not consider themselves DPOs and some may not be recognised by others as such. However, DPOs were interpreted by their position in this legislation, namely, whether they are potential users of disability services or not. Of course, not all DPOs inhabit the same position in relation to the disability legislation reform. For example, it has not been questioned whether persons with cerebral palsy

(represented by the CP Association) should be eligible for disability services, but the eligibility of persons with certain kinds of visual impairments (represented by, for example, the Finnish Federation of the Visually Impaired) has been contested and this draft proposal of 2017 threatened it even further. Therefore, the 'burden of proof' for eligibility fell on the compromised DPOs that had to argue *why* they should be included. The comments were analysed with these differences in mind.

As an analytical tool, Boltanski and Thevenot's justification theory was applied. The justification theory is well-suited to analyse the different arguments in public debates, and it has been used, for example, in analysing opioid maintenance treatment (Perälä et al., 2013), private transport use (Salminen, 2016) and an ecological dispute (Hast, 2013). In their theory, they argue that many social situations require justification of action: these justifications are based on certain sets of values they call the *orders of worth* or *economies of worth* (Boltanski & Thévenot, 1999). The disputes where justifications are needed follow certain rules, such as when the arguments need to be relevant and objective. Boltanski and Thevenot (1999, p. 361) take a dispute of two drivers after a collision as an example. In the dispute over responsibility, one cannot cast the blame on the grounds that they're having a bad day because their boss humiliated them – this is a personal reason and not applicable in an objective dispute. After excluding personal and irrelevant reasons, the actors can enter the 'scene' with a common understanding of relevant justifications. These justifications are based on different sets of values, or 'orders of worth' in Boltanski and Thévenot's words. In relation to the disability legislation reform, I wanted to see what kind of arguments and justifications were deemed relevant and what kind of justifications were used.

The arguments are justified using six (or in its later formulations, seven) 'worlds' or 'economies of worth', namely *inspired, fame, domestic, civic, industrial* and *market worlds* (Boltanski & Thévenot, 1999). These worlds present the idea of a 'good life' based on Western classical root texts and introduce what is valued in those spheres (and in good life). For example, an argument could be justified through the *market world*, in which finances are valued. Hence, one could argue that something is not right because it costs a lot of money.

In contrast, an analysis focused on the *civic world* would reveal opinions and views on equal rights. The civic world values the common good of all people, aside from all personal desires and wishes. Equality is important, as the collective is more important than individuals. From the perspective of the civic world, concerning the disability legislation reform, the hope is that, above all else, legislation would serve the common good and advance equality in society.

In the article, the statements were first categorised according to these worlds. The statements were read, and the sections grounded in one (or more) of these worlds were coded. As many arguments were justified through equality, I chose to focus on that and discarded the sections that were based on worlds other than the civic one.

After choosing to focus on equality, the analysis was continued with Krippendorff's (2019) problem-driven content analysis. Content analysis has developed from quantitative analysis focusing on frequencies to more interpretive examination suitable for the qualitative paradigm (Graneheim et al., 2017, p. 29). Even though Krippendorff's (2019) formulation of content analysis leans more on the positivistic side, it provided a basis on which to build. Krippendorff identifies problem-driven analysis as beneficial for understanding epistemic questions, that is, acquiring knowledge that is currently unavailable and which could be found by systematically analysing existing texts. By analysing the existing commentary on the age-related restriction, this dissertation sheds light on why the restriction cannot be agreed upon from an equality perspective.

Content analysis can be inductive, deductive or abductive or, in other words, data- or text-driven, theory- or concept-driven or a combination of these (Graneheim et al., 2017). Krippendorff (2019, p. 387) clarifies this further: inductive analysis moves from particular questions to generalisations whereas deduction applies generalisations to particular contexts. Here, Krippendorff (2019, p. 387) maps his problem-driven analysis as abductive – combining theory and data to use particular data to answer a particular research question.

The problem-driven content analysis consists of nine stages, from creating the research question to finding relevant texts to allocating resources (Krippendorff, 2019, p. 386). Here, I have categorised the nine stages into three parts, which are then applied to my own research: (1) the 'what': formulating the research question, establishing the relevance of the text to the research question, finding the relevant texts, defining and identifying the specific units in the texts to analyse and finding the sufficient amount of these units; (2) the 'how': formulating the coding strategies and keeping notes of the procedures, choosing the right analytical actions, and (3) finalising the plan: creating standards for the reliability of the data and significance of the results, and allotting sufficient resources for the analysis steps. For Krippendorff, the analysis would require standards for statistical testing to establish statistical significance levels, but in this research, the quantitative aspects of the analysis were omitted and only features suitable for this qualitative study were used. Next, the following describes the steps of the analysis, applying this framework of content analysis.

First, a research question needed to be formulated from the problem that was presented. According to Krippendorff (2019, p. 386), research questions in content analysis include the following three characteristics: the content analysis addresses a previously unstudied phenomena in the context in question, the question can have different potential answers, and the question could also be answered in some other way, at least in principle. In this research, the following characteristics were identified: the argumentation of an age-related restriction in the context of Finnish disability legislation reform has not been studied before, the equality-related justifications had many potential answers, and the question could have been answered also, for example, by interviewing people. The specific units to analyse were the parts of the statements that had some indication of

equality, and the amount of those units was sufficient, but also not too numerous to conduct analysis. However, at this point, it needs to be recognised that these statements were given to a proposal for an Act that would dictate disability services for many: the interest groups had to act in their benefit, in a situation that threatens to reduce services.

Second, the coding was carried out and documented. As the amount of text was manageable for a single researcher, there was no need to invite a team of coders and write clear instructions, as Krippendorff (2019, p. 394) recommends for content analysis of large data corpuses. For him, the replicability of analysis is one of the most important aspects for this kind of content analysis, but as this analysis required a certain amount of interpretation, it is not possible to ensure complete replicability. Krippendorff suggests strategies of coding with predetermined coding instructions, but in this research, the data was approached almost as in text-driven analysis. I had knowledge of equality theories, but the themes I have derived mostly from the data. For the analytical procedures, Microsoft Excel was utilised to map the data, as the text corpus was small enough to reread and recode.

The third step was to make sure that the quality of the analysis was sufficient. For Krippendorff, this part includes statistical testing to make sure there are no reliability issues between coders, for example. However, in this research, it is more important that the analysis was conducted systematically and carefully. Each statement that was included in the analysis was carefully considered and interpreted as objectively as possible. I also recognise that there are limitations to this analysis that need to be considered, the context of the statements (the need to influence decision-making related to essential services) in particular. In addition, the actors have answered an open question, and the conceptualisations of equality found in the statement are, of course, my interpretations guided by the aforementioned theories.

Other limitations exist in relation to the data collection and analysis. Only the statements were analysed, and the previous policy documents leading to that moment were utilised as background information. In addition, some of the comments could have been interpreted as obvious and not comparable, for example, the comments of legal experts and small NGOs of a small disability group.

In the end, only a small portion of the statements were analysed. Of the 97 comments, only the comments including equality-based justifications from the civic world perspective were analysed. This amounted to 59 analysable comments.

4.2 Selective literature review

For the second article, we wanted to study conceptualisations of the intersection of disability and ageing in disability studies and ageing research. From each field, one respected and established social scientific journal that published articles in

English were chosen. Two journals best fit our aims and were sufficiently comparable: *Ageing & Society* (AS) and *Disability & Society* (DS). The basic information on the journals can be found in Table 4.

Table 4. Information on the journals

	<i>Disability & Society</i>	<i>Ageing & Society</i>
Established	1986-1993 as <i>Disability, Handicap & Society</i> 1994 onwards <i>Disability & Society</i>	1981
Publisher	Taylor & Francis	Cambridge University Press
Impact factor 2022 *	2.4	2.5
Volume per year	10 issues per year	12 issues per year

* As stated on their websites.

As can be viewed from Table 4, there are some differences between the two journals, but these are not drastic. The journals' volumes are distinct, but both have published enough articles at the intersection of disability and ageing to make the study of their conceptual approaches possible. Both journals are published by UK-based publishers, but they welcome – and accept, as was visible from our review – submissions from all over the world.

Both were established in the 1980s, even though the history of the two research streams is very dissimilar. In the 1980s, disability studies had just arrived on the academic scene after disability activists had started to advocate for disability rights around the world. Disability activism shifted the focus from the medical to the social: the influential social model recognised environmental barriers as creators of disability, on top of the individual impairment. Before that, the study of disability was aimed at curing and rehabilitation of the impairment, but in the 1980s it became a subject of social scientific inquiry as well. *Disability & Society* (then *Disability, Handicap & Society*) was the most influential among the first academic journals of social scientific disability studies. Disability is still studied in health and rehabilitation research as well, but that research remains separate from social scientific disability studies. This history, being a part of a continuum started by disability activism, most likely still has an impact on the contents of the journal. Ageing research has stemmed from different grounds. There has not been the same kind of social movement and resistance to the medical approach as there has been in disability studies. In ageing research, health and social sciences often overlap (for example, social gerontology), although the scope of ageing research is broad in both health and social sciences.

Even though neither of the journals explicitly identified as 'social scientific', the topics mentioned in their scopes suggest that they welcome articles that study social circumstances rather than health. On the website of *Ageing & Society*, the

journal states that it is 'an interdisciplinary and international journal devoted to advancing the understanding of ageing and the circumstances of older people in their socio-economic and cultural contexts'. As the journal is interdisciplinary, it has also published articles using perspectives from disability studies, and the scope of the journal does not restrict cross-disciplinary approaches. It focuses on the 'circumstances of older people in their socio-economic and cultural contexts', and could thus be expected to include more societal viewpoints than gerontology in general. In addition, *Ageing & Society* states that it is 'committed to publishing original and high-quality research papers that substantially contribute to ongoing debates in social gerontology'. According to this statement, the scope of the journal is more social than traditional gerontology, and it thus fits our purposes and serves as a point of comparison to social scientific disability studies.

The end of the scope statement affirms that '*Ageing & Society* welcomes submissions using different theoretical and methodological approaches as long as they aim to advance research, policy and practice and encourage the exchange of ideas across the broad audience of multidisciplinary academics and practitioners working in the field of ageing'. Therefore, the journal adheres to a multidisciplinary approach and encourages new ideas from other fields as well: no restrictions are placed on collaboration or exchange of ideas with disability studies. Policy is mentioned in the statement, too, which fits our purposes well as we were looking for the possible impact of conceptual confusion on social policies.

According to their website, *Disability & Society* is 'an international disability studies journal providing a focus for debate about such issues as human rights, discrimination, definitions, policy and practices. It appears against a background of constant change in the ways in which disability is viewed and responded to'. The journal states that they are interested in debates about human rights, discrimination, policy and practices, and these themes are what can be anticipated. Discussion of the definition of disability can be expected as well, and because of that, more varied conceptualisations of disability can potentially be found in this journal than in *Ageing & Society*. Similarly to *Ageing & Society*, the journal focuses also on policy and practices, which is favourable for our aim to compare the two journals.

The self-description of *Ageing & Society* did not mention the voice of older persons, but *Disability & Society* states that '[t]he journal publishes articles that represent a wide range of perspectives including the importance of the voices of disabled people'. In this emphasis these journals differ, and more participatory research and viewpoints of disabled people can be expected to be found in *Disability & Society*.

Relating to definitions, *Disability & Society* invites 'papers where definitions of disability are acknowledged to be relative and segregated approaches are seen as inadequate and unacceptable - placing greater emphasis on inclusion. Perspectives are also invited which critique ways in which policy intentions may or may not have the desired effects in the everyday lives of disabled people'. This quote shows the critical view the journal has on definitions and on policy

interventions. It can be anticipated that *Disability & Society* perhaps places more importance on definitions than *Ageing & Society* does: at least there is no mention of them in the description of the scope of AS. *Disability & Society* has been criticised for preferring articles that are sympathetic to the social model of disability, but according to Oliver (2004), it has also published multiple articles critiquing and questioning the model. There is no mention of any models in the scope of the journal and the current scope emphasises instead more varied and critical views related to definitions.

The scope of *Disability & Society* also contains a mention of engaging with other oppressed groups: '[d]isability scholars engage and identify with other oppressed groups and the journal leads the way in forging new paths for disability studies'. The aim of 'forging new paths for disability studies' looks promising from our viewpoint, particularly in relation to ageing research.

The selective literature review was chosen for its systematic approach and ability to synthesise large amounts of studies to answer one question, even though it does so in a narrower sense than in a systematic review. The aim was to find out the conceptual frameworks as well as to make comparisons of large research streams, and this led us to a selective literature review. In order to compare ageing research and disability studies, our searches needed to be limited to journals that focus distinctly on ageing or disability. The range of different ageing journals compared to disability studies journals was dissimilar and that is why we decided to focus on two journals that were comparable enough for our study.

The field of literature review in itself is wide, and there are multiple different approaches to it. A systematic review is in the most comprehensive end of the spectrum, whereas reviews with no specified method, sometimes called narrative reviews, are at the other (Aveyard, 2019, p. 12). This literature review is not as rigorous as dictated by the Cochrane Collaboration – an organisation ensuring the provision of high-standard systematic reviews of medical interventions and providing strict guidelines for them – but still follows the same procedures and proceeds in a highly systematic way. However, we did not search for unpublished material and limited the search to two journals, an approach that is unconventional in traditional systematic reviews. This approach means our literature review is selective and not as inclusive as a purely systematic review.

Originally established in the medical field to help the decision-making of clinicians, systematic reviews have been utilised in synthesising research quantitatively. However, qualitative systematic reviews as well as a mixed-method approach have become more popular (Cranwell, 2021). Our analysis was qualitative, as we analysed conceptual frameworks thematically without any quantitative testing. Nevertheless, we followed the steps of a systematic review (Aveyard, 2019; Dempster, 2003): we refined the research question, formulated a protocol with plans and a design of the search, retrieved the articles and extracted the data, and finally did our analysis and drew conclusions. For this article, the review was mostly done by me, but the design was agreed on by all and decisions were made collaboratively. In addition, Hisayo Katsui participated in the

thematic analysis. What follows is a presentation of the steps that were taken to conduct the review.

First, *the research question* that would be answered with this review was refined. As we wanted to explore the conceptual approaches of each of the journals and compare them, we first needed to ask: (1) what are the key conceptual approaches to older persons with disabilities used in ageing and disability studies? According to Dempster (2003), the research question of a systematic review should be one that could not be answered by primary research: our question aims to find out conceptual approaches in the research fields, and it could not do so without systematically reviewing the research. Secondly, we wanted to compare the conceptual approaches that we found in the two journals, asking: (2) what are the main conceptual differences between the two research fields?

Second, *a protocol was formulated*. Eligibility and validity criteria were established as well as a search strategy and an analysis plan for the articles. Multiple rounds of test searches were conducted in different databases, including, for example, Scopus, Web of Science, ProQuest, Social Services Abstracts and Academic Search Elite. In the end, Web of Science (WoS) was chosen for the final searches, since both journals are indexed there, and the hits seemed the most comprehensive. The information on where the journal was indexed was found from the journals' websites. There were options that provided similarly good results for one of the journals in other databases, too, but often they were not sufficient regarding both journals. In addition, the information on the articles was easily retrieved from the WoS website and exported into a Microsoft Excel file with all the articles for both journals.

We chose to use the word 'disability' as our search term for indicating disability-related articles (and exclude, for example, impairment) since it bears different conceptualisations in the two research streams at the intersection of disability and ageing. To obtain the most relevant articles, we decided to do two searches: first, with the same search terms for both journals which amounted to 113 articles in AS and 173 articles in DS, and second, with different search terms (disability in *Ageing & Society* and ageing in *Disability & Society*). The second search reached 31 articles in AS and 22 in DS. The search terms are presented in Table 5.

Table 5. Eligibility criteria for the selective literature review

	DS	AS
Search terms in the primary search	old OR older OR ageing OR aging OR aged OR elder* AND disab* (ALL FIELDS)	
Search terms in the secondary search	old OR older OR ageing OR aging OR aged OR elder* (TOPIC)	disab* (TOPIC)
Inclusion criteria	Peer-reviewed Regards old age and disability Published in 1990–2020	Peer-reviewed Regards ageing and disability Published in 1990–2020
Exclusion criteria	Book review or other commentary Does not discuss disability in relation to ageing into old age, but, for example, ageing from childhood to adulthood	Book review or other commentary Mentions disability briefly

Third, *the articles were retrieved and the data were extracted*. The citations and abstracts were retrieved from WoS and the titles were checked to see possible obvious exclusions. Also, the full articles were retrieved from the journals' websites to permit a more thorough search within the articles. The abstracts were skimmed through to see whether the articles really regard ageing and disability, and not only one of the two topics. During this phase, 61 articles were excluded in AS and 154 in DS. If the intersection of disability and ageing was not evident from the abstract, the article was searched for the search terms to see whether the article really fit our aims. In AS, 7 articles were excluded and 8 in DS during the review of the articles. After excluding the articles that did not fit our criteria, the data corpus was ready for analysis. In the end, there were 109 articles to analyse, 76 in AS and 33 in DS. Figure 2 shows the selection of the articles.

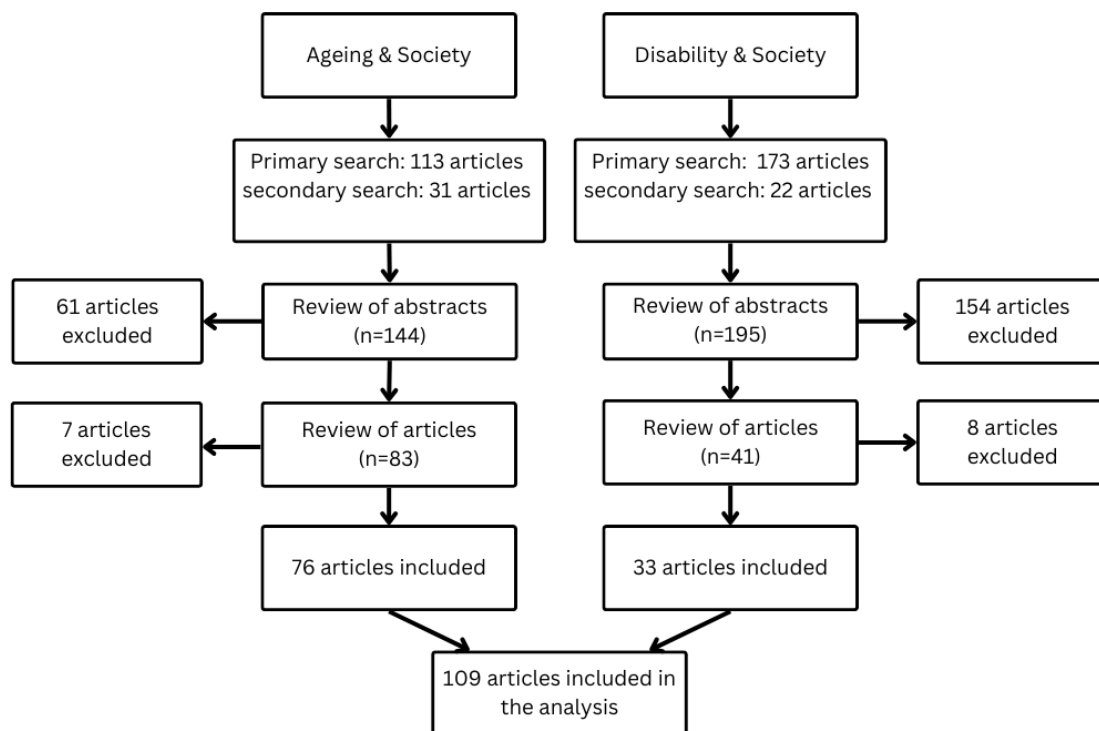


Figure 2. Flow chart of article selection

Fourth, *the articles were analysed thematically* to find answers to our research question. The analysis was performed abductively wherein there were theories that guided the examination of the conceptualisations of disability and ageing. However, we did not aim to find conceptualisations that follow, for example, the social model or the medical model but rather thematically analysed what kind of conceptualisations there were and formulated the final categories from there.

The analysis was carried out in three stages, each gaining depth from the previous one. First, Atlas.ti was utilised to find the most used words in the abstracts, which allowed a comprehensive view of the whole data corpus. This revealed some differences between the two journals, with the most common words in *Disability & Society* being 'disability', 'disabled' and 'people', and 'care' and 'disability' in *Ageing & Society*. In the second stage, the abstracts were read multiple times while taking notes in order to start forming codes. The articles were first coded by their abstracts, and if there was no indication of the conceptual ground, the parts where disability was mentioned was searched and the code was formed based on those sections of the articles. One article had one code to indicate the article's conceptual base surrounding disability. If scrutinised more closely, there may have been variations within the articles in how the conceptualisation of disability is differed slightly throughout an article. This can be the case if disability itself is not defined thoroughly in the article and

the use of the concept of 'disability' can be contradictory (see also Grönvik, 2007b). However, there were no obvious cases of conceptual contradiction and hence this thematization was continued with.

After the initial coding, the codes were checked and grouped into larger categories. In each journal, 12 codes were identified. Six codes were found in both journals. Larger categories were then formed according to whether the approach to disability was individual-functional or sociomaterial. For example, the codes 'bad health', 'impairment', and 'individual inability' in DS were categorised into 'disability as individual limitation', which was later named the individual-functional approach to disability. The results of the analysis are presented in section 5.

There are limitations to this data collection. Even though the review was conducted systematically, it was not a systematic review *per se* – it included two journals, which makes it selective and not as comprehensive as a systematic review would have been. However, we wanted to have a glimpse of how disability at the intersection of disability and old age is understood in at least somewhat similar social scientific journals. There are other social scientific journals, as well, but the metrics and scopes of the journals we chose were similar enough to analyse the research articles systematically. However, we cannot exclude the possibility that some other two journals could have been a better fit to be analysed together.

It is relevant to recognise that the scopes of the journals were, of course, not the same, but also not poles apart. *Ageing & Society* is not a health research journal but rather situates itself in social gerontology and interdisciplinary research on ageing and society. We knew that gerontological journals often lean towards health sciences and therefore most likely would adhere to the more medical understanding of disability. We wanted to eliminate that fundamental difference between health sciences and social sciences, and therefore chose the most social scientific ageing journal that fit our other criteria.

One could also argue that since the journals – and specifically *Disability & Society* – are UK-based, that will have an impact on the journals' orientation on the concept of disability. Since the social model of disability originated in the UK and *Disability & Society* is the first disability studies journal founded in the UK (under the name *Disability, Handicap & Society*), it can be argued to be a very pro-social model and hence not represent all the diversity of disability understandings. However, we did find that the social model was only one of many constructions of disability that its articles represented.

4.3 Written accounts and reflexive thematic analysis

One part of my data corpus was written accounts of older persons with disabilities. This data was used in the third article of my dissertation. The data collection was planned and conducted by me.

A call for letters was published through a web-based data collection platform called Penna, which is administered by the Finnish Social Science Data Archive (FSD) at Tampere University. The Penna platform was established in 2017 to collect essay-type textual data for research and university studies. All data collected in Penna are anonymous and protected by FSD's data protection practices. The data are archived in FSD with the writers' permission (FSD, 2022).

The call asked for accounts from older persons with disabilities. Old age or disability was not specified as criteria and self-identification was relied on. The call was published in Finnish, meaning only Finnish answers were received, apart from one that was a text written in English. This text did not concern Finland and was excluded. In Finnish, the word for 'disabled' is used very sparingly (*vammainen*), and often older persons with age-associated disabilities are not referred to with that term. The aim was to keep the call inclusive and so broader terms were used instead. For example, one term used, *toimintarajoite*, can refer to any kind of impairment or disability. Additionally, the call did not specify what is meant by old age, and who are old enough to participate. This was an intentional choice to recognise the constructed nature of old age, and the individual perception and identification of it.

The data collection method was chosen since it was relatively easy for the respondents: they could spend time thinking and writing the letters and acquire all the necessary assistance with the writing. With anonymous letters, the threshold for writing and exposing intimate issues can be low as no one will know who the respondents are – not even the researcher. With an online-based tool such as Penna, geographical location is not an issue, and its distribution is easy and quick (Clarke & Braun, 2013, p. 161). However, this kind of data collection method has its limitations, including the exclusion of marginalised groups, the need for computer access and skills, and no possibility of follow-up data collection (Clarke & Braun, 2013, p. 161).

The call for letters was open from 19 October 2021 to 31 December 2021. The call was distributed through different social media platforms as well as the university website. Additionally, the call was sent to different actors that might reach older persons with disabilities, that is, different NGOs and DPOs as well as authorities such as municipal councils of persons with disabilities (*vammaisneuvostot*). These actors then distributed the call through their networks and email lists.

Background questions of the call included gender (man, woman, other or no identification), age (answer options from 50 to 90 or older, in five-year ranges), whether or not they had received municipal services on the ground of ageing or disability (yes or no) and what kind of impairment they had (in walking/moving around, seeing, hearing, learning, memory, communication, other). Age and gender were mandatory questions, whereas the others were voluntary.

In the end, 24 letters were received, of which one was submitted twice, two had answered only the background questions, one was written entirely by a relative and one did not concern Finland. Hence, in the end 19 accounts were included in the analysis. The shortest one was 14 words and the longest was 796

words. The background information on the participants is presented in Table 6. For the invitation to write and its English translation, see Appendix 1 and 2.

Table 6. Background information of the participants

Gender	Age	Experience of municipal services	Length of letter, words
woman	55–59	yes	141
man	60–64	yes	442
woman	60–64	yes	744
woman	60–64	no	274
woman	60–64	no	796
woman	65–69	no	14
woman	70–74	yes	52
woman	70–74	no	77
woman	70–74	yes	102
man	70–74	no	28
woman	70–74	n/a	538
woman	70–74	yes	235
woman	70–74	no	154
woman	70–74	no	203
man	75–79	n/a	140
woman	75–79	yes	127
man	75–79	yes	24
woman	80–84	yes	326
woman	85–89	yes	151

The data gathering method of written accounts is not conventional, but increasingly used in qualitative research. It has both benefits and downsides. When experiences are written down and sent without identifying information, there is no possibility to ask questions or for clarifications. Therefore, if something is not clear, the meaning depends entirely on the researcher's interpretation. This issue is not unfamiliar to qualitative research, but even more so in this kind of data collection. In addition, writing, and writing on a web-based service, requires certain skills and therefore may exclude some people. The call was posted on an internet-based platform, and even to find this call, one needed to have access to the internet. The call was distributed as widely as possible, but social media does not find all and many are not on any emailing lists. Physically, writing requires motoric skills and the ability to form words. Even though it was possible to use assistance in answering, the requirement of writing could have been a barrier for some people.

In relation to language, non-Finnish speakers could not answer, even though not all Finns speak Finnish as their mother tongue. This was a limitation in the call, but the decision was made to stay within our resources. In addition, there may have been accessibility issues we did not consider. The call was

distributed in Portable Document Format (PDF) but at first it was not readable for screen readers that are widely used, for example, by people with visual impairments. After getting feedback on this issue, the PDF was modified to accommodate assistive tools. Not all issues emerge, and there may have been more.

Even though the call did not mention the COVID-19 pandemic, and nothing was asked about it, it occurred during the pandemic and the situation may have affected the accounts. Services or views on different kinds of help may have changed during the pandemic. Such insecure times may have had an influence on how the writers viewed, for example, their social relationships and dependencies.

Braun and Clarke's reflexive thematic analysis was used as a data analysis tool (2016, 2019; Clarke & Braun, 2018). The reflexive thematic analysis is based on their earlier formulation of thematic analysis in psychology (Braun & Clarke, 2006, 2019), but clarifies and sharpens their understanding of thematic analysis that has been misunderstood in some research using their method. Often, thematic analysis has been understood as a single method, even though there are multiple approaches to it (Braun & Clarke, 2019). Braun and Clarke (Braun & Clarke, 2019, p. 591) stress the 'knowingness' of doing research: being mindful of ontological, epistemological and methodological choices in each step of the process, in contrast to doing research as following a certain 'recipe'. In their reflexive thematic analysis, they emphasise the need for deliberate choices and careful reflection on them.

According to Braun and Clarke (2019), thematic analysis is and has to be reflexive as all the choices are made by researchers, and the data does not in itself give answers and the themes do not just exist on their own – the researcher formulates the question and interprets the data through that. In reflexive thematic analysis, Braun and Clarke (2006, 2021) present six stages in which the analysis moves forward: (1) familiarisation of the data and note-taking, (2) systematic initial coding, (3) generating themes, (4) reviewing and developing themes, (5) refining and naming the themes, and (6) writing the report.

In this co-written article, I conducted the analysis. In stage one, I started by getting familiar with the data. I first read the written accounts to obtain a broad view of the corpus and, at the same time, took notes. After reading and re-reading the texts, in stage two, I started to systematically create initial codes. For example, descriptions of different sources of help were coded as 'help from relatives', 'disability services' or 'peer support'. During the coding, the texts were read repeatedly to review the consistency of the coding. The coding was done by using the qualitative data analysis software ATLAS.ti. At this point, I noted that many of the participants described the kinds of help they received in different instances, and the way they described their own situation with their impairments. I started generating broad themes in stage three, first focusing on what kind of help was mentioned and how.

In the fourth stage, the themes were refined. The quotations were read more than once to make sure all relevant aspects of the texts were noted. At this point,

the connections to in(ter)dependence started to seem important and together with the co-author we chose to analyse the data within that conceptual framework. The themes were reviewed by refining the codes focusing on depictions of in(ter)dependence. For example, codes such as 'worry about getting old', 'losing independence' and 'no self-determination' were themed under 'fear of dependency'. In the end, three themes were generated according to how in(ter)dependence was perceived: fear of dependency, negotiating and justifying help and being independently dependent.

As the analysis followed neither completely a theory-based nor a data-based approach, it can be considered as abductive thematic analysis. The idea for the themes came from the data, but the exact themes could not have been found in the data if the concept of in(ter)dependence was not used.

The data was collected in accordance with the guidelines of the Finnish National Board on Research Integrity (TENK). In the data collection, no personal information such as names or contact information were asked for, so there is no possibility of knowing the identity of the participants. This is one of the strengths but, at the same time, also one of the weaknesses of this data collection method: on the one hand, texts can be considered to be anonymous but, on the other hand, there is no way of knowing who actually answered and in what kind of a situation. However, the letters may have included some information that could be identifiable for people who were already familiar with the participants. For example, many wrote about their impairments and how they started, and hence, there was a possibility of them being identified. Any information that could reveal the identity of the participants, such as specifics of the impairments, cities, and places of work, was therefore removed from the chapter in which these written accounts were used.

Participation was voluntary, as the call was open and distributed through social media and emailing lists of associations and other non-governmental organisations. Hence, it needs to be recognised that this means of data collection has ruled some people out. The data collection may have reached people who are active in associations and follow social media, and this most likely has influenced the data. In addition, this data collection method has required certain skills to participate, and thus the experiences of many people have probably been excluded. It would be important for future research to utilise other means of data collection so as to include a broader spectrum of people.

4.4 Researcher position and limitations of the study

This dissertation follows the qualitative paradigm, which already has certain ontological and epistemological underpinnings in comparison to a quantitative research framework. The qualitative research paradigm has a non-positivistic approach to questions. For qualitative research questions, there is no absolute correct or incorrect knowledge, but rather multiple versions of reality that are dependent on the context (Clarke & Braun, 2013, p. 22). In this sense, qualitative

research is relative as the context in which the knowledge is generated needs to be considered. In the qualitative paradigm, the researcher's position also requires reflection, as complete objectivity is impossible. Hence, a reflection on one's subjectivity is in order when doing qualitative research.

In my case, my position has not influenced research participants as much as it could have, had I done interviews, for example. I gathered most of my data from pre-existing sources: policy documents for the first article and research articles for the second. Only in the third article did we use data that was planned and collected by me. In the first and second article, I actively chose what to analyse and how to do it, as a person with certain experiences, knowledge, expectations and aims, but my subjective influence in the data collection can be considered to be smaller than in the third article. In the third article, subjectivity could have played a part in the data collection process, because I formulated the call for accounts. As a result, there is a possibility I had an influence on the accounts that were given. I was mostly an unknown researcher in a university doing research: this most probably was the only thing the participants noted of me while writing. However, if someone knew me, had interacted with me or then just had seen me somewhere, they knew that I was a younger white woman with no visible disabilities. In other words, I myself am not an older person with disabilities, or even a person living with explicitly expressed or visible disabilities. This may have affected how the participants chose to write, or even chose not to write. From this viewpoint I need to consider my subjectivity in relation to the whole research.

In addition, qualitative research requires interpretation of the data. I have interpreted the data from my own starting points, guided by my experiences and knowledge, and there is no guarantee I have understood the texts in the way the writers of the statements, research articles and written accounts intended.

One limitation of this study is the limited amount of empirical data from older persons with disabilities. During the COVID-19 pandemic, the plans to interview older persons with disabilities had to be changed and I decided instead to collect written accounts. The limitations of this method of data collection were discussed in the previous section. However, this research could have benefited from discussions with older persons with disabilities or other more participatory data collection methods, and future research should focus on the views of the people the research concerns.

5 RESULTS FROM THE ARTICLES

In this chapter, I present the results from the original articles. Along with the results, I respond individually to the research questions I posed at the beginning of this summary.

My dissertation consists of three sub-studies and this summary article. In the sub-studies, I answer the three-tier question: How do disability and old age intersect in (1) policies, (2) concepts, and (3) everyday life? Article I answers the first, Article II the second and Article III the third part of the question. Hence, I view the disability-ageing nexus from three different angles, and each of these is the focus of one article. The first article takes its starting point in *policies*, looking in particular at the reform of disability legislation in Finland. The second article reviews published research and the *concepts* of disability in the intersection of disability and ageing. The third article centres on *everyday life* and analyses empirical data collected from older persons with disabilities themselves with a focus on in(ter)dependence.

5.1 What is fair? Examining Finnish disability policy

In many countries, the policies within the nexus of disability and ageing have been complex and can create unequal situations (e.g. Hoppania et al., 2017; Jönson & Taghizadeh Larsson, 2009). Article I focuses on the first part of the research question: How do disability and old age intersect in policies? The situation in Finland was studied by analysing public statements given to a draft proposal of the new Disability Services Act, which introduced an age-related restriction.

At the moment, disability services do not have any age-related restrictions other than the one in personal assistance, and the mean age of disability service users has been rising. At the same time, older persons' services are focused on long-term care, and their need has also been increasing due to demographic change. To clarify the boundary between these services, an age-related restriction

has been proposed, and I wanted to find out how this policy change suggestion was perceived by the commenters.

According to the results, there is no consensus on how the services should be organised or what the Disability Services Act should contain. The only thing all commenters seemed to agree on was that the current Act was not ideal. Some saw the current legislation as being too 'embracing' while some argued that it was not inclusive enough. Some were concerned about certain disability groups, which was to be expected as many commenters were organisations representing people with certain types of impairments. Equality and fairness were perceived differently according to how disability itself was conceptualised. The age-related restriction was justified on different grounds, of which I focused on equality.

Equality and equity are often used inconsistently, and the difference may be difficult to grasp. In this dissertation, the two concepts are distinct: equality means equal shares for everyone, whereas equity means fairness in the sense that everyone gets a *fair* share, allocated considering individual differences (Espinoza, 2007). Hence, what is fair may not be equal. In disability policy, equity can be seen as the means to equality in the society – in order for everyone to get an 'equal share' of participation in the society, for example, everyone needs their fair share of support to do that. In this article, Blanchard's (1986) equity norms were used as an analytical tool to understand the ways in which equality was argued to be achieved according to the commenters.

There were different ideas of equity: (1) the equity of equal 'normality', (2) the equity of equal needs, and (3) the equity of equal disadvantages. These represent three ways of deciding the applicability of the Act to a person, or three attributes on which the eligibility is determined. I utilised Blanchard's (1986) equity norms, according to which social equity is measured. In his theorisation, he offers a set of understandable definitions of equity that can provide insight into evaluating public policies. Somewhat similarly to Thevenot and Boltanski's (1999) justification theory, Blanchard's theory reminds us that in order to evaluate (or argue for) something, there needs to be mutual understanding on *what* is going to be evaluated and *on what grounds*. For example, Blanchard's (1986, p. 33) norm of 'strict equality' means that regardless of anything, everyone will get an equal share of goods. In his formulation, 'each norm is a different conception of fairness' (Blanchard, 1986, p. 33). I applied this idea to the debate about age-related restriction.

First, the equity of equal 'normality' determines eligibility according to what is or is not considered 'normal'. Regarding the age-related restriction, this means the question of whether certain disabilities can be considered a part of the normal ageing processes. Some commenters suggested that older persons with age-correlated disabilities – the prevalence of which increases with age – should not be included in disability services. The age-normality of disability was also used in the statements in the sense that the impairments that were at risk of being categorised as 'normal' in old age were explicitly claimed *not* to be: for example, some visual impairments are sometimes considered to be part of normal ageing, but here, many commenters argued that they are not and therefore should belong

under disability services. In that sense, very few rejected the idea of ‘normal ageing’ itself, but rather argued that the impairments in question are not part of it.

Second, the equity of equal needs focuses on whether the applicants have similar needs. The commenters relying upon this domain of fairness reviewed the eligibility according to what type of needs the applicants had and whether or not the needs could be met by disability services. This comes close to many other social services that are discretionary in the sense that they are not rights based like disability services are. The needs-based equity norm was used in both supporting and opposing arguments. In the supporting ones, it was argued that if there are similar kinds of needs, there should be similar responses to them, regardless of what has caused the disability that is behind the need. In the opposing ones, the arguments claimed that the needs of older persons with disabilities are substantially different from those of younger persons with disabilities and, hence, the services should be organised separately and older persons excluded from disability services.

In the third domain, the equity of equal disadvantages, it was noted that these specific, rights-based disability services should be restricted to the most disadvantaged group. In some comments, the most disadvantaged group is (younger) persons with disabilities, whereas some commenters note that older persons with disabilities also belong in this group of the most disadvantaged persons since older persons’ services are insufficient and of low quality.

The findings of Article I suggest that there is no common understanding of what is fair in relation to the new Disability Services Act, since fair to someone may be unfair to someone else, and this seems to vacillate according to the conceptualisation of disability. The service system at the nexus of disability and ageing is complex and confusing: it is unclear where an older person with disabilities ‘belongs’, and which services would best meet their needs.

5.2 Disability concepts in ageing research and disability studies

Article II answers the second research question: How do disability and old age intersect in concepts? Through a selective literature review we analysed the conceptualisations of disability at the intersection of disability and old age in two exemplar journals from ageing research and disability studies.

Article I shows that there is a lack of a unified concept of disability in relation to policy and public debate. The literature suggests that the conceptualisation of disability is different in ageing research than it is in disability studies, with ageing research being more medical (Naue & Kroll, 2010), and the lack of joint conceptualisation may be one reason for policies to develop in separate siloes (Leahy, 2018). Concepts are important to policies, and it has been especially argued that models of disability translate to disability policy (Smart, 2009). In our article, we wanted to analyse how this argument holds true

in the two exemplar journals, that is, how different conceptualisations of disability manifest themselves in the journal articles.

We aimed to choose journals that would include social scientific viewpoints, and the two journals, *Ageing & Society* and *Disability & Society*, provided those. We found that the definitions or conceptualisations of disability differed in these two: ageing research relied on more individual and functional definitions of disability while disability studies provided a more social understanding of disability.

In our article, we named these different approaches 'individual-functional' and 'sociomaterial'. These approaches follow the most typical and fundamental division in disability models: the individual and the social (e.g. Vehmas, 2004), but we saw them as broader conceptualisations of disability. With sociomaterial approaches, we do not *only* mean that disability is understood to be created by the environment but also that disability can be understood as something that emerges from the interaction between the individual person with an impairment and the surroundings (the Nordic relational model) as well as a minority identity, through which one can find a community but also advocate for rights (the minority model). We do include the medical approach to disability in the individual-functional approach, but also disability as a limitation – for example, measuring disability with limitations in ADL (activities of daily living), which is common in ageing research. In our view, the starting point is of interest: in the social understanding, it is not just the impairment but everything around it that creates the disability whereas in the individual view, it is the individual that is assessed in defining disability. For example, standing up from a chair can be examined from both perspectives. In the social understanding, one would consider, for instance, the height and other attributes of the chair, and whether the need to stand up is caused by the shelves being too high. If one's viewpoint is more individual, one could assess muscle strength and one's physical ability to stand up.

Our findings suggest that ageing research remains more medical in its perception of disability, as the term was often used synonymously with impairment. In contrast, one of the starting points of the early disability movement (which can be considered as the basis of the academic discipline of disability studies) was the social model: disability is something imposed upon persons with impairments, and it is essential to separate the individual impairment from the disability. Hence, the gap between disability studies and ageing research has remained wide, as the main concept of disability studies has a different meaning in ageing research. On the other hand, the individual approach to disability that ageing research seems to inhibit is something that the social model was created to resist.

The two conceptual veins were visible in both journals, albeit to different degrees. The main finding is that the concept of disability differs according to the research field, which can hinder research as well as policies within that intersection. At the interaction of the two conceptual veins, we suggest three possible paths that can be useful for mutual learning: (1) emphasising the self-

determination and agency of older persons with disabilities, (2) making intersectionality visible and questioning normality and (3) integrating care discourses with human rights approaches.

5.3 Stories of in(ter)dependence: experiences of ageing with disabilities

Article III answers the third part of the research question: How do disability and old age intersect in everyday life? In this article, we analysed the accounts from the viewpoint of older persons with disabilities, focusing on in(ter)dependence. Our research question connected the concept of in(ter)dependence to experiences, since the initial skimming of the data revealed multiple indications of it in the texts. In this research, 'ageing with disabilities' is used to refer to all persons growing old with disabilities: not only those growing old with a life-long disability, but also those who have acquired disabilities in later life and are ageing with them. The call for accounts did not distinguish between AwD and DwA, and in this dissertation, all persons with disabilities, regardless of the time of onset, are considered to be ageing with disabilities.

Independence and dependency have been theorised in varied ways, both in ageing research and disability studies. The ideal of the self-sufficient independent human being is promoted in many parts of the world, and many ageing policies aim at being independent as long as possible, which here means not needing care or other services for as long as possible. In social gerontology, independence is conceptualised, for example, as 'a sense or state of physical, psychological and spiritual autonomy, self-identity, self-respect, control and degree of functional capacity' (Phillips et al., 2010, p. 131). Disability activism, and especially the Independent Living movement, rearticulated independence as something else: the main components being choice and control, but nothing related to functional capacity. In disability activists' view, they were 'independently dependent' as they were in control of their life (independence) and they needed assistance in everyday life (dependency) (Barnes & Mercer, 2006). However, the promotion and emphasis on independence in the Independent Living movement has been criticised for raising independence as the ultimate goal in life, and dependency is still seen as a failure and 'denigration of the person' (Kittay, 2011, p. 51). Nevertheless, it has been argued that both independence and dependency are necessary concepts to discuss in order to recognise possible power relations in, for example, care situations (Fine & Glendinning, 2005; Kittay, 2011). In this article, we wanted to see if and how these concepts translate into the lives of older persons with disabilities.

Through reflexive thematic analysis (Braun & Clarke, 2006, 2019, 2021), we formulated three themes that present the ways the participants describe their everyday lives from the viewpoint of dependence and independence. First, dependency was depicted as something to be feared, something extremely

negative. This also relates to the ideas of successful and active ageing that have been the guiding principles of ageing policies: to stay active and self-prevent the deterioration of health (Timonen, 2016). Becoming dependent and needing help becomes a failure, as one did not 'age successfully'. However, the fear of dependency can also stem from the fear that long-term care is not available in sufficient time or volume. The care crisis has been widely reported in Finland, and it has been observed that many older persons experience care poverty (Kröger et al., 2019). It is unsurprising that getting old and needing care become feared.

Second, there were preconditions for getting help as well as justifications before accepting the help – one needed to know where to get help, help needed to be accessible, and it had to be accepted. Participants wrote about the lack of knowledge about services and difficulties in finding relevant information regarding what kind of help is available. Bureaucracy was mentioned as an obstacle in getting help as there are multiple applications for services and are often strenuous to complete. In addition to all the skills and energy that finding and getting help requires, participants noted the need to be brave enough to open one's mouth – to dare to demand. The acceptance of help was negotiated, for example, through reciprocity: getting help from adult children may be acceptable because one provides care for one's grandchildren. The aim of 'being independent as long as possible' can also be counterproductive in that it applauds surviving without help and hence makes it harder to ask for necessary help – let alone demand it.

Third, dependency was also negotiated in more neutral terms, as something that enables participation: this was close to 'being independently dependent' (Barnes & Mercer, 2006). Some participants described neutrally their assistance and how it affects their daily life. In a sense, their description seemed to reflect the relative understanding of independence – or of interdependence, which stresses the interconnectedness of humans and the relative nature of independence (Reindal, 1999). The only fear they brought up was the fear of having to give up the assistance they were getting. Some were worried that as they get older, they could lose their (disability) services. The exclusion of older persons from disability legislation has been debated for years (Era, 2021), and the problems of older persons' services in Finland are well recognised (Kröger et al., 2019).

Our results show that there are still many barriers for older persons with disabilities to ask for and receive the help they need. The ideal of independence as self-sufficiency, and the goal of successful ageing in ageing policies encourages the understanding that needing help is 'failed ageing'. We argue that a more relational understanding of independence could be adopted in ageing and disability policies to lower the threshold to asking for and receiving sufficient help.

6 DISABILITY IN OLD AGE: CONCEPTUAL CONFUSION

This dissertation has aimed to find answers to the following threefold research question: How do disability and old age intersect in (1) policies, (2) concepts and (3) everyday life? The first article answered the first part of the question from the policy viewpoint, the second article discussed research, and the third article focused on everyday life. In *policies*, there seems to be conceptual confusion in what constitutes disability in old age: there was no consensus in the public comments on what exactly is disability in old age that should be included in disability services, but many agreed that older people who are ageing ‘normally’ should be excluded. Similarly in *concepts*, ageing research and disability studies conceptualise disability differently, which can contribute to the issue that there is no common understanding of disability in old age outside of academia either. In *everyday life*, older people with disabilities face different kinds of barriers (both internal, such as fears or attitudes, and external, such as lack of information on available services) in asking for help and acquiring necessary services. In this chapter, I discuss the conceptual confusion at the intersection of disability and old age and consider an approach to disability that recognises the complexity of the concept but also seeks to put the theories to use.

Disability in old age is imbued with conceptual confusion. Following critical disability studies thinking, it is not easily categorizable, similar to disability in general. In the end, it is difficult to define the ‘ability’ that renders some people ‘disabled’ (Goodley, 2014), and a postconventional approach contests the rigid category of disability and the conventional binary thinking surrounding the concept (Shildrick, 2012). From this perspective, specific disability services and policies would not be needed, since there would be no category of ‘disabled people’ to whom the services could be targeted. However, blurring the boundaries of disability brings in the risk of blurring the experiences of disabled people. Hence, on the one hand, I follow the postconventional resistance of the disability/ability binary, but on the other hand, I join critical realists in recognising the category of disabled people in a practical sense: there is a need for the category of disability to recognise the experiences of living with

disabilities and the needs for societal change related to ableism and disablism and different barriers.

I suggest that it is possible to agree on both ideas by looking at disability from two different viewpoints: pragmatic and ontological. Sometimes it is necessary to create categories, and the purpose dictates the category or the definition of disability (pragmatic). From this viewpoint, disability conceptualisations work as tools to further certain goals. For example, the social model is useful *in practice*, but it is not a complete theory that would define disability indefinitely. Similarly, in policy, disability categorisations work towards the goal of ensuring rights and the categorisation is necessary, even if not all those who fit the category of 'a disabled person' consider themselves as such. The *ontological* viewpoint recognises that disability is experienced in multiple ways that may not be captured by any of the disability models or categories. The everyday lives of older persons with disabilities do not necessarily conform to the conceptualisations at the pragmatic level, but disability is something that defies definition, or fits into many or no categories. These dimensions intersect, but it can be useful to recognise them separately.

I agree with Oliver (2004) that the important thing with disability models is how they are used, and as Grönvik (2007a) observes, I find use for many models and definitions of disability if they are well-argued and purposeful in the situation at hand. In a similar vein, Smart (2009, p. 3) notes that diversity in disability models can be enriching, while Levitt (2017, p. 736) argues that perspectives from multiple models can contribute to the understanding of disability better than from a single model. I add to this line of arguing that diversity of disability conceptualisations is enriching, but it is also useful to look beyond the models or definitions to understand the purposes and consequences behind them and use them accordingly.

This dissertation has focused on disability policy in Finland, in which there seems to be no consensus on what constitutes disability (that would entitle a person to disability services) in relation to ageing. In the discussion of age-related restrictions and the exclusion of older persons from disability services, many arguments boil down to what is and is not 'normal' in old age. When viewed from a more pragmatic perspective, however, disability must be defined in some way so that services can be organised in line with the realities of resources as well as to ensure equal rights. Pragmatically, this dissertation discusses how the boundaries of disability are drawn in relation to ageing and argues that these boundaries need to be critically examined. Ontologically, this research has questions normality and the binary view of disability and ability, and how conceptions of ideal ways of being dependent or independent manifest themselves in everyday life.

6.1 Disability as a pragmatic concept

In order to organise disability services, especially in the time of resource scarcity, some categorisations are necessary. Definitions of disability can stem, for example, from disability models, and international policy documents are built based on different models. Models of disability shape policies (Smart, 2009). However, they seem to be understood and used differently. For example, for some, the UNCRPD model is close to the biopsychosocial model (Leahy, 2018), whereas some see it as close to the social model (Harpur, 2012). Aspects of different disability models are debated and criticised actively in disability studies.

However, as suggested earlier, more important than any specific model and what it entails, is how it is used. Grönvik (2007a) argues that we should not aspire to achieve a consensus on the 'best' definition of disability but rather acknowledge with which definition we are working with in each instance. Similarly, Oliver (2004) noted in relation to the social model of disability that instead of arguing over it, we should put it to use. Models of disability are important in their context and purpose: none of them are all-encompassing, all-explaining ontological models, but rather tools for different purposes. For example, the social model of disability made a great impact on disability policies and the lives of disabled people worldwide as it turned the gaze from the individual's problem to the barriers, that is, the things that can be really changed, as impairments are intrinsic to human existence and will continue to exist in the world. The biopsychosocial model in the ICF may be good for conducting research, for example, to understand disability demographics population-wise. Minority and identity models will help us understand disability culture and the impact disability identity has for people and understand the inequalities experienced by disabled people as a group.

In Finland, there are discretionary services and services with subjective rights (enforceable legal rights) and the difference is that, with discretionary services, there are no rights securing them and services can be denied due to, for example, a tight budget. With subjective rights, it is more straightforward, and no one who meets the criteria will be left without the services in question. Most disability services have been rights based with strict criteria that keeps the group of service users small. It is easily understood that as long as the services are organised this way, some restrictions must be made regarding who are included in the scope of the disability legislation guiding the services. What needs to be considered and questioned is the grounds on which the restrictions are built.

In my research I found that the age-related restriction was argued for and against from many viewpoints. Of these, I focused on arguments based on equality. There seemed to be no consensus regarding which attributes should be used to assess disability (in relation to the Act): by normality, needs or disadvantaged position in society. The question of normality has been important to discussions in (critical) disability studies, as disability has often been at least

in some ways defined and understood as the opposite of the so-called normal (Goodley, 2014).

In my data, the notion of normal ageing was used to argue for excluding older people from disability services. In the light of the medical understanding of disability, some impairments in old age are normal in the sense that they are usual and ordinary. However, if viewed from a more sociomaterial perspective, the situation is more complex than that. The disability legislation reform in Finland claims to steer away from the diagnosis-based definition of disability, yet it has still suggested an age-related restriction that would emphasise the cause of the impairment, hence employing diagnosis-based criteria (Mustaniemi-Laakso et al., 2023).

Impairments and illnesses in old age can be normal in the sense that they are usual and ordinary, and many conditions correlate with age. The separation of age-correlated disabilities is reflected in concepts in research: ageing with disabilities is discussed as distinct from disability with ageing. However, disability intersects with ageing in a more complex way, as one can age with disabilities and acquire disabilities in older age, and conditions and situations vary. It is difficult to draw the line between DwA and AwD, although it is often used as a boundary in disability policies. For example, in Sweden, one cannot be granted personal assistance after the age of 65, but one can retain it (Jönson & Taghizadeh Larsson, 2009). The results of this dissertation reflect the same: age-related disabilities are argued to be excluded from disability services.

In relation to ageing, normality resonates differently it does than in relation to disability: during life stages other than old age, disability is thought of as abnormal. Related to ageing, impairments are regarded as normal but unwanted. This leads to the conclusion that if impairments are associated with old age, they are *not* associated with younger ages and therefore may contribute to stereotypes and ableism. The ideas of normality affect younger ages in a way that enforces the idea of disability as abnormality and may enforce ableist norms of function. Then again, normality in old age means that disability is the norm, and older people are socially constructed as frail and dependent (Walker & Walker, 1998), and therefore they do not need support to live an 'ordinary' life compared to age peers, since they already are. This creates a paradox: in order to ensure disability rights for older persons with disabilities, one should argue for disability to be regarded as 'abnormal' in old age, too, which seems counterproductive. The issue lies with recognising universal vulnerability, namely, that disabilities in every age are similarly 'normal'. At the same time, however, it should also be acknowledged that the specific needs of particular embodiments entail some degree of categorisation, in other words, that disability services are necessary only for some (Mustaniemi-Laakso et al., 2023).

As mentioned, models of disability contribute to framing how we respond to disability, forming the basis for action and serving a certain purpose. Even though the pragmatic and ontological perspectives on disability are viewed here as separate, the ontological starting points can be fruitful in developing the pragmatic conceptualisations of disability in policy.

6.2 Disability through an ontological lens

This dissertation shows that normality is one line of argument in determining the category of 'disabled people' in Finnish disability policy. Disability in old age was seen as normal, and many arguments related to what is and is not part of normal ageing. Not many rejected the idea that there are disabilities that are part of normal ageing, just as not many questioned the idea of normal ageing itself. Here, I argue, that we need to move beyond normality.

Many disabled activists have suggested before that normality is normativity reflecting the current time and current context at best: there is no absolute normal. As much as disabilities are normal in old age, they are normal in every age – as Garland-Thomson (2002, p. 336) put it, 'disability is the most human of experiences'. However, the fact that impairments are more probable in old age does not make them less disabling together with environmental barriers.

Disability has been, and continues to be, treated as something 'outside' the nondisabled population and it has been analysed as a deviance from the 'normal'. To contest this, critical disability studies has argued that disability is a universal phenomenon that touches everyone, and that nondisabled people are only 'temporarily abled' (e.g. McRuer, 2013). Some scholars reject the disability/ability binary altogether and see disability as a humanity issue (Shildrick, 2012). I join them in understanding categories as fluid and ever-changing, but I recognise the power of definition and identification for the purpose of political action and societal change. Hence, I reject the disability/ability binary on an ontological/conceptual level yet recognise disability on the practical level. However, in an anti-discriminatory utopia, there would be no need for disability activism and demanding equal rights for persons with disabilities: the fluidity of human forms, conditions and suffering would be recognised, and each would be supported in a way that best fits that particular human.

In this research, I have shown that dependency seems to be feared, but support can also be seen as an enabler to participation. Independent living is often the goal in disability services, as advocated for by disability activists worldwide. However, in this too, the aim for independence remains (Kittay, 2011). Independence in the IL sense is a useful tool to advocate for rights to participate alongside nondisabled people, but one needs to be mindful of the risks that emphasising independence may bring: the devaluing of dependency. This dissertation has shown that dependency is feared, and people will attempt to cope alone as long as possible, and asking for help seems like putting a burden on others. Independence is the norm and the expectation, and if one loses it, it can feel like 'hitting a wall', as one of the research participants wrote.

Even though 'care' has been 'conceptually contaminated' from the viewpoint of disability studies (Kröger, 2009), some aspects from care ethics could be beneficial for public policies and, in this case, disability policy in Finland. Care and the usefulness of care ethics for disability frameworks has been

contested, but also accepted with some conditions. For example, Morris (2001, p. 15) accepted that care ethics can be beneficial if it 'is based on the principle that to deny the human rights of our fellow human beings is to undermine our own humanity'. Similarly connecting care ethics and human rights, Robinson (2008) argues that the ethics of care could benefit human rights-based models of human security by adding caring values and sensitivity to the role of power relations in human security.

I suggest that bringing the ideas of relational independence or interdependence to social policy could help move beyond the ideals of independence as self-sufficiency, while still considering dependency as a natural aspect of human life. I agree with Kelly (2010), who argues that it would be beneficial to utilise more interdependent models alongside the ones emphasising independence. Nevertheless, I also acknowledge the concern regarding the emphasis on independence.

Care and support are needed in different stages of life, whatever and whenever that may be for each: if people are seen as interdependent and dependency is understood as a very human condition, there would be no need to fear dependency in the sense that it is a failure to live up to the standards of the society. Of course, being dependent makes us vulnerable to neglect and oppression, but the issue is not with dependency but with the people and structures that exploit that. This comes close to ideas behind the social model of disability, where the issue lies not within the individual, but the barriers of society.

In sum, borrowing from feminist and critical disability studies as well as care ethics, disability can be viewed, ontologically, as a very human condition and there is nothing 'special' to it. Human life contains multiple variations of embodiments, but also pain and suffering that cannot be disregarded.

7 CONCLUSION

Paradoxes lie at the nexus of disability and old age: how should disability in old age be understood? On the one hand, disability, as all human life, is not easily categorizable, as is agreed upon in critical disability studies and the postconventional framework. On the other hand, in regard to policy, some definitions need to be made in order to target disability services to those who need them.

Disability is a complex phenomenon, and no two situations are exactly similar. The same can be said about disability in old age, which is often separated from disability in younger ages. Older persons with disabilities may be treated differently depending on whether they are considered 'just old' or 'disabled' – that is, whether they are seen to 'belong' in disability services or in services for older people. Different research and policy silos have different underpinnings in terms of what disability is (both ontologically and pragmatically) and what kind of support is appropriate. Varied conceptualisations of in(ter)dependence reflect this divide. Next, I draw some conclusions from the presented discussion and consider the policy implications of this dissertation, and then close with avenues for possible future research.

First, instead of searching for a unified and 'best' conceptualisation of disability, I suggest we need to recognise and accept the complexity of the concept. Different models of disability work well for their purposes, but they are not all-explanatory theoretical or ontological models of disability, nor should they be regarded as such. However, different dimensions of disability intersect and inform each other: policy can benefit from disability conceptualisations of different disability models, but also from deeper ontological considerations, some of which I have presented in this research. The important thing is to critically consider the purposes and consequences of the conceptualisations in question.

Second, the different ideals of independence can influence the everyday lives of older persons with disabilities. Oftentimes, dependency is feared, but some see themselves as 'independently dependent'. In individualistic cultures, we are taught to fend for ourselves, and dependency is seen in a negative light.

Disability activism has challenged this assumption by reimagining independence to be about choice and control, not about doing things alone. However, some have critiqued this notion as well: it values independence more than dependency, instead of taking a neutral stance on both. Here, we arrive at a paradox: how to promote the idea that independence is not the ultimate state of being that we should strive for and seeing that, in a way, independence is a myth, but still support the idea that independence can be achieved through being dependent on something or someone? I suggest that this, too, is a matter of pragmatic and ontological division. In practice, we need the concept of independence to organise policies that support people to live the life they want – and this is what disability policies often aim to do, and this is how independence is understood. However, on an abstract or ontological level, independence is a myth: none of us are completely independent and dependency touches everyone. Nevertheless, it is necessary to ask *why* dependency is feared and begin to work towards a society in which there is no need to fear it.

Third, the fuzziness at the nexus of disability and ageing can influence lives on a practical level as well. Older persons with disabilities may not have the knowledge of what kind of support they can get and from where. There may be a lack of communication between disability services and older persons' services, which can lead to serious information breakage regarding one's services. One reason for the fear of growing old among disabled people can be the fear of losing services, as mentioned in my data. Fitzgerald (2021) suggests a new way of organising long-term care policies according to critical care ethics. She argues that according to critical care ethics, the assessment for receiving services could be more careful and individual, rather than putting up age limits and other categorisations.

Some policy recommendations could be suggested on the basis of the results. This dissertation shows that there is no unified understanding of disability in either research or policy. The conceptualisations of disability in disability policies have often been heavily influenced by disability activism and conceptualisations in disability studies, and hence adhere to the more sociomaterial understandings of disability. Disability policy in Finland aims to follow the sociomaterial approach and steer away from the medical view of disability, but still indicates that it is necessary to have some restrictions based on a medical diagnosis. I suggest that policies need to acknowledge the grounds on which they are built, and what the intended and unintended implications are. Additionally, I suggest integrating perspectives from critical disability studies and critical care ethics into Finnish disability policies to challenge the boundaries that are to some extent built upon assumptions of normality.

Future research should focus on the views of older persons with disabilities. There is a lack of knowledge on the everyday lives of older persons with disabilities and how their needs are being met in the service system. The written accounts in this research are only a starting point for further exploration of the varied experiences people may have. Data could be collected by some other

means. Interviews or observations, for example, could help elaborate more on the issues the participants face at the intersection of disability and old age.

One limitation of my research and an avenue of future research are issues of identity. In relation to disability and ageing, identity plays a key role: people acquiring disabilities in later life are considered less likely to form a disability identity than younger disabled people are, even though recent research has shown identity formation at the intersection of disability and ageing to be more complex and nuanced (Leahy, 2023). Therefore, older persons with disabilities do not necessarily see themselves as disabled, but rather 'just old' which may have an effect on their willingness to apply for disability services. It can also affect whether older people participate in disability activism or other disability-related activities. It can be one reason for the in-betweenness of older persons with disabilities. However, I did not focus on identity in this research, and it should be further explored in the intersection of disability and ageing.

Another limitation is that this research mostly considers the concept of *disability*, but not that of old age, which is the other half of the intersection. This inevitably leaves many aspects unexplored that could have been important. Similarly to the concept of disability, old age is open for interpretation: when does old age start and how are categories regarding older people created? Social gerontology has long discussed the social construction of old age (Gilleard, 2023), and the issue has been acknowledged also in the research at the intersection of disability and old age (Jönson & Norberg, 2021). Future research on this topic should take this aspect into account and explore it further.

Another avenue worth exploring further is the conceptual work both in Finnish and in English. As my research demonstrates, disability in old age is fuzzy, and the Finnish terms may be even more confusing. This, again, can have a major influence on policies and how they are applied, and who are they imagined to target. The Finnish term *vammainen* is narrow and many people who become disabled in later life reject the term, but at the same time, this conceptualisation is not easy or clear. This, of course, is the case in many cultures and languages, but it would be interesting to explore in the Finnish context due to possible changes in definitions and terminology in the disability legislation: how could the change in legislation translate into the everyday lives of older persons with disabilities?

This dissertation has highlighted the complexities that lie at the intersection of disability and old age. It argues that instead of finding an all-encompassing understanding of disability – or of disability in old age – we should examine the purposes and consequences of its different conceptualisations. 'Disability' can mean many things, and it needs to be considered when, why and what kind of boundaries are needed.

SUMMARY IN FINNISH

Väestö ikääntyy ympäri maailman. Vammaisuus ja toimintarajoitteisuus on yleisempää korkeassa iässä, mutta usein silti ikääntyneet toimintarajoitteiset henkilöt ovat monessa maassa jääneet vammaispolitiikkojen ja -palveluiden ulkopuolelle. Vammaisuus ja toimintarajoitteisuus ymmärretään usein eri tavalla korkeassa iässä kuin nuorempien kohdalla: toimintarajoitteet nähdään usein tavanomaiseen ikääntymiseen kuuluviksi eikä niiden näin ollen mielletä oikeuttavan erityispalveluihin.

On huomautettava, että suomeksi ”vammaisuus” ei ole sellaisenaan yhtä käytetty ikääntymisen yhteydessä kuin englanninkielinen ”disability”. Suomeksi ”vammaisuus” on tarkkarajaisemmin käytetty, ja usein erityisesti ikääntyessä syntyneitä toimintarajoitteita ei ole kutsuttu vammaisuudeksi. Haluankin suomeksi puhua sekä vammaisuudesta että toimintarajoitteisuudesta, jotta tutkimukseni rajautuu tarkoituksenmukaisesti myös suomen kielellä.

Monissa maissa eroa vammais- ja vanhuspalveluiden välille on pyritty tekemään erilaisten ikään liittyen rajausten kautta, joko kronologisen ikärajan kautta tai muulla tavalla erottamalla. Suomessa vammaispalveluissa ei ole ollut ikärajausta muuten kuin henkilökohtaisen avun kohdalla, joka on rajannut ulos sellaiset henkilöt, joiden toimintarajoitteet ovat seurausta ikääntymisen myötä tulleesta vammasta tai sairaudesta. Kuitenkin pitkään jatkuneessa vammaispalvelulain uudistuksessa on pyritty selkeyttämään eroa muidenkin vammaispalveluiden kohdalla, ja erilaisia ikääntymiseen liittyviä rajoituksia on ehdotettu.

Tässä tutkimuksessa selvitän ikääntymisen ja vammaisuuden risteämistä niin palvelujärjestelmän, käsitteiden kuin arkielämän kokemustenkin näkökulmasta. Tutkimuksellani pyrin kriittisesti tarkastelemaan rajanvetoja ja määritelmiä, ja samalla osaltani edistämään vuoropuhelua eri tutkimuskenttien mutta myös palvelualojen välillä.

Tutkimuksessani kysyn: miten vammaisuus ja ikääntyminen risteävät (1) suomalaisessa palvelujärjestelmässä, (2) käsitteissä ja (3) ikääntyvien vammaisten ja toimintarajoitteisten henkilöiden arjessa?

Väitöskirjassani tarkastelen vammaisuuden ja ikääntymisen risteyskohtaa politiikkadokumenttien, kansainvälisen tutkimuksen ja ikääntyneiltä toimintarajoitteisilta henkilöiltä pyydettyjen kirjoitusten kautta. Aineistojen analyysit on tehty käyttäen erityyppisiä temaattisia sisällönanalyyskejä ja valikoivaa kirjallisuuskatsausta. Tarkastelen aihetta erityisesti kriittisen ja feministisen vammaistutkimuksen teoreettisen kehyksen kautta, hyödyntäen myös hoivaetiikan näkökulmia.

Tutkimukseni osoittaa, että vammaisuudesta ikääntyessä ei ole selkeää ja yhteistä ymmärrystä. Suomessa vammaispalvelulain uudistuksessa on kiistelty siitä, missä määrin ikääntyneet vammaiset ja toimintarajoitteiset henkilöt voisivat olla oikeutettuja vammaispalveluihin. Erityisesti ikääntyessä tulleet vammat rajautuivat vammaisuuden käsitteen ulkopuolelle uudistuksen argumentoinnissa. Monesti nojattiin ”normaaliin” tai tavanomaiseen ikääntymiseen, jonka mukaan tietyt vammat, sairaudet ja niistä seuranneet toimintarajoitteet kuuluvat

ikäntymiseen, eikä niiden pitäisi oikeuttaa erityispalveluihin. Tämä seuraa aiemmassa tutkimuksessa havaittua kahtiajakoa ”vammainen” ja ”vain vanhojen” välille (Priestley, 2014). Myös kansainvälisessä tutkimuksessa vammaisuuden käsite vaihteli. Ikäntymisen tutkimuksessa vammaisuutta käsiteltiin enemmän yksilöllisenä ominaisuutena, kun taas vammaistutkimuksessa vammaisuus oli laajempi sosiomateriaalinen ilmiö. Tämä taas vahvistaa sen merkitystä, mille alueelle ikääntynyt vammaisen henkilö luetaan: vammaistutkimus ja -politiikka nojaa erilaisiin pohjaperiaatteisiin kuin ikääntymisen tutkimuksen ja politiikan kenttä.

Tutkimukseni selvitti myös, kuinka ikääntyminen ja vammaisuus risteävät arkielämässä. Ikääntyneet vammaiset ja toimintarajoitteiset henkilöt kuvasivat enemmän toimintakykyään, tuentarvettaan ja palveluitaan kuin pohtivat vammaisuuden ja ikääntymisen risteämistä. Arkielämässä merkitystä oli sillä, miten, millä tavoin, mistä ja milloin apua ja tukea saadaan. Kirjoittajilla oli erilaisia jäsenyyksiä riippuvaisuudesta ja itsenäisestä elämästä, jotka heijastelivat vammaispolitiikan itsenäisyyskäsitystä, mutta myös yksin pärjäämisen ideaalia. Kirjoittajat kertoivat lisäksi haasteista avun saamiselle, joista osa oli sisäisiä ja osa ulkoa päin tulevia. Esimerkiksi avun pyytämistä kuvattiin vaikeana, ja toisaalta myös julkisten palveluiden hakeminen näyttäytyi haastavana epäselvien hakemusten ja palveluiden takia.

Väitöskirjassani ehdotan vammaisuuden käsitteen ymmärtämistä toisaalta pragmaattisesta ja toisaalta ontologisesta näkökulmasta sen sijaan, että pyrkisi saavuttamaan konsensuksen parhaasta vammaisuuden määritelmästä. Pragmaattisesta näkökulmasta vammaisuuden määritelmää on tarkasteltava sen tarkoituserien ja seurausten kautta. Toisinaan vammaisuutta on määriteltävä, mutta määritelmän syyt ja seuraukset huomioiden: esimerkiksi on syytä kiinnittää huomiota siihen, miksi vammaispalveluissa vammaisuus määritellään niin kuin se määritellään ja mitä seurauksia tällä määritelmällä on. Ontologisesta näkökulmasta taas voidaan pohtia vammaisuuden ja samalla ihmisyyden laajempia kysymyksiä: miten vaikkapa jäsenämme erilaista kehollisuutta ja millä perustein ja miksi teemme jakoa ihmisten välillä. Tässä avuksi ehdotan yhteisriippuvuuden käsitettä, jonka mukaan kaikki ovat riippuvaisia muista eri tavoin, vaihdellen ja muovautuen elämänkaaren läpi.

Väitöskirjani tulosten pohjalta ehdotan, että vammaispalveluissa ja -politiikoissa tulisi tunnistaa perusteet, joille käsitteet on rakennettu ja niiden aiotut sekä tahattomat vaikutukset. Lisäksi kehoitan vammaisuuden käsitteen kriittistä tarkastelua ikääntymisen näkökulmasta ja sen varmistamista, etteivät rajanvedot rakennu normaaliuden oletuksille.

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APPENDICES

APPENDIX 1: Invitation to write (in Finnish)

Ikääntymisen ja vammaisuuden rajapinnalla tasapainoileva: Kirjoita tutkijalle omasta elämästäsi

Kun ikää tulee, voi tulla vammoja ja toimintarajoitteita. Toisaalta myös vammaiset henkilöt ikääntyvät. Useissa tutkimuksissa on nostettu esiin, että ikääntyneiden vammaisten henkilöiden oikeudet toteutuvat heikommin kuin muiden. Vammaispalvelut pyrkivät turvaamaan yhdenvertaisen osallistumisen vammaisille henkilöille, mutta vammaispalveluja ei ole suunniteltu ikääntymisen mukanaan tuomiin tarpeisiin. Vanhuspalvelut taas eivät välttämättä ole riittäviä ja sopivia ikääntyville vammaisille henkilöille. Vaarana on putoaminen näiden palveluiden väliin.

Haluaisin kuulla kokemuksia Sinulta, joka ikäännyt vamman kanssa, tai joka olet vammautunut tai jolle on tullut toimintarajoitteita ikääntymisen myötä. Minkälaisena olet itse kokenut ikääntymisen tai iän mukanaan tuomat toimintarajoitteet? Kuinka ympäristösi on suhtautunut tähän? Kuinka palvelujärjestelmä on tukenut tässä elämänvaiheessa? Oletko havainnut erilaisia myönteisiä tai kielteisiä asenteita joko vammaisuuteen tai ikääntymiseen liittyen?

Kerään tutkimustarkoitukseen kirjoituksia vammaisuuden ja ikääntymisen kokemuksista. Tutkimus toteutetaan Suomen Akatemian rahoittamassa Ikääntymisen ja hoivan tutkimuksen huippuyksikössä. Voit kirjoittaa vapaasti kokemuksistasi ja ajatuksistasi ikääntymiseen ja vammaisuuteen liittyen.

Voit kirjoittaa niin lyhyesti tai pitkästi kuin haluat ja käyttää halutessasi seuraavia kysymyksiä inspiraationa:

- Minkälaisia ajatuksia ikääntyminen vamman kanssa tai iän mukanaan tuomat toimintarajoitteet sinussa ja lähipiirissäsi herättävät?
- Oletko saanut riittävästi tukea ja apua toimintarajoitteiden tai vammojen tuomiin haasteisiin? Keneltä tai mistä olet saanut tukea ja apua?
- Oletko kokenut, että sinua kohdellaan eri tavalla nyt, kun olet ikääntynyt tai kun sinulle on tullut toimintarajoitteita tai vammoja? Kuka tai mikä taho kohtelee eri tavalla?
- Koetko identiteettisi muuttuneen nyt, kun olet ikääntynyt tai kun sinulle on tullut toimintarajoitteita tai vammoja?
- Kuinka arkipäiväsi ovat muuttuneet ikääntymisen, vammojen tai toimintarajoitteiden myötä? Saatko riittävästi tukea ja apua esimerkiksi harrastuksiisi? Mistä saat tukea?

Kirjoituksen lähettämisen yhteydessä sinulta kysytään muutamia taustatietokysymyksiä. Kirjoituksestasi voidaan julkaista otteita tutkimuksissa ja niiden yhteydessä voidaan julkaista antamiasi taustatietoja. Älä käytä nimiä kirjoittaessasi itsestäsi tai muista yksityisistä henkilöistä. Vältä myös tarkkojen paikkojen mainitsemista kirjoituksessasi, jos sen perusteella voi paljastua sinun tai mainitsemasi kolmannen henkilön henkilöllisyys.

Kirjoituksesi arkistoidaan pysyvästi Yhteiskuntatieteelliseen tietoaarkistoon myöhempää tutkimus-, opetus- ja opiskelukäyttöä varten, jos annat siihen luvan. Henkilötietoja käsitellään tietosuojalain mukaisesti akateemisen ja kirjallisen ilmaisun tarkoitukseen.

Tietoaarkisto voi tarvittaessa muokata arkistoitavia kirjoituksia tietosuojavaatimusten ja muiden laillisten vaatimusten täyttämiseksi. Ennen vastaamistasi tutustu Pennan käyttöohjeisiin.

Tutkimukseen osallistuminen on vapaaehtoista. Voit peruuttaa osallistumisesi keruun voimassaoloaikana käyttämällä kirjoituksen lähettämisen yhteydessä saamaasi yksilöllistä linkkiä. Palaa kirjoitukseesi ja valitse 'Peru osallistuminen ja poista vastaus'. Vahvistettuasi valintasi kirjoituksesi ja antamasi taustatiedot poistuvat Pennasta kokonaan.

Lähetä kirjoituksesi viimeistään 31.12.2021 osoitteessa:

<https://services.fsd.tuni.fi/penna/vammatjaikaantyminen/51>

Kiitos!

Lisätiedot:

Salla Era

Väitöskirjatutkija

Ikääntymisen ja hoivan tutkimuksen huippuyksikkö

Jyväskylän yliopisto

salla.ma.era@juu.fi

APPENDIX 2: Invitation to write (in English, translated by the author with the assistance of DeepL Translate)

You, who are balancing between ageing and disability: write to a researcher about your life

As people age, injuries and impairments can occur. On the other hand, people with disabilities also age. Several studies have noted that the rights of older persons with disabilities are less realised than others'. Disability services aim to ensure equal participation for persons with disabilities, but disability services are not designed to meet the needs of ageing. On the other hand, services for older people may not be sufficient and suitable for ageing persons with disabilities. There is a risk of falling between these services.

I would like to hear the experiences of you who have aged with a disability, or who are disabled or who has become disabled as a result of ageing. How have you personally experienced the disability that comes with ageing or old age? How has your environment responded to this? How has the service system supported you at this stage of your life? Have you experienced different positive or negative attitudes towards either disability or ageing?

For the purpose of this research, I am collecting written accounts on the experiences of disability and ageing. The research is part of the Centre of Excellence in Research on Ageing and Care funded by the Research Council of Finland. Feel free to write about your experiences and thoughts on ageing and disability.

You can write as short or as long as you like and use the following questions for inspiration if you wish:

- What are your and your close ones' thoughts on ageing with disability or age-related restrictions?
- Have you received sufficient support and help with challenges brought by your disability or impairment? From whom or where have you received support and assistance?
- Have you felt that you are treated differently now that you are older or have acquired disabilities? Who or what instance treats you differently?
- Do you feel your identity has changed now that you are older or have acquired disabilities?
- How have your everyday life changed as a result of ageing, disability or impairment? Do you get enough support and help, for example with your hobbies? Where do you get support?

When you submit your application, you will be asked a few background questions. Excerpts from your text may be published in research reports and may be accompanied by any background information you provide. Please do not use names when writing about yourself or other persons. Also avoid mentioning exact locations in your text if it may reveal your identity or the identity of a third party you mention.

Your writings will be permanently archived in the Social Science Data Archive for future reference in research, teaching and study, with your permission. Personal data will be processed in accordance with the Data Protection Act for the purpose of academic and written expression.

The data archive may, if necessary, edit archived writings to comply with data protection requirements and other legal requirements. Before responding, please consult the Penna's instructions for writing.

Participation in the data collection is voluntary. You can withdraw your participation during the collection period using the individual link you will receive in your email. Return to your entry and select 'Cancel participation and delete reply'. After confirming your choice, your entry and the background information you provided will be completely removed from Penna.

Please send your entry by 31 December 2021 at the latest to:
[link to the data collection]

Thank you!

[researcher's contact information omitted]



ORIGINAL PAPERS

I

EQUALITY ACCORDING TO WHOM? DEBATING AN AGE-RELATED RESTRICTION IN THE UPCOMING DISABILITY LEGISLATION REFORM IN FINLAND

by

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Equality according to whom? Debating an age-related restriction in the upcoming disability legislation reform in Finland

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ABSTRACT

Within many countries, the policies of disability and old age have been developing on distinct paths. Even though the prevalence of disability is higher in older populations, older persons tend to be excluded from disability discourses. Taking Finland's disability service legislation reform as an example, this article elaborates on the justifications for excluding or including older persons from disability policies. The paper analyses the public statements given in 2017 to a proposal that introduced an age-related restriction to disability services in order to understand how the restriction is argued for and against, and what kind of conceptualisations of old age and disability the statements portray. This study found that although equality is the most important principle underlying the reform, the conceptualisation of equality varies. Depending on who is included in the disability discourse, the idea of what is fair differs. Hence, it is necessary to recognise the differing understandings of equality in the debate regarding the age-related restriction. In addition, I argue that equality research can be helpful in assessing the fairness of public policies at the intersection of ageing and disability.

Introduction

Achieving disability equality is one of the main goals of disability policies. However, older persons with disabilities tend to be excluded from disability policies, which can create unequal situations (see, e.g. Hoppania, Mäki-Petäjä-Leinonen, & Nikumaa, 2017; Jönson & Taghizadeh Larsson, 2009). In recent years, the bridging of the relatively separate fields of disability and ageing has been called for in both research (e.g. Freedman, 2014; Jönson & Taghizadeh Larsson, 2009; Kröger, 2009; Leahy, 2018; Priestley & Rabiee, 2001; Yoshizaki-Gibbons, 2018) and policy (e.g. Putnam and Bigby, 2021; Bickenbach et al., 2012; Bigby, 2002).

The prevalence of disability in older populations is higher than it is with younger populations (Jönson & Taghizadeh Larsson, 2009). In the EU countries on average, 17.9% of the population aged 16 to 64 reported having activity limitations, whereas the percentage of activity limitations in the 65+ age group was 48.5% in 2018 (Grammenos, 2020; Table 1). In Finland, 3.4% of the population used disability services in 2018 (National Institute of Health and Welfare, 2018). In a report from six large Finnish municipalities, 60.7% of all disability services users were aged 65+ in 2018 (Ahtiainen, 2019). Despite this, many national policies generally view age-related disabilities as distinct from other

disabilities, and have excluded older persons with disabilities from disability policies and discourse (see, e.g. Jönson & Taghizadeh Larsson, 2009; Lavikainen, 2016; Leahy, 2018).

In research, the concepts of *ageing with disability* and *disability with ageing* have been used as a way of dividing two populations: the former concerns persons who have been born with disabilities or acquired disabilities earlier in their life whereas the latter refers to disabilities that begin in old age (Verbrugge & Yang, 2002). In her research situated in Ireland, Leahy (2018) argues that the separation of disability services and older persons' services can stem from conceptual issues: the lack of a clear concept of disability with ageing in the services tends to lead to equating old age with impairment and general decline.

According to Molton and Ordway (2019), ageing with disability and disability with ageing have been researched in separate siloes where people with long-term disabilities are invisible in ageing studies as well as older adults in research on disabilities. Hence, they argue, there is a need for greater collaboration between disability and ageing scholars in order to contribute positively to the lives of persons ageing with and into disabilities. In their analysis, they found that there is more cross-citation of disability studies in ageing research than the other way around; this implies that ageing research might be more interested in applying disability frameworks and especially disability studies might benefit

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Table 1
Background information on the comments given to the draft proposal in 2017.

Commenter	Submissions retrieved from the website		Written comments included in the analysis	
Municipality	18		16	
Joint municipal authority for a special care district	8		7	
Other joint municipal authority	9		6	
A ministry	6		3	
Governmental or other public authority	16		7	
NGO	64	35	40	22
Other types of NGO		29		18
Disability service user	6		0	
Other private person	7		5	
Other commenter	25		13	
Total	159		97	

from strengthening knowledge transmission with ageing research (Molton & Ordway, 2019).

The intersection of disability and old age has been studied from the viewpoints of older persons, persons with disabilities and experts. Naue and Kroll (2010) suggest that older persons do not want additional stigma on top of that already associated with old age, which can be a barrier to creating the aforementioned conceptualisation. Priestley and Rabiee (2002) found similar results in their comprehensive research regarding older persons' views about disability in the United Kingdom, where they studied the issue by interviewing and surveying people involved in organisations working for and with older persons. They found that even though there is much common ground between the disabled persons' movement and older persons' organisations, older persons tend to seek social inclusion precisely by distancing themselves from disability. In addition to older persons resisting a disability identity, there can be opposition from disability groups as well. Priestley and Rabiee (2001) found that disability groups had two differing views: some considered older persons with disabilities 'disabled', irrespective of the time of the disabilities' onset, while others regarded the impairments of older persons as just something that happens naturally with age. Leahy (2018) interviewed people working in policymaking, service provision, and non-governmental organisations (NGOs) that focus on ageing or disability. The results suggest that there is a tendency to view older persons with disabilities as 'elderly' than 'disabled' (see also Jönson & Taghizadeh Larsson, 2009), which is in concert with the previously mentioned studies as well. Kelley-Moore (2010) conceptualises the idea of normal ageing through Bury's (1982) perception of biographical disruption: disabilities in older age are not seen as biographically disruptive but are rather seen as normal and hence not needing disability services.

The need to focus on issues regarding the rights of older persons with disabilities has been brought up by the UN Special Rapporteur recently since "[their] human rights ... are not being respected" (United Nations, 2019, para. 2). Human rights and equality are essential principles in disability policies, and *equality* is a frequently referred concept in disability studies. However, it seems that only a few studies on the intersection of disability and old age focus on human rights or employ theories of equality in analysing the situation of older persons with disabilities.

In this article, I will concentrate on equality-based justifications for including and excluding older persons with disabilities from disability policy. I will analyse the public comments on a draft proposal for the new disability legislation, in which an age-related restriction was suggested. I am interested in what kind of tensions lie beneath the publicly expressed views on eligibility for disability services in the discussion of the Finnish disability services legislation reform. Therefore, I ask: How is the principle of equality perceived in justifying arguments for and against the proposed age-related restriction, and what kind of

conceptualisations of old age and disability do the arguments embody?

In the following, I will first provide a brief overview of the concepts of equality and equity that I will use in my analysis. After that, I will clarify the policy context of Finland. Then, I will introduce the methodology with which I arrived at my findings, after which I will present the categories that I found in the comments related to equality. Finally, I will conclude with a discussion of the different conceptualisations of disability and old age that result in different ideas of equality.

Equality and equity in disability and ageing policies

In order to understand the unequal situations and discrimination (e.g. Jönson & Taghizadeh Larsson, 2009; Raymond, 2019) caused by the aforementioned divide of disability services and older persons' services, one needs to understand what is meant by equality and equity. Often researchers, policy analysts, and others do not differentiate between equality and equity (Espinoza, 2007). Very little research on the intersection of disability and ageing that I know of has discussed the issue from an equity point of view – or elucidated what they mean by the often-used word *equality*. In relation to the Finnish disability policy reform, this is undoubtedly difficult as there are no separate meanings and words to *equality* and *equity* in the Finnish language.

Equity means fairness (Blanchard, 1986). However, it does not mean equal shares for everyone, but rather unequal shares according to one's needs (ibid.). In other words, someone may need more resources or support than others, and it is equitable to provide that support even though it means some get more than others. *Equality* has a long line of theorising, and therefore has a variety of conceptualisations. For the purposes of my article, I juxtapose it with *equity* and consider it along the lines of *basic equality* defined by Baker, Lynch, Cantillon and Walsh (2016: 23): "[basic equality is] the idea that at some very basic level all human beings have equal worth and importance, and are therefore equally worthy of concern and respect". In the domain of disability policy, *equity* is of utmost importance: persons with disabilities need individual-specific support in order to participate in society. Hence, with this support, persons with disabilities can achieve *equality* in society. Therefore, I see equity as a means to equality; that is, there is no road to true equality without equity.

Historically, ageing research and policies have reflected a medical standpoint concentrated on understanding and preventing disease and loss of function, whereas disability studies have in recent decades relied on the social model, emphasising independence and questioning the medical framework (Monahan & Wolf, 2014). Even though in the disability field, the social model of disability has been dominant, critique has been presented; for example, criticism for ignoring impairments and the need for impairment-specific medical attention (see, e.g. Shakespeare, 2006). To further the common language of disability and ageing, and ease the divide between policies, a biopsychosocial model (Leahy, 2018) and social model of ageing (Naue & Kroll, 2010) have been suggested. Naue and Kroll (2010) propose a social model of ageing that would include the aforementioned criticism of the social model but also utilise its benefits for ageing policies, more resembling a biopsychosocial model. Similarly, Leahy (2018) suggests that universal, biopsychosocial understandings of disability could provide necessary linkages between disability and ageing.

In addition to the aforementioned proposed models of disability and ageing, equality-based solutions leading to less-excluding disability policies have been proposed as well. Jönson and Taghizadeh Larsson (2009) suggest using an interest group approach in order to tackle the negative effects of age norms and age-graded reference groups. They note that age-graded references have been used by younger persons with disabilities in the struggle for equal rights in order for them to be able to live as others of a similar age do. Furthermore, Jönson and Harnett (2016) continue this thought by applying an equal rights framework in care home settings and argue that external reference groups could help older persons to claim rights. If older persons with disabilities are

perceived to be 'just old' and disabilities in old age are considered 'natural' (Priestley, 2003), policies based on age-graded reference groups can be regarded as ageist. In their participatory action research, Raymond and Grenier (2015) conclude that ageing frameworks should accommodate more diversity and varying life courses.

The aforementioned tensions in the intersection of disability and ageing have been studied less in Finland, with the exception of research done by Hoppania et al. (2017). In their article, they discuss the situation of older persons with dementia within the service system, suggesting that such persons should be viewed through the framework of disability legislation instead of the legislation directing older persons' services. They argue that the service provision for older persons with dementia can be considered discriminatory and create unequal situations since the older persons have not been regarded as eligible for the disability services, unlike younger persons with dementia. The same complexity and potentiality of unequal treatment can be seen with other age-correlated disabilities in Finland.

Policy context: Finland

In this article, I discuss the intersection of disability and old age in disability policies through a Finnish example. Hence, it is necessary to clarify the policy context of Finland.

Services for different user groups – for example, older persons' services and disability services – are organised and funded separately. The specific piece of legislation directing the services for older persons is the *Act on Supporting the Functional Capacity of the Older Population and on Social and Health Care Services for Older Persons (980/2012, henceforth, 'the Older Persons' Services Act')*. This Act is secondary to other general legislation concerning older persons (e.g. the Social Welfare Act 1301/2014). Disability services, on the other hand, are legislated by the *Disability Services Act (380/1987)* and the *Act on Intellectual Disabilities (519/1977)* in addition to general legislation (e.g. the Social Welfare Act 1301/2014).

The disability service legislation in Finland is being revised. Its main objective is to merge the Disability Services Act 380/1987 and the Act on Intellectual Disabilities 519/1977. In addition to merging the two Acts, the contents and coverage of the new Act will be revised as well: an age-related restriction to disability services has been suggested on multiple occasions. In the current disability service legislation, persons whose service needs mainly stem from age-related disabilities are not specifically excluded from disability services except for personal assistance (Disability Services Act 380/1987). The definition of *age-related disabilities* in personal assistance has engendered many appeals to the Supreme Administrative Court, and the decisions have guided the application of the Act. For example, the Supreme Administrative Court ruled in one case that an 85-year-old person with mobility and cognitive impairments due to a stroke was not eligible for personal assistance since the risk of stroke increases with age; hence, these needs were interpreted to be related to ageing (Supreme Administrative Court, 2012 10.12.2012/3389, published as KHO 2012:111). The problematic aspect of this is that a younger person in a similar kind of situation can be eligible unless the cause of the stroke is undeniably proved to be age-related. Hence, for an older person, an impairment may be interpreted age-related until proven otherwise, whereas for a younger person, it is quite the opposite. It was suggested that a similar age-related restriction be applied to all disability services in a draft proposal presented to the public in 2017 in order to provide an opportunity to comment on it.

According to the draft proposal, the act would not be applied to a person whose assistance and support needs mainly result from conditions that have originated, worsened, or increased because of old age, or from deterioration due to old age (Ministry of Social Affairs and Health, 2017). In the draft proposal, it is then further suggested that, in the future, these persons' service needs would be covered by the Social Welfare Act and the Older Persons' Services Act; the definition of *age-related disabilities* was in fact tied to the definition in the Older Persons'

Services Act. According to the Older Persons' Services Act, "older person means a person whose physical, cognitive, mental or social functional capacity is impaired due to illnesses or injuries that have begun, increased or worsened with high age or due to degeneration related to high age" (Older Persons' Services Act 980/2012, §3.2). In law, there is no distinct chronological age limit to be included in older persons' services.

However, the Social Welfare Act and the Older Persons' Services Act do not include as many services aimed at increasing participation, self-determination, and inclusion as the Disability Services Act does. In addition, these Acts do not include subjective rights to related services, and the services are not cost free to the service users, as many disability services are. A subjective right in Finland means an enforceable entitlement to certain services, irrespective of municipal resources. Hence, it can be argued that this kind of age restriction would weaken the services provided for older persons whose disabilities can be interpreted as age related.

Finland ratified the United Nations' Convention on the Rights of Persons with Disabilities (UNCRPD) in 2016. The UNCRPD does not consider the time of the onset of the impairment (i.e. whether it is age related or not) in its definition of *disability* (United Nations, 2006, Article 2). The UNCRPD adopts a human rights-based approach. The human rights-based approach steers away from previously used models of disability, especially the medical model of disability (United Nations, 2014). The human rights-based approach leans on ideas from the social model of disability yet does not adopt it fully. This constitutes a paradigm shift in understanding disability, in which a disability is no longer seen either as a medical problem or as an issue created by the environment or society. As the UNCRPD is ratified, this has to be taken into account in preparing legislation.

The government proposal (159/2018) was given to parliament in September 2018. In it, the coverage of the proposed Act is stated as follows: this Act is to be applied if the person does not get sufficient and suitable services according to the Social Welfare Act 1301/2014, the Older Persons' Services Act 980/2012, or any other Act. The government proposal (159/2018) lapsed before the general election of 2019. The reform work continued under the subsequent government along the same tracks, however no new draft Act has been proposed at the time of writing (March 2021).

Data and methods

My data consists of the public comments on the draft proposal for the new disability legislation (2017). The draft proposal of 2017 included both a rationale and a detailed rationale as attachments, and all the documents were introduced to the public when gathering comments. In the analysis, I will focus on the comments since the aim of the study is to investigate the argumentation and justifications for and against the age-related restriction.

Comments to the draft proposal were gathered from May 17th to July 17th in 2017. Some actors ($N = 123$) – including appropriate ministries, governmental authorities, municipalities, joint municipal authorities, political parties, NGOs, and other authorities – were requested to comment on the draft proposal, and a public call for comments was posted as well. According to the summary of statements, altogether 162 comments were given, with the largest proportion of them (41%) being from NGOs (Huhta, Pohja, & Tulkki, 2017). However, only 159 comments were available online (Ministry of Social Affairs and Health, n.d.). Some actors submitted comments as an appendix as well, and therefore the number of actors (150) was actually smaller than the number of comments. I focus on the comments rather than the commenters.

I analysed the written comments on the age-related restriction in question, which was mentioned in 97 of the 159 comments. I mostly categorised the commenters according to their own identification in the questionnaire; the answer options are presented in Table 1. In order to better recognise the differences between actors, I analysed disabled

persons' organisations (DPOs) separately from other NGOs. The 97 comments contained 161 argument units, as one comment could consist of multiple arguments. Altogether, the statement forms amounted to 2321 pages, but after extracting the written comments regarding the age-related restriction, 29 pages with font size 8 text and 1.0 spacing were left.

The comments were submitted in Finnish or Swedish. In this paper, I have translated all the quotations from Finnish or Swedish into English. The original comments are found on the website of the reform ([Ministry of Social Affairs and Health, n.d.](#)). When using citations, I provide the name of the commenter with which the comments can be found on the website mentioned above.

In the draft Act included in the draft proposal, the age-related restriction is provided in § 2.3. It states that, according to the Older Persons' Services Act (980/2012) § 3.2, the Act will not be applied to an older person whose physical, cognitive, mental, or social functional capacity is impaired due to illnesses or injuries that have begun, increased, or worsened with old age or due to degeneration related to high age. The other two sub-sections of § 2 deal with the more general definition of *disability* and organising responsibility according to other legislation.

Comments were collected with a questionnaire containing both multiple choice and open questions. The questionnaire contained 41 questions, with four of them focusing on the coverage of the proposed Act. The questions regarding the coverage and their answer options are presented in [Table 2](#). The last question of the questionnaire is included as well since some had elaborated more on the age-related restriction there. In addition to a few answers to Question 41, I analysed the comments given to Question 8, which is an open question regarding the scope of application of the Act, including the age-related restriction.

In the analysis, I utilise the theory of justification developed by [Boltanski and Thévenot \(1999\)](#) as a coding instrument to understand how the arguments for and against the age-related restriction are justified, and I utilise problem-driven content analysis as the method of analysis ([Krippendorff, 2004](#)) with a focus on equality. I chose to concentrate on equality issues since I consider it an important principle to discuss as it most likely guides our approach to disability, both in reference to this particular proposed Act and also more broadly in society. It is essential to bring the questions around equality into wider and more public consideration.

[Boltanski and Thévenot \(1999\)](#) argue that, in moral and political disputes between different actors, argumentation is justified through different 'worlds' or 'economies of worth' that they name *inspired*, *domestic*, *fame*, *civic*, *market*, and *industrial worlds*. These worlds include the idea of a 'good life', based on classical Western philosophical root texts ([Boltanski & Thévenot, 1999](#)). In the following, I present the six worlds in question with examples of what they would mean if they were used to oppose the age-related restriction in the dispute at hand.

The inspired world: In this world, things like creativity, emotions, and

artistic sensibility have worth. In this world, it could be argued that older persons with age-related disabilities need the services to engage in cultural activities and, without them, they are left without key features in life.

The domestic world: Here traditions, family life, and a strict sense of authority and hierarchy are of most importance. An argument could thus be that we need to respect our elders, and therefore we should not exclude them from any services they need, including services for persons with disabilities.

The world of fame: A persons' worth depends on their fame and being recognised by others. A valid justification for opposing the age-related restriction in this world could be that a famous and well-respected disability activist supports the inclusion of older persons with age-related disabilities in disability services.

The civic world: In the civic world, what matters is equality and common good. It could thus be stated that it is unjust and unequal to exclude older persons with age-related disabilities from disability services since they need them too.

The market world: The market world revolves around wealth, buyers, and sellers. If older persons with age-related disabilities were included in disability services, it could be argued that money would be saved elsewhere, for example, in home care and other care services.

The industrial world: In the industrial world, expertise and efficiency are the sources of worth. An argument could state that many experts and legislations regard the age-related restriction as unequal and we should trust these experts.

Justification theory ([Boltanski & Thévenot, 1999](#)) is useful in understanding the rationales different actors present in political and societal disputes, and it has been widely used for that purpose (see, e.g. [Perälä, Hellman, & Leppo, 2013](#) [on opioid maintenance treatment]; [Salminen, 2016](#) [on private transport use]; [Hast, 2013](#) [on an ecological dispute]). I will employ justification theory as a coding instrument through which I can recognise important arguments and counter arguments within the dispute over the age-related restriction.

During the analysis, I read the equality-related arguments multiple times to recognise patterns and categories. After recognising specific categories, I found resemblance to equity theories, specifically the work done by [Blanchard \(1986\)](#).

Some clarifications need to be made in relation to the Finnish language that I have translated into English in the quotes. Two words were commonly used when describing normal ageing or normal life: *normaali* and *tavanomainen*. The first is quite unambiguously 'normal' whereas the second is more difficult to interpret in English. It translates as 'usual' or 'ordinary' which are words that are not very often used in international research related to normal ageing. However, the meaning of *tavanomainen* is quite similar to 'normal' but it does not have as negative an undertone as 'normal' has. In order to not falsely put negatively loaded words into the commenters' statements, I wanted to clarify this. Nonetheless, in relation to my analysis, the factual meaning is the same: something that is not unusual or unexpected.

Table 2

Questions in the questionnaire regarding the coverage and the answer options (translated from Finnish by the author).

Question	Answer options
5. On the basis of § 2, is it clear in which situations the special Act is applied?	Yes No No opinion
6. In the 3rd sub-section of § 2, a restriction to the coverage is provided. Is the restriction clear?	Yes No No opinion
7. Is the restriction necessary?	Yes No No opinion
8. Other notions about the contents of § 2.	[Open space]
41. What else would you like to bring up concerning the draft proposal?	[Open space]

Findings

It is not surprising that cost, legality, and equality are mentioned when discussing a disability policy reform (see [Table 3](#)). For the purposes of this article, I have only analysed the justifications that base their arguments in the civic world, more specifically in the ideals of equality for it is perhaps the most essential principle in disability policies. Regarding this reform, the differences between understandings of legality and cost are undoubtedly to be resolved among legal experts. However, it is essential to discuss the issues around equality widely and publicly. [Table 3](#) shows the numbers of arguments, justifications, and the equity norms I found in my analysis, categorised by the direction of the arguments.

As [Table 3](#) shows, most of the arguments were critical of the presented age-related restriction. However, many were not against the idea

Table 3
The categorisation of the comments into arguments, justifications and equity norms.

	Arguments	Justifications					Total	Equity norm			
		Civic	Market	Industrial	None	'Normalities'		Needs	Disadvantages	None	
For	35	6	12	11	9	38	2	1	3	0	
Against	110	50	1	44	21	116	27	10	6	7	
Neutral	13	3	0	6	4	13	0	2	0	1	
Total	161	59	13	1	34	167 ^a	29	13	9	8	

^a The arguments were in some cases justified with a collaboration of two worlds, which is why the number of arguments can differ from the number of justifications.

of an age-related restriction itself. Justifications for being against the restriction were mostly made through the equality-focused civic world and the efficiency-focused industrial world, whereas the cost-based market world was mostly involved in arguing for the restriction.

The commenters used equality as a principle in justifications in both supporting and opposing the proposed age-related restriction or the idea of an age-related restriction. It was usually not explicitly voiced but, based on justification theory (Boltanski & Thévenot, 1999), I interpreted it as the underlying principle guiding the argument.

As the commenters argued for equality, they suggested different means of achieving it (i.e. there were different ideas of equity and fairness). I categorised them into three domains of equity: (1) the equity of equal 'normality', (2) the equity of equal needs, and (3) the equity of equal disadvantages. The first of the three, the equity of equal 'normality' was the most prominent one as many commenters pointed out what is and should be considered 'normal'. This is not surprising, since notions related to normality and normal life could also be found in the detailed rationale of the proposed Act itself. The second, the equity of equal needs, was a little less pertinent, but clearly visible. Many commenters focused on needs, regardless of whether their comment was supporting or opposing the restriction. The third, the equity of equal disadvantages, was the least common of the three, but recognizable. This category regards both the principle of restricting the services to the most disadvantaged groups and who can be considered disadvantaged.

The equity of equal 'normality'

The equity of equal normality category reflects disability through the idea of normality. In Blanchard's (1986) equity norms, this relates to the ascription norm. According to that norm, resources should be distributed according to some specific characteristic, such as age, nationality, gender, or (in my application) the idea of normality determined by the commenters. The commenters viewed certain disabilities as normal in relation to ageing, and therefore they did not support them to be included in disability services. Both supporting and opposing arguments were found in this category, some claiming certain disabilities as belonging to normal ageing and others to not belong.

Some commenters, like the following care workers' union, highlighted that not all disabilities in older age are caused by ageing:

There is a risk that, based on the restriction, persons who have acquired disabilities after turning 65 years old will not get special [disability] services according to this [draft proposal] Act, but the Social Services Act will be applied to them. However, not all disabilities acquired by older persons are disabilities linked to normal age-related illnesses. The reason for a disability's emergence cannot be age ... (Super [a care workers' union]).

The commenter notes that not all disabilities acquired in older age are linked to normal age-related illnesses. On the other hand, they also maintain that the reason for a disability's emergence cannot be age. That is, some disabilities are linked to ageing, but not caused by it. As many other statements, this comment seems to include the view that disabilities that are in fact linked to normal age-related illnesses could be excluded from disability services. The question lies in what can be considered as normal age-related illnesses.

Many commenters were concerned about the fate of certain impairments. Most DPOs that represent certain disability or impairment groups wanted to stress that the impairment in question cannot be considered normal ageing. Issues regarding persons with, for example, memory disorders, hearing loss, and visual impairments were especially mentioned as being at risk of wrongful exclusion, as can be seen in the argument below about visual impairments:

The Finnish Federation of the Visually Impaired highlights that acquiring visual impairments is not normal ageing. There's always a disease behind the visual impairment that has caused it. It is not normal, ordinary frailty of old age or the usual deteriorating health in old age. (Näkövammaisten liitto [The Finnish Federation of the Visually Impaired]).

The argumentation around normal ageing was focused on distancing certain impairments and situations from it. Most commenters in this category wanted to make sure that certain impairments or situations would not be interpreted as normal ageing, since in this case, normal ageing was a negative situation as it would deprive them of the eligibility to receive support and services. This begs the question: What then are the effects of so-called normal ageing that should be excluded?

The findings from other studies show that age-related disabilities are not considered to disrupt the process of ageing since they are regarded normal. In other words, normative ageing inevitably includes disability (Kelley-Moore, 2010). However, disabilities in childhood, adolescence, or adulthood can be considered disruptive since a person should be active during those stages of life and attention should be focused on supporting their participation (see, e.g. Priestley & Rabiee, 2002; Leahy, 2018).

Some were concerned with how the restriction would recognise that some disabilities worsen with age. Even though the decreases in health would be related to ageing, the origin of the health deterioration would be in the previous impairment:

Oftentimes, ageing can exacerbate a disability that has started due to illness or injury. It can then be difficult to distinguish between an injury or illness and the symptoms of ageing, which is likely to lead to unequal treatment of clients: with one [client] the need for help or support is primarily seen as related to old age and with another [client], the same need is seen to be caused by illness or injury. (FYSI ry, Suomen Fysioterapia- ja Kuntoutusyritykset Oy [an organisation of private rehabilitation businesses]).

Many commenters noted that the age-related restriction in this form would not bring equality, but still supported the idea of an age-related restriction. For example, one municipality maintained that the restriction and its proposed definitions were needed but were still not clear enough, and the interpretation difficulties would remain:

The definitions in the coverage of the proposed Act are necessary and the relations between different Acts should be clearly defined. Both the article in the proposed Act and the proposal for its rationale leave the application of different Acts unclear. It is still open for interpretations about what old age is and how the illnesses and impairments caused by the ageing of a person with disabilities are interpreted. (Tampereen kaupunki [the City of Tampere]).

As the structured question was 'Is the restriction necessary?', these kinds of comments enforce the idea that many would wish to see a clearer distinction between disability services and older persons' services. The number of persons aged 65+ in disability services has been increasing (Sotkanet.fi), which may engender concerns about disability services costing more or having to divide the costs between more service users. This can raise concerns of equality among persons with disabilities of different ages. Many commenters wanted to stress that whatever happened, "[n]o one should be left behind, and the services of persons with disabilities must not be weakened as they age" Espoon vammaisiamies [the disability ombudsman of Espoo].

The equity of equal needs

Some commenters supported or opposed the age-related restriction by claiming that it should be restricted according to needs, which is straightforwardly the same as Blanchard's (1986) equity norm of needs. According to this norm, resources should be distributed according to needs: persons who have the same kind of needs should have the equal support or resources. Supporters of the age-related restriction seem to make a distinction between the needs of older persons and (younger) persons with disabilities, whereas opponents maintain that age-related restriction is unnecessary since services should be determined according to one's needs regardless of the origin of the needs.

In addition to the distinction of needs, some stressed that because persons with disabilities need the services long term or even for their whole life, the services should be aimed at them specifically, as the following argument from a DPO shows:

We think that this age restriction is essential. Even though the elderly have to be able to get their necessary services, their services should be organised by applying the Older Persons' Services Act and the Social Welfare Act. Persons with disabilities will use the services for years, decades, or even their whole life. Hence, it is essential to secure services according to their individual needs with special legislation. The limited application of the [Disability Services] Act towards the older population was the aim [of this legal change] to begin with ... (Kehitysvammaisten tukiliitto, KVTL [Inclusion Finland KVTL, an organisation of persons with intellectual disabilities and their families]).

This evokes the question of individual needs and who has them. In previous research, it has been concluded that people in fact get more heterogeneous as they age (Dannefer, 1987). However, in my data, the individual needs of persons with disabilities were highlighted as opposed to the needs of older persons. Again, we come back to the idea of normal ageing and a normal life course that were referred to in the detailed rationale of the proposed Act that can be found problematic: as some needs are 'normal' at a certain age, they might not be considered 'individual'.

In comparison, some opponents of the restriction note that disability legislation should concern everyone who has the need for support because of an impairment, and restricting it is discriminatory. They make no note about the reality of the needs or their age relatedness. In their opinion, all disabilities are worthy of special services according to individual needs and the emphasis should be on the recognised service need and not the origin of the need:

We think it is discrimination that age affects whether or not one gets disability services; so, the age restriction should not be implemented. We think that the Act should apply to every person who needs necessary and frequent help or support in their daily life due to a functional limitation caused by a long-lasting impairment or disease. (Tapaturma- ja sairausinvalidien liitto [an association of persons with physical disabilities caused by illnesses or accidents]).

Not many commenters used the word 'discriminatory', but a few did.

Their opinion seemed to be quite clear and the closest to Blanchard's (1986) equity norm regarding needs, which clearly dictates the basis of equity: the same needs deserve the same resources.

The equity of equal disadvantages

The last equity norm I recognised in my data was the equity of equal disadvantages. This did not relate straightforwardly to any of Blanchard's (1986) equity norms. However, Miller (2001: 131–132) refers to a principle he names 'desert' in his theory of social justice: resources should be distributed to those who deserve them. I see some resemblance to deservedness in my category of equal disadvantages.

Some argued that the specific disability services need to be targeted to the most underprivileged group in the society (i.e. persons with disabilities). One commenter noted that, in order to maintain subjective rights, it is essential to restrict disability services to the relatively small group with individual needs:

The precondition for subjective rights, both socio-economically and individually, is that it is not a universal service and that the services are intended to target a relatively small group of the socially most disadvantaged persons that are in need of special solutions. (Invalidiiliitto [the Finnish Association of People with Physical Disabilities]).

Some argued for the inclusion of older persons on the grounds of other services being insufficient, which makes the older persons disadvantaged. For example, one commenter noted that "the Older Persons' services Act does not provide adequate services for older people with disabilities to enable them to live independent, content-rich lives" (Pohjois-Pohjanmaan Näkövammaiset ry [Association of Visually Impaired Persons in Northern Ostrobothnia]).

The insufficiencies of older persons' services have been recognised in Finland and extensively discussed in recent years. The dissertation research of Hoppania (2015) has shown that, in spite of the (then) new legislation, it has failed to bring any substantive improvements to older persons' services. This inability of older persons' services to provide sufficient support for older persons with disabilities arguably brings more applicants to disability services.

Discussion

In recent years, there has been increasing demand to link ageing and disability research and policies since the separate silos have been argued to create unequal situations for older persons with disabilities (see, e.g. Jönson & Taghizadeh Larsson, 2009; Leahy, 2018). This article set out to scrutinise the equality-based justifications for and against the separation, and the conceptualisations of old age and disability that lie beneath it. I found that the understanding of disability varies, and the meaning of equity vacillates with it.

Applying Blanchard's (1986) equity norms, I found three types of measures of equity in my data: *the equity of equal 'normality'*, *the equity of equal needs*, and *the equity of equal disadvantages*. The first, *the equity of equal 'normality'*, was the most prominent since many commenters referred to what is normal ageing and what is not. This could stem from the fact that the detailed rationale of the Act referred to normal ageing as well, and suggested that needs should be compared to those of other people of the same age. This raised concerns related to many impairments that correlate with age, that the commenters wanted to detach from normal ageing. However, the idea of normal ageing itself was also considered problematic in some of the comments since it is nearly impossible to determine which impairments are caused by ageing and which are not. Some commenters rejected the idea altogether that the mechanism by which an impairment is caused could be age.

The second domain of *equity of equal needs* included both supporters and opponents of the age-related restriction as well. Some claimed that

anyone who needs disability services should get them, and to fail to do so is discriminatory. On the other hand, some supported the restriction by stating that persons with disabilities have individual needs and therefore disability services should be focused on them. This can be interpreted to imply that older persons do not have similar needs that would require disability services.

Finally, the *equity of equal disadvantages* refers to societal positions that older persons and persons with disabilities hold. Some commenters maintained that disability services should be restricted to the most disadvantaged group, that is, persons with disabilities. However, some commenters claimed that in fact, older persons with age-correlated disabilities are disadvantaged at present since older persons' services do not cover their needs.

All of these categories boil down to the fact that people understand disability differently. Even in the restriction-supporting group, many concluded that disability services should be available to all persons with disabilities, irrespective of their age, but oftentimes older persons with age-related disabilities, or persons ageing into disability, were not included in the 'persons with disabilities' category. This is consistent with previous studies focusing on the perceptions about older persons with disabilities as they are often seen as 'just old' rather than 'disabled' (see, e.g. Leahy, 2018; Priestley & Rabiee, 2002).

I see the 'just old' paradigm as a pertinent one, since it can be supported by older persons (both with and without disabilities) and younger persons with disabilities alike. Previous studies suggest that older persons may not want additional stigma on top of the stigma of old age, and persons with disabilities may consider age-related disabilities as just something that happens with age. Jönson and Taghizadeh Larsson (2009: 76) argue that, in Swedish disability policies, "an apparent ageism in disability activism and policy may be understood as an effect of a historical struggle against injustices and discrimination" – the same might be underlying in Finnish policies as well. It can be argued that persons who are 'just old' do not have the same kind of history of discrimination and struggle, and therefore, providing older persons with age-related disabilities with the same positive rights may appear unequal.

Walker and Walker (1998) see the position of the disability movement slightly differently. They suggest that the distinction between older and younger persons with disabilities "absolves policymakers from the responsibility of taking action to recognise the needs of older disabled people, but the theoretical or practical case for the disability movement doing so is not apparent" (126). In my study, I found that not only policymakers supported the clearer distinction, but many organisations of persons with disabilities did so as well. Thus, my findings that both persons with disabilities and policy-makers can support the exclusion of older persons from disability policies appear to comply with Jönson and Taghizadeh Larsson's (2009) observations about Swedish disability policies and activism as well as Leahy's (2018) examination of Irish policies, services and activism on disability and ageing.

As many commenters noted, the number of older persons is increasing, and older persons' services are insufficient. This shortcoming in services was pointed out in my data but with the notion that disability services cannot compensate for it. It has long been argued that older persons are provided with less services because poverty (Walker, 1980) and disability (Townsend, 1981), for example, are considered to be natural in old age. I wonder whether this ageist perception of old age still lies beneath the services in Finland: the services for older persons are fewer and less secured than disability services, many of which are protected by subjective rights. An older person with any kind of disability may not get sufficient and suitable services from older persons' services, as argued, for example, by Hoppania et al. (2017) regarding older persons with dementia. In addition, the government proposal (159/2018) that followed clarified the differences of disability services and older persons' services, the former emphasising participation and equity in accordance with each age group, the latter on good quality care and safety, and preventing future service needs. The proposal seems to lean

on the normalisation principle that brought about significant improvements in the Nordic disability policies in the 1970s (Nirje, 1969). The normalisation principle argued that persons with disabilities should have a 'normal life' compared to their peers, which was revolutionary at the time. However, it has been criticised for its stereotypical age-graded references (Jönson & Taghizadeh Larsson, 2009; Walker & Walker, 1998). Instead of the normalisation principle, Walker and Walker (1998) proposed applying the principle of social integration in social and health services. Leahy's (2018) suggestion of a biopsychosocial model twenty years later could also provide improvements, as might Naue and Kroll's (2010) formulation of the social model of ageing.

As the understanding of disability varies, the perception of what is fair and what increases equality fluctuates with it. Thus, equality in reforming disability policy seems to be connected with how we understand disability itself. In these comments, equality lies beneath both the supporting and opposing arguments, but the essential difference is the inclusion of older persons with disabilities in the disability discourse. Along the lines of the equal rights framework suggested by Jönson and Harnett (2016) for the residential care of older persons, I suggest that equality and equity theories could provide new insight into the intersection of disability and old age. Jönson and Harnett (2016) propose that, instead of age-graded references, we should find other references that could help cover the individual needs that older persons also have.

Blanchard (1986) proposes his equity norms to help with assessing the fairness of public policy. Regarding this reform in Finland, it seems that there is no consensus regarding the equity norms by which this policy should be assessed: by the 'normality' of the disability, by need, or by disadvantage, or perhaps by all of them in some order. I argue that more focus needs to be put on the differing meanings of equality and equity in order to create equal disability policies.

Conclusion

In this article, I have shown that conceptualisations of equity and fairness vary, and I argue that they vary according to how disability itself is understood. The idea of equality-increasing legislation can be different, depending on whether 'disability' is considered to include age-related disability or not. The thought of normal ageing prevails as disabilities in older age are not seen as biographically disruptive (Kelley-Moore, 2010) but are rather seen as normal and hence not needing disability services. Older persons' services, on the other hand, are not sufficient for older persons with disabilities (see, e.g. Hoppania et al., 2017). For someone who includes age-related disabilities in the disability discourse, it seems unfair to exclude them from disability policies, but someone who sees age-related disabilities as just something that happens with age may regard otherwise. If older persons with age-related disabilities are considered as 'just normal old people', it would seem unfair to include them in disability policies. This study verified that we need to recognise the different conceptualisations – and the possibilities of conceptualisation – of equity when reforming policies that aim at increasing equality. Being fair to someone may apply unfairness to someone else. In this context, whose voice is prioritised is an important question to pose.

My study is not without its limitations. I analysed public comments, which provided insight into what the stakeholders want to express *publicly*. Therefore, the comments may have been more polished than what would be obtained in an interview, for example. In addition, the analysis rests on my interpretation of what can be seen as related to equality in their comments. There is the possibility that I have interpreted some comments differently from what the commenter had really meant. Further, the comments I analysed were given to an open question about the scope of the proposed Act with the notion that if the commenter wants to say something in addition to the structured questions, they could comment. Therefore, those who answered the question may have strong opinions about the scope of the Act. Since the restriction was included in the proposal, those who oppose the restriction need to

convince the legislators to change or remove it, and this is likely to have an effect on the overall argumentation in the comments. For instance, more analysable arguments were found in the opposing answers, whereas the supporting ones did not often elaborate on why they supported the restriction. In order to obtain more elaborate and balanced answers, an interview method would be useful in studying these issues. In addition, to continue this study in the nexus of the conceptualisations of disability and equality, the focus could be directed to analysing the concept of disability in old age more systematically in research and policies.

Despite these limitations, my study gives information about an issue that has not been studied in Finland before. This study also engages with broader discussion on the intersection of disability and old age, and provides an example of what an equality-based approach could bring to the table in the nexus of disability and ageing.

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II

FROM CONCEPTUAL GAPS TO POLICY DIALOGUE: CONCEPTUAL APPROACHES TO DISABILITY AND OLD AGE IN AGEING RESEARCH AND DISABILITY STUDIES

by

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ARTICLE

From Conceptual Gaps to Policy Dialogue: Conceptual Approaches to Disability and Old Age in Ageing Research and Disability Studies

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Abstract

In this study, we investigated the conceptual approaches to disability and ageing in two leading social scientific journals (*Ageing & Society* [AS] and *Disability & Society* [DS]) of the research fields that form the bases of policies on disability and ageing. This study aimed to identify the journals' trajectories of conceptual development and their differences, and through that, find possible pathways for further interaction between the yet largely separate policy frameworks for disability and ageing. Our analysis showed considerable differences between the conceptual approaches of the two journals, with the dominant approach in DS being sociomaterial and individual-functional in AS. We conclude this paper by identifying the conceptual gaps in the respective journals, suggesting a further collaboration between the approaches in research as well as policies. These gaps could be potentially narrowed, leading to a constructive dialogue on older disabled people.

Keywords: Ageing; disability; impairment; old age; conceptual

Introduction

Even though research on disability and ageing has historically developed on different paths, research on the intersection of these two fields has recently increased (e.g. Kröger, 2009; Jönson and Taghizadeh Larsson, 2009; Freedman, 2014; Leahy, 2018, 2021; Yoshizaki-Gibbons, 2018; Era, 2021; Putnam and Bigby, 2021). Persons with early-onset disabilities live longer than before and, at the same time, the number of people acquiring disabilities with ageing has been increasing, resulting in a further overlap between the two research fields (Molton and Ordway, 2019). This development has led to an increasing overlap and blurring of the boundaries between disability and long-term care policies: there are more and more older people using disability services and, at the same time, the number of people with early-onset impairments using long-term care is increasing. However, the interplay between ageing and disability policies is clouded by unresolved issues: older disabled people are often marginalised in disability policies (Jönson and Taghizadeh Larsson, 2009), whereas ageing discourse tends to emphasise healthy and active ageing, which may not be inclusive (Naue and Kroll, 2010).

The former Special Rapporteur on the Rights of Persons with Disabilities (Devandas-Aguilar, 2019) has stated that older disabled people have weaker rights than disabled people of other ages. Older disabled people may not be included in disability policies, nor in ageing policies (Raymond and Grenier, 2013; Raymond, 2019). This condition may lead to double jeopardy as older disabled

people fall in between the two separate strands of services, policies and communities. One reason for this in-betweenness can be conceptual barriers and approaches between the two research and policy fields (Leahy, 2018: 42; Molton and Ordway, 2019).

Accordingly, this article takes its starting point in the conceptual barriers within these two research fields of ageing and disability. We aim to discuss the conceptual differences and similarities of the two research streams to contribute to mutual learning and constructive dialogue that could lead to equal inclusion of all older disabled people in policies and research.

In many ways, disability models dictate how disability is approached in societies, and influence which disciplines and professions study and teach about disability (Smart, 2009). Furthermore, models of disability influence the public perception of disability, as well as shape the identity of disabled people (Smart, 2009). If the approach to disability is individual and functional, the responses will be individual, and the professionals dealing with disabilities will be from the fields of medicine and rehabilitation, for example. On the other hand, if the approach to disability is more social, the responses to disability are similarly social, for example, considering the accessibility of the environment. Often this is visible in disability and ageing policies: disability policies focus on ensuring participation in society with disability, whereas ageing policies are more medically oriented and deal with medical and long-term care (Monahan and Wolf, 2014; Leahy, 2018). Hence, the conceptualisation of disability in ageing and disability policies has great implications for how the service system is organised at the intersection of disability and old age. As research informs policy, we review exemplars from disability studies and ageing research to better understand the divide in policies.

The conceptual understanding of disability in research on disability has developed from a medicalised *individual model* that views disability as a personal tragedy, to *social models* that recognise the barriers to participation that disabled people face (Oliver, 2009). The social model of disability has been used in developing influential policy instruments, such as the United Nations' Convention on the Rights of Persons with Disabilities (UNCRPD) and the World Health Organisation's (WHO) International Classification of Functioning, Disability and Health (ICF), although the conceptualisation of disability differs from the social model in both. In disability studies, the theoretical and philosophical discussion around the concept of disability is active. Ageing research, on the other hand, has theorised disability in relation to, for example, theories of the fourth age and frailty, but also from the viewpoint of environmental and social barriers (Leahy, 2021). Nevertheless, the concept of disability has tended to be more medically focused in ageing research (Monahan and Wolf, 2014), even though as a research field it is broad and multidisciplinary and also includes theories and ideas far from medical thought.

Disability in old age, however, is still a relatively new concept. In literature, ageing with disability and disability with ageing (or ageing into disability) have often been differentiated from each other. Ageing with disability refers to a situation where a person with early-acquired or congenital impairments ages, whereas disability with ageing refers to the process of acquiring impairments in old age, with no previous disability (Verbrugge and Yang, 2002). Disability research often focuses on ageing with disability, whereas disability with ageing is studied in ageing research (Molton and Ordway, 2019: 5S). Often, disability with ageing has not been considered to 'belong' in the disability sphere: disability in old age is regularly understood as a 'normal' process that inevitably happens with ageing (Kelley-Moore, 2010). Similarly, Priestley and Rabiee (2001, 2002) have found that ageing and disability communities may not recognise older persons with age-related disabilities as disabled as this type of disability is often viewed as a phenomenon that 'happens with old age'.

Research on the conceptual base of the nexus of old age and disability is relatively scarce, although theoretical work has been done, for example, related to the intersection of ableism and ageism (Yoshizaki-Gibbons, 2016), social locations of older disabled people (Grenier *et al.*, 2016), cultural construction of disability and old age (Priestley, 2003a, 2005), 'normal' ageing (Kelley-Moore, 2010), as well as ageing with disability from a life course perspective (Priestley,

2000, 2003b; Jeppsson Grassman and Whitaker, 2013). Even though work has been done in the intersection of disability and old age, the *concept* of disability in older age is less widely explored and there is a need for a more unified understanding of it (Leahy, 2018). To contribute to developing such an understanding, this study analyses how disability has been conceptualised in the intersection of disability and ageing in two example journals, one from ageing research (*Ageing & Society*) and one from disability studies (*Disability & Society*).

In this article, we aim to provide answers to the following research question: what are the key conceptual approaches to disability in the nexus of disability and ageing in two example journals from the fields of ageing research and disability studies and how do the approaches differ between the journals? By answering these questions, we aim to identify some of the key conceptual gaps between the two research streams and contribute to their constructive dialogue. Our final goal is to examine how older disabled people could be better integrated into the discourse of ageing and disability studies as well as in disability and care policies.

Conceptual approaches to disability and old age

To develop disability policies, analysing concepts is essential as ‘conceptual understandings of disability continue to shape policies’ (Fisher and Robinson, 2023: 4). In their introduction to disability policies, Fisher and Robinson (2023) show how policies vary depending on how disability is understood: if the understanding of disability is medical and individual, the interventions may be focused on individualistic health interventions by medical professionals. On the other hand, with a more social approach to disability, support for participation in society is of importance. Disability models have played a major defining role in the concept of disability. According to Smart (2009: 3): ‘[M]odels of disability define disability, determine which professions serve people with disabilities, and help shape the self-identities of those with disabilities’. She also stresses the models’ power in service organisation and delivery (Smart, 2009).

As a concept, disability has been understood in diverse ways throughout history. The most usual way of looking at disability conceptualisations is to divide them into individualistic and social approaches (Vehmas, 2004). For the purposes of this article, we name these two categories *sociomaterial and individual-functional approaches*. After their description, we discuss how these approaches are present in two influential international policy documents, the ICF and the UNCRPD.

Sociomaterial approaches

Since the emergence of disability studies as a research field, disability studies have conceptualised disability mostly through *sociomaterial approaches* to contrast the traditional, medicalised view of disability. Until then, disability was primarily seen as a medical condition and a personal tragedy, and the power over the definition of disabilities was mainly with medical professionals (Vehmas, 2004). With other social movements, the 1960s and 1970s saw an increase in disability activism and, through consistent advocacy, a major change in how disability was conceptualised. In the mid-1970s, a group of disabled activists in the UK called the Union of Physically Impaired Against Segregation (UPIAS) presented a revolutionary idea that it was not impairment that was the main reason for social exclusion of people with impairments but how the society responded (Oliver, 2009: 43). From this thought, Oliver (2009) formulated *the social model of disability*.

The social model makes a distinction between *impairment* and *disability*, where disability is something which is imposed on people by the barriers that exist in the environment, in addition to their bodily impairment (Barnes, 2012: 13). The social model has faced critique in disability studies, for example for disregarding the body and the diverse lived experiences of people with impairments (e.g. French, 1993; Shakespeare and Watson, 2001; Thomas, 2004). The social model has many adaptations in different cultural locations: for example, in North America and Canada, disability has been studied as a cultural and minority identity (Siebers, 2008), and Nordic scholars

have followed a relational model that takes a more interactional and relational stance on disability (Gustavsson *et al.*, 2005: 32).

Even though ageing research has had a more medical orientation, some strands in ageing research focus on sociomaterial issues, as well. In environmental gerontology, disability in older age has been analysed through the concept of person-environment fit (Wahl and Weisman, 2003; Wahl *et al.*, 2009), which comes rather close to a relational or interactionist approach to disability in disability studies. Critical gerontology as a field contests the overmedicalisation of ageing and questions the biomedical underpinnings of ageing research and policies (Baars, 1991; Ranzijn, 2015), as does cultural gerontology (Twigg and Martin, 2015). Critical and cultural gerontologists have presented critiques to contest, for example, the paradigms of successful (Minkler and Fadem, 2002) and active ageing (Timonen, 2016) that often present disability as an individual functional limitation. In addition, representational and cultural issues – similar to those in disability studies – have been studied extensively (e.g. Twigg and Martin, 2015; Martin and Twigg, 2018). Many similarities and ways of bridging critical gerontology and disability theory have been found throughout the years (e.g. Kennedy and Minkler, 1998; Yoshizaki-Gibbons, 2021). However, in ageing research generally, disability as a concept has mostly been understood as an individual characteristic rather than a social issue: ‘something a person has rather than experiences’ (Leahy, 2021: 9).

Individual-functional approaches

Disability studies have relied on the social models emphasising independence and questioning the medical framework, whereas ageing research and policies have had a more medical orientation to disability concentrating on understanding and preventing disease and loss of function (Monahan and Wolf, 2014). We name these approaches *individual-functional approaches*. According to Leahy (2021: 22–26), gerontological biomedical research mostly understands disability in general as the inability to do certain actions, whereas environmental and social gerontology sees disability more broadly and considers its environmental and social conditions. In mainstream gerontology, broader approaches to disability remain marginal as theorising is dominated by discussions about frailty or ‘the fourth age’, that is, the period after an active retirement age characterised by decline and impairment (Leahy, 2021). In addition, the rhetoric of active, successful, and healthy ageing emphasises the individual nature of disability and policy focus on preventative action rather than participation in society regardless of disability (see, for example, Gibbons, 2016 on compulsory youthfulness).

Conceptual approaches in international policy documents

The models or approaches to disability are not only theoretical foundations for research but they also form the grounds of some influential international policies on disability. We discuss here two major policy documents that are important to the field of disability and ageing: the ICF of WHO and the CRPD of the UN. They are very different in nature since the UNCRPD is a legally binding instrument that national legislation has to comply with when ratified. The ICF, on the other hand, is a classification instrument that can be used as a tool in formulating policies to assess disability. Nevertheless, these two documents are often referred to in research, as well, to indicate that the understanding of disability complies with the document.

The ICF seeks to integrate the medical and social models as a ‘*bio-psycho-social synthesis*’ and therefore takes a biopsychosocial approach to disability and functioning (WHO, 2013: 5). The emergence of the biopsychosocial model can be traced back to the medical field in the 1970s, where Engel (1977) developed the model to broaden the medical model in way that would consider the social and emotional aspects (Borrell-Carrió *et al.*, 2004). Some scholars see the biopsychosocial model as a middle ground between the social and the medical (Leahy, 2021).

Table 1. Information on the journals

	<i>Disability & Society</i>	<i>Ageing & Society</i>
Established	1986–1993 as Disability, Handicap & Society 1994 as DS	1981
Publisher	Taylor & Francis	Cambridge University Press
Impact factor 2022*	2.4	2.5
Volume per year	10 issues	12 issues

*As stated on their respective websites.

However, it can be interpreted individualistically, resulting in harmful policies (e.g. Chou and Kröger, 2017; Shakespeare *et al.*, 2017; Hunt, 2022).

Despite its wide use, the ICF and the biopsychosocial model have critics in the disability field. Oliver and Barnes (2012: 26) argue that although its purpose is well-intended, the starting point of the biopsychosocial model is still the individual and the body, which the disability movement always aimed to contest. In addition, Kennedy (2017) argues that the biopsychosocial model emphasises psychogenic explanations to impairments rather than their impacts of them, and therefore policies based on the model may be dismissive, or, ‘blaming the victim, all over again’ (Shakespeare *et al.*, 2017: title). The ICF has also been applied in ways that strengthen the medical approach to disability in disability policies (Chou and Kröger, 2017; Shakespeare *et al.*, 2017).

Today, one of the most significant documents on disability is the UNCRPD adopted in 2006. It is a binding international legal instrument that must be implemented in countries where it is ratified, and hence, influences disability policies worldwide. The UNCRPD focuses on human rights and thus embodies a *human rights-based approach*. The approach of the UNCRPD has been interpreted to represent the social model of disability (Egdell *et al.*, 2018) and the biopsychosocial model (Leahy, 2018). However, even though inspired by the social model thinking of interactions between disabled people and disabling barriers, the human rights-based approach to disability is distinguished from these models as it is based on international human rights laws, namely the UNCRPD in this case. The approach of the UNCRPD has spread throughout disability studies, as has the specific human rights model that has stemmed from it (e.g. Degener, 2017; Committee on the Rights of Persons with Disabilities, 2018). Both the human rights-based approach and the human rights model emphasise the recognition of disabled people as rights-holders and the States’ obligation to ensure those rights (Office of the High Commissioner for Human Rights, 2014; Committee on the Rights of Persons with Disabilities, 2018).

The disability models and approaches we presented here are not exhaustive. In our analysis, we focus on the most fundamental distinction between the social and individual approaches. We make this distinction here to analyse the conceptual differences between ageing research and disability studies and to contribute to the development of constructive dialogue between these two research fields.

Methodology

To study the conceptual approaches within the intersection of disability and ageing, we selected two journals that best fit our aims. From both fields of ageing research and disability studies, we searched for a journal that (1) publishes in English, (2) is international, (3) is mostly social scientific and focuses on societal issues, (3) has published in 1990–2020, and (4) is well-known and widely cited in its research field. In addition, we aimed to find two journals that would be relatively comparable in terms of journal metrics (see Table 1). Based on these criteria, we identified two journals, *Ageing & Society* and *Disability & Society*, which are both UK-based. Although their publication volumes are dissimilar, both have published a sufficient amount of articles that fit our

Table 2. Search terms and inclusion and exclusion criteria

Journal	<i>Disability & Society</i>	<i>Ageing & Society</i>
Search terms in the primary search	old OR older OR ageing OR aging OR aged OR elder* AND disab* (ALL FIELDS)	
Search terms in the secondary search	old OR older OR ageing OR aging OR aged OR elder* (TOPIC)	disab* (TOPIC)
Inclusion criteria	Peer-reviewed Regards old age and disability Published in 1990–2020	Peer-reviewed Regards old age and disability Published in 1990–2020
Exclusion criteria	Book review or other commentary Does not discuss disability in relation to ageing into old age, but, for example, ageing from childhood to adulthood	Book review or other commentary Mentions disability only briefly

purposes, that is, to identify the differences and trends within the fields. Table 1 presents the basic information of the journals.

In this article, we focus on the conceptual approaches used in research published in AS and DS during the thirty-year timespan of 1990–2020. We focus on the concept of ‘disability’ and articles that specifically use that term. Hence, we do not use search terms like ‘impairment’ or impairment-specific terms like ‘stroke’, for example. With this restriction, we realise we may exclude some important contributions to this nexus. However, we focus here on scrutinising the concept of disability because of its varied understandings that impairment-specific definitions often do not have. Data were gathered systematically from the two journals. The database search was conducted through the Web of Science for both journals. To find all relevant articles, we conducted a primary and secondary search. In the first search, we used the same search terms for both journals, which found most of the relevant articles. Nevertheless, with the second search using different search terms, we still found certain articles that fit our inclusion criteria. After the two-phased search, we read and selected the abstracts of the found articles according to the inclusion criteria (Table 2). After excluding all items that did not fit our criteria, 109 articles were left: seventy-six from AS and thirty-three from DS.

Fig. 1 shows the volume of articles that discuss ageing and disability in the two journals. The volume has been increasing, particularly in AS. In 2020, both journals increased their volume of articles on the intersection of ageing and disability. It is noteworthy that more articles were found in AS than in DS.

The analysis was carried out by the first and second authors: the first author searched and explored the data by doing word searches in ATLAS.ti, read and re-read the abstracts and did the first round of coding, then the second author confirmed the coding and did initial thematisation, based on which the final categorisation was then made by the first author.

First, we searched for the most used words with ATLAS.ti. This procedure provided indications of the themes that the articles focused on and the kind of terms they used. For example, we found that the most used words in the abstracts in DS were ‘disability’, ‘disabled’ and ‘people’, whereas AS focused more on ‘care’ and ‘disability’.

Second, we read the abstracts thoroughly to gain an idea about the articles and used thematic codes to indicate how disability is approached in the abstracts. For abstracts without any indication of the conceptual approach to disability, we searched disability-related words in the main text of the articles to find the parts that discussed disability. Based on those parts, we created twelve codes in AS and twelve in DS, from which six were common to both. After coding the articles, the codes were then merged into larger categories. For example, in DS, codes ‘bad health’, ‘impairment’, and ‘individual inability’ were merged into ‘disability as individual limitation’.

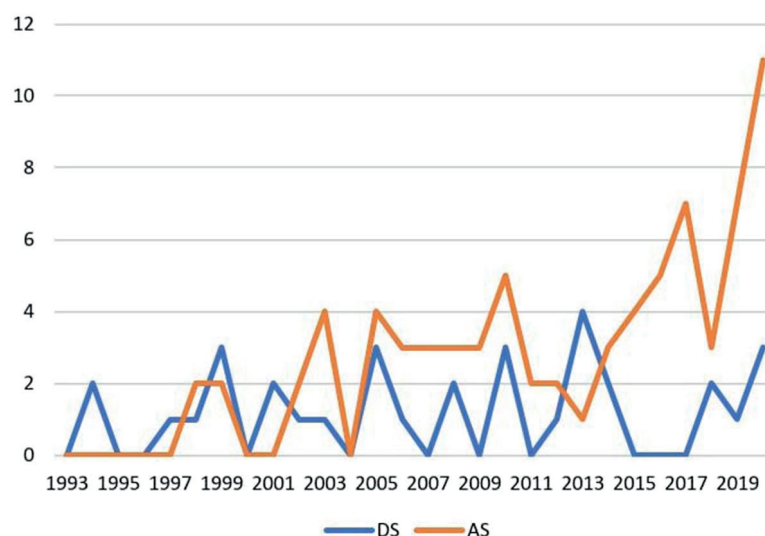


Figure 1. Number of articles discussing ageing and disability in AS and DS, 1993–2020.

We interpreted the approaches by how disability was described. For example, if disability was defined by using specific tests of physical capability, we interpreted it as being measurable and functional. If disability had no specific definition, we interpreted its conceptualisation by the surrounding words and ways of writing about it. For example, if disability was referred to as ‘a disability’ and an older person with disabilities as ‘an older person who suffers a disability’ (Breda and Schoenmaekers, 2006: 540), it was interpreted as a synonym for impairment in this analysis. The reason is that it implies one specific condition that a person suffers rather than a broader interaction of many elements. If the authors used the word ‘impairment’ in a different sense than ‘disability’, disability was interpreted as referring to a broader concept than the individual condition (e.g. Simcock, 2017). Similarly, if discussions on the surrounding barriers in the emergence of disability were provided, we interpreted it as a reference to social approaches to disability. The categorisation of the analysed articles and full citations are provided as Supplementary Material. Supplementary Material is available at <https://doi.org/10.1017/S1474746424000058>.

Finally, we analysed the conceptual approaches more closely and selected parts of the articles that expressed well such approaches. In the Findings section, we examine the conceptual approaches that are present in these text sections.

Findings

Ageing & Society

The dominant conceptual approach in AS considers disability as an individual limitation: disability was mostly studied as an impairment of a person who needs care, and it was seen as quantifiable and recognisable. However, another less dominant approach was also visible: disability with a social perspective, especially leaning towards the social models of disability. Next, we will present the two approaches in detail.

Individual-functional approaches

Most of the AS articles shared the approach to disability as an individual limitation, where disability was discussed as a measurable issue mostly related to the functional capacity of

individuals. The topics of the articles varied; many articles discussed the care of older disabled people, whereas others studied the effects of disability on, for example, socio-economic situation (Olivera and Tournier, 2016). Long-term care for older persons was the most frequent topic in AS.

Throughout the studied period, care was depicted as a necessity for older persons with disabilities. In care topics, disability was discussed from slightly different viewpoints, though within the individual-functional approaches. In many articles, disability was studied as a predictor of care needs. Their results showed that older persons with disabilities need and receive considerable care (e.g. Davey *et al.*, 2007). In addition, the care trajectories of older disabled people were discussed as well as the careers of informal and formal carers (e.g. Romoren, 2003).

For example, Hu and Ma (2018: 772) defined disability by activities of daily living (ADL) and instrumental ADL (IADL):

People who reported having IADL disabilities only or having difficulty in performing any of the ADL tasks were regarded as having mild disability; people with one ADL disability were regarded as having moderate disability; and people with two or more ADL disabilities were regarded as having severe disability. The rest were considered independent people.

The above definition considers disability literally, that is, dis-ability of I/ADL, not being able to perform these activities. Hence, disability in this context may not be synonymous with impairment but rather with inability. However, from a wider perspective, disability is derived from the individuals and their condition.

Within the individual-functional approaches, the articles were mostly large-scale quantitative studies using surveys of older persons (e.g. Davey *et al.*, 2007; Rogero-Garcia *et al.*, 2008; Hu and Ma, 2018) and their caregivers (e.g. Schofield *et al.*, 1998; Barnes *et al.*, 2012), combined with register data (Liao *et al.*, 2018).

Only a few qualitative studies that used an individual-functional point of view were among the articles on the intersection of disability and old age. For instance, Degiuli (2010) conducted interviews with Italian family carers. Disability was mentioned by the interviewees, and discussing the findings, the author briefly refers to a disability assessment performed in geriatric units (Degiuli, 2010: 770). Hence, disability is perceived as an assessable element. In addition to disability measures, certain studies did not define disability but used it relative to health and functioning. For example, Romoren's (2003: 471) 'study aimed to examine the illnesses and disabilities and the informal and formal care received by the subjects up to their deaths'.

In quantitative studies, disability does need to be defined to analyse statistical significance. However, it is noteworthy that disability automatically refers to functional limitations. It is either defined as such, or not explained but rather used as a synonym for impairment.

Sociomaterial approaches

Even though fewer than articles conceptualising disability as an individual limitation, certain AS articles engaged with disability studies, particularly the social model of disability that became widely known in the 1990s. However, in the late 2010s, articles started to focus less on the social model and more on broader theoretical frameworks of disability studies.

Rather unexpectedly, articles utilising the social model of disability did not present any critique or discuss it further. The social model was often mentioned as the way disability is understood in the article in question or as a way of understanding disability in general. For example, although the approach had been social throughout the article, Ward *et al.* (2008: 646) mentioned the social model in the discussion only: '[A]s the social model of disability gradually becomes more influential in thinking about, and the practice of dementia care, a very different framework for interpreting conditions in care homes is emerging'.

In the late 2010s, the social model was mentioned as one of the ways of conceptualisation. For example, Korotchenko and Clarke (2016) discussed the social model and its critiques with citations from disability scholars and social gerontologists. Similarly, Labbé *et al.* (2020) considered the understanding of disability and power wheelchairs from a life course perspective, citing relevant literature on ageing and disability and (rehabilitation-oriented) disability studies.

Even though there has been engagement with disability studies in AS, care topics have been discussed rather separately. Two articles discussing care are linked to disability studies (Bond, 1999; Rodrigues, 2020). For instance, Bond (1999: 565) focuses on dementia and suggests a social model of dementia:

A social model of dementia which adopts the social model of disability . . . would focus on the way that people with dementia and their informal caregivers interpret their own experiences of living with dementia and the meaning that their situation has for them.

At the beginning of our studied period in the 1990s, social approaches to ageing and disability in AS are mostly related to the social model of disability, whereas subsequent approaches are broader and engage with several theories from various research fields. As research leaned towards interdisciplinary work, research on the ageing–disability nexus did so, as well.

Disability & Society

In DS, some articles discussed disabled older people, whereas some described older persons and disabled people as discriminated against and underrecognised groups. In DS, disability within the intersection was discussed mostly from the viewpoint of societal challenges. In most articles in DS, disability was separated from impairment following the social approaches to disability. Contrary to AS, most articles in DS were qualitative. Moreover, the articles published in DS had minimal engagement with ageing studies and discussions on ageing. Very few had a straightforward focus on ageing. Social perspectives on disability were the dominant approach, whereas individual-functional approaches were fewer.

Sociomaterial approaches

Most of the articles published in DS distinguished impairment from disability. Impairment refers to the physical condition, whereas disability refers to a broader aspect, including social and environmental barriers. Certain articles followed the social model of disability, though other sociomaterial understandings were also found, for example, approaches focusing on the gaps and misfitting of embodiment and context.

The social model of disability was explicitly supported in articles concerning groups with different specific impairments, such as cystic fibrosis (Edwards and Boxall, 2010), arthritis (Barlow and Williams, 1999) and dementia (Boyle, 2008). The social model was argued to be utilised in policies and individual lives. For example, Boyle (2008: 760) notes that:

[A]pplying the social model of disability to people with dementia is useful in highlighting the extent to which their behaviour is pathologised, in problematising the use of psychiatric drugs to ‘treat’ behaviour and in identifying when such treatment threatens their right to liberty.

The usefulness of the social model of disability is noted above as it is viewed as a possible path to problematising medicalisation and recognising other elements contributing to the emergence of disability as well as claiming rights.

Certain studies discussed disability together with social approaches but did not explicitly adhere to a social model of disability. For example, Sapey *et al.* (2005) discussed the social model widely but supported a human rights-based approach in the end. Other studies also implicitly adhered to sociomaterial models but did not necessarily mention them (e.g. Gant, 1997). For example, Priestley and Rabiee (2002: 600) mentioned the lack of a social model in older persons' organisations and distinguished between disability and impairment.

Walker and Walker's (1998) article follows a social constructionist approach to disability and old age. They presented a critique of the normalisation principle (making everyday life course as regular as possible for disabled people) and suggested that the social construction of old age hinders the participation of older disabled people:

However, the limitations of the normalisation concept are clearly demonstrated with regard to older people with learning difficulties because the experiences of their reference group in this case older people are themselves often limited and restricted by society's attitudes. (1998: 130)

In their view, normalisation, in this case, does not bring any improvements to older persons with intellectual disabilities as the reference group of older persons is socially constructed as a dependent and fragile group.

Intersectionality in DS was increasingly noticeable in recent years. Intersectionality – a concept to analyse multiple identities and oppression, developed by Crenshaw (1989) in relation to the intersection of race and sex – has in recent years been taken up alike by disability studies scholars (e.g. Garland Thomson, 2005; Goodley, 2014; Yoshizaki-Gibbons, 2016) and academics from the ageing field (e.g. Calasanti and King, 2015; Holman and Walker, 2021; Hussein, 2023). Intersectionality as a concept is not attached to either of the dominant conceptual approaches we analyse here, as it can be useful in the nexus of disability and old age regardless of the conceptualisation of disability. However, it was observed only concerning the sociomaterial approaches in our data, and only in DS.

In DS, for example, intersectionality was visible in articles that focused on older women with impairments (Barlow and Williams, 1999; Proctor, 2001), disability and ageing (Webber *et al.*, 2010; Thomas and Milligan, 2018) and ageing, disability and gender (Vernon, 1999). Many did not mention intersectionality in their analysis but discussed the situation of persons facing challenges due to complex needs or positions (Clare and Cox, 2003; Willoughby, 2014). For example, Vernon (1999: 396) criticises disability studies for ignoring multiple identities of disabled persons and suggests that disability scholars should take a more intersectional approach, though the word 'intersectional' is not used:

Social model theorists are right to emphasise the pervasiveness of disability. However, there is an underlying assumption that the other experiences of disabled people, such as racism, sexism and heterosexism, are taken care of by other social movements. This would be true, except that disabled people, because of the stigma of being impaired, are also excluded from the movements of race, gender and sexuality. Therefore, it is all the more important that the disabled people's movement does not exclude or marginalise the experience of disabled people who are a multiple Other.

This article was written over twenty years ago, and intersectional approaches have since increased. For instance, Thomas and Milligan (2018: 124) suggested an intersectional approach to understanding individuals living with dementia:

A variety of social markers, sometimes fluid and shifting, accompanies ascribed identities and self-identities through the life course. The concept of intersectionality can play a useful role here.

In DS, dementia was mostly discussed along with the social approaches to disability, with thorough elaboration on why it would be useful to view dementia from that viewpoint. Most of the dementia-focused articles applied the social model of disability or suggested its application to dementia (Proctor, 2001; Boyle, 2008; Thomas and Milligan, 2018; Alden *et al.*, 2019).

Only a few articles in DS used the concept of care, particularly those that adopted the dominant sociomaterial approaches. However, one article addressed the issues of older carers of disabled people (Argyle, 2001). In contrast to the articles discussing care in AS, this study was qualitative with no specific measures for disability. In this article, disability scholars are cited, and the identities of disabled and non-disabled people are discussed due to the overlapping identities of care recipients and carers.

Individual-functional approaches

Certain articles in DS represented a counter-approach discussing disability as an individual limitation. This discourse was similar to the dominant approach in AS, which was also used in DS with large quantitative datasets and statistical analyses. However, this approach was minimal in DS articles as only six articles represented disability as an individual limitation.

One of the articles used large-scale data in studying involuntary retirement (Denton *et al.*, 2013). In this article, disability is understood as impairment:

However, our research has shown that fair or poor health at the time of retirement, severe or a very severe disability and multiple disabilities increase the likelihood of involuntary retirement. (2013: 349)

Another article discussed accessibility using one city as a case study (Levesque, 2020). In the article, the author scrutinised accessible rural transportation services and argued that persons with disabilities may be left in a precarious situation. He used Statistics Canada as a source for disability definition that guides the interpretation of disability as a measurable physical condition:

There are many types of disabilities with the three most common being pain, flexibility and mobility issues. Complicating matters is the fact that two-thirds of persons with disabilities have more than one type of disability. Disability also varies in its severity from mild to very severe. (Levesque, 2020: 3)

As mentioned earlier, DS did not have many care-related articles. Besides Argyle (2001), one such article was by Webber *et al.*, (2010) who studied staff responses to ageing-related health changes in care homes for persons with intellectual disabilities. The article did not explicitly define disability as an individual limitation, but the article resembles those published in AS. This article was distinct from other articles published in DS in that it is gerontologically oriented, using ideas of ageing-in-place and active ageing. Similarly, atypical to DS was naming the staff as 'care staff' that 'care for' persons with intellectual disabilities; 'care' is overall a highly contested concept in disability studies (see, e.g. Kröger, 2009).

Limitations

This study is not without limitations. In this research, we analysed articles from two journals that can offer only a scratch of the surface, as there is much theoretical work done in other journals on both fields, as well. In addition, the journals are both based in the UK, and even though they publish research from around the world, there is a possibility of selection bias. Future research could include systematically all research that has been done on the topic without journal restrictions and elaborate more on the contextual differences in each country in the analysis of

disability and ageing policies and practices. Furthermore, future research could review theories rather than focus on concepts as we have done in this study. Many social theories include elements of disability or insight into its conceptualisation, for example, disengagement theory or political economy approach to ageing (Putnam, 2002; Leahy, 2021), but such theories were out of our scope.

Discussion and conclusions

This research aimed to examine how the concept of disability is understood in the nexus of disability and ageing in a disability studies journal (DS) and an ageing-focused journal (AS). We asked what the key conceptual approaches to disability in the intersection are and how the approaches differ between the journals. Studies on the nexus of disability and old age have recognised the different conceptual bases of ageing and disability studies. However, our study is one of the first to review and compare published research articles of these two fields from a conceptual viewpoint.

To answer the research question, we analysed the articles in terms of the two major strands of disability conceptualisation: sociomaterial and individual-functional approaches. Similar to other research (Oldman, 2002; Kelley-Moore, 2010; Leahy, 2018), our analysis suggests that ageing research is more medically focused than disability studies that are informed by the social approaches to disability. In DS, most of the articles followed a sociomaterial approach explicitly or implicitly, and individual-functional approaches were in the minority with only a few articles employing such an approach. The majority of AS articles, on the other hand, had an individual-functionally oriented approach. However, AS articles showed more communication with disability studies and sociomaterial approaches than DS did with elements of ageing research. It seemed that when the revolutionary idea of the social model of disability emerged in the disability field in the 1990s and 2000s, it trickled into ageing research as well. However, similar cross-fertilisation from ageing research to disability studies was minimal.

The increasing publication of articles on disability and ageing is an important step forward. However, our analysis of the two journals verified that the two research fields of disability studies and ageing research have significantly different dominant approaches and lack proper communication with each other. This may have been contributing to a policy situation where many older disabled people, including those ageing with disabilities as well as those acquiring disabilities in old age, have been falling between existing social protection safety nets (Leahy, 2018). As the number of those who are at the risk of falling between is predicted to increase over the coming years, increasing attention to the intersection of disability and ageing is necessary not only for research, but also for policy (see Era *et al.*, 2020).

The policy implications of the conceptual confusion and lack of communication found in the intersection of disability and ageing are substantial. As the fields of disability and ageing inhibit a different conceptualisation of disability, it matters whether an older disabled person is considered 'old' or 'disabled' in terms of policies. In many countries, the policies on disability and ageing work in separate siloes (e.g. Jönson and Taghizadeh Larsson, 2009; Leahy, 2018), and may work with different understandings of disability, as concepts translate into policy (Smart, 2009; Fisher and Robinson, 2023).

In terms of policy, when the conceptualisation of disability is individual-functional, interventions are accordingly individual – curing or preventing health decline that is considered the cause of disability. Our findings show that related to old age and disability, ageing research inhibits a more individual-functional approach than disability studies. Translating into policy, services for older people respond to disability in such a way that emphasises individual 'fixes' to individual problems: for example, prevention of fall-induced impairments so that one could use public transport, and if impairments did happen, one would be provided care. On the other hand,

when the conceptualisation is more social, the interventions focus on making society more inclusive and supporting the participation of individuals in society rather than curing or preventing impairments: for example, when a fall does happen and leads to impairment, transport would be made accessible, or transportation services would be provided to ensure participation to society. In our study, this kind of approach was dominant in disability studies but not in ageing studies. This duality of conceptions may cause unequal situations for older disabled people as policy interventions vary according to the field they 'fall onto': one person may be considered through the lens of care, whereas another will have their rights to participation enforced, and someone may even be left without necessary services. We suggest that a closer alliance of these approaches could be beneficial in (re)forming ageing and disability policies.

Although the dominant disability policy approach is moving towards the human rights-based approach with the enactment of the UNCRPD, the dominant ageing discourse continues to focus strongly on the care paradigm. In this conjunction, both approaches have a great potential to accommodate the largely neglected needs of older disabled people when constructively combined. We suggest three potentially fruitful ways of combining these two seemingly separate approaches: (1) stressing agency and self-determination of older disabled people, (2) highlighting intersectionality and thereby questioning normality, and (3) integrating the care paradigm into the human rights discourse.

First, older disabled people have not gained much agency either in policymaking or research. This condition may be because they are retired citizens and the grey disability movement is yet to gain strength, being weaker than the general disability movement. Participatory methodology used in disability studies could be employed to interview very old disabled people, which would be an important way forward in research and policymaking. Based on our selective literature review, the co-creation of knowledge and agency in research and policymaking remains significantly scarce though greatly important. Without listening to the experiences and voices of older disabled people, they remain left behind in both spheres.

Second, ableism and ageism are well-recognised forms of discrimination (Devandas-Aguilar, 2019). Both are paramount in the experiences of older disabled people. The intersection of these two forms of discrimination is manifested, for instance when this group is disregarded by both disability services and older people's services. This situation provides an opportunity to question the assumed normality (Barton, 1993) in general and social inequality and injustice in our society in particular (Heikkilä *et al.*, 2020). Accordingly, the combination has great potential in furthering our theories in disability studies and ageing research.

Third, the care paradigm and human rights-based approach have a great potential to fill certain gaps in existing, fragmented social protection systems (see Kröger, 2009). There have been efforts to enact a UN Convention on the Rights of Older Persons that would remind the UNCRPD. In 2012, the UN General Assembly adopted a resolution to consider the proposal to enact an international legal instrument on this topic. Learning from the UNCRPD, the human rights discourse has limitations. For instance, love and care are not recognised human rights as such to respect, protect and fulfil (Katsui and Ned, 2024). However, they are indispensable parts of human life and particularly important in old age. Therefore, combining the two dominant approaches would create constructive ways to address the diverse needs of older people better than through only one approach.

Based on our selective literature review, we have recognised significant paradigm differences between the two academic fields. These differences contribute to the policy divide, where older disabled people are treated differently depending on whether they are considered 'old' or 'disabled', regardless of their needs. Constructive dialogue between the fields of disability and ageing would be a way forward in diminishing the divide.

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III

BEING INDEPENDENTLY DEPENDENT: EXPERIENCES AT THE INTERSECTION OF DISABILITY AND OLD AGE IN FINLAND

by

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3 Being independently dependent

Experiences at the intersection of disability and old age in Finland

Salla Era and Teppo Kröger

Introduction

In this chapter, we discuss the situation of older persons with disabilities in Finland from the viewpoint of personal experiences, focusing on in/dependence. Older persons with disabilities tend to be overlooked in both disability and ageing policies while there is little bridging between these policies, and it has been suggested that one reason for this is conceptual issues (Leahy 2018). We want to go deeper into these conceptual issues: the very concept of disability has different meanings, which may impact the intersection (Era, Katsui and Kröger, forthcoming). Close to the conceptualisation of disability lies the notion of in/dependence, which is discussed widely in both ageing and disability domains. In this chapter, we analyse texts written by older persons with disabilities in Finland with a focus on in/dependence. We ask *how in/dependence is displayed in the accounts of older persons with disabilities, and how they negotiate different meanings of in/dependence*.

In the following sections, we will first introduce the situation of older persons with disabilities in Finland and elsewhere, after which we will briefly discuss what we mean by in/dependence and its related concepts. Then we move on to describe our analysis, briefly looking at the data and methods, and to our findings around reflections of dependency. Finally, we will discuss the findings and their contribution to the research on the nexus of disability and old age.

Ageing and disability in Finland

The population is ageing rapidly, both in Finland and worldwide. Along with the general population, also persons with disabilities are living longer (Freedman 2014; LaPlante 2014). Population-based calculations of Statistics Finland predict that the number of people aged 75+ will double from 2010 to 2040, increasing by 108 per cent in this period (Tilastokeskus 2022). Disability, on the other hand, is more common in the older than the younger population (Jönson and Taghizadeh Larsson 2009). In EU countries, on average, 17 per cent of 16–64-year-olds reported disabilities in 2018, whereas

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the share of reported disability was 47.8 per cent among people over the age of 65 (Grammenos 2021, 16).

Around 3.3 per cent of Finland's population used disability services in 2020 (THL, 2022). In Finland, the proportion of older persons who use disability services is noteworthy: a report by the six largest municipalities in Finland – Helsinki, Espoo, Tampere, Vantaa, Oulu, and Turku – indicates that in 2021 the share of persons over the age of 65 among the users of disability services was 59.2 per cent (Kuusikko 2022).

As the above statistics indicate, older persons report more disabilities than the younger population, and older persons are a major user group of disability services. Even though there is such overlap between old age and disability, older persons with disabilities tend to be overlooked in the service systems of many countries, and often on the system level, the services are organised separately for older persons and persons with disabilities (e.g., Jönson and Taghizadeh Larsson 2009; Leahy 2018; Priestley and Rabiee 2002). This is applicable in Finland as well: older persons with disabilities are often seen as 'just old' rather than 'disabled' (Era 2021; Hoppania, Mäki-Petäjä-Leinonen and Nikumaa 2017). Acquiring impairments in older age is considered to be the norm of an ageing body and part of so-called normal ageing, reasoning which has been used in arguments supporting the exclusion of older persons with disabilities from disability services (Era 2021; Priestley 2006).

Formally, services for older persons and disability services are in Finland organised separately by different specific pieces of legislation. However, Finland's disability service legislation was recently reformed, and the situation for older persons with disabilities has changed as well. The most important discussion during the reform process from the viewpoint of older persons with disabilities has been around an age-related restriction that has been suggested to be applied to disability legislation on multiple occasions.

Disability services in Finland are organised according to the Act on Disability Services and Assistance (Laki vammaisuuden perusteella järjestettävistä palveluista ja tukitoimista, 1987; 2023) and the Act on Intellectual Disabilities (Laki kehitysvammaisten erityishuollosta, 1977), in addition to general legislation guiding social services (for example, the Social Welfare Act [Sosiaalihuoltolaki, 2014]). The new legislation was planned to come into force in October 2023, but after the new government was formed in the summer of 2023, the implementation has been postponed. In addition, the new government has reopened the already approved Act in order to specify its scope in a way that would ensure sufficiently low expenditure. One proposed way of specifying the scope was, once again, to impose an age-related restriction. At the time of finalising this chapter in December 2023, the new Act is planned to come into effect in January 2025, but the contents of the Act and its implementation are yet to be seen.

In the previous Disability Services and Assistance Act (1987), there were no age-related restrictions, except for personal assistance, a legal right to which was added to the Act in 2008. At that time, persons whose impairments

were the result of health decline related to advanced age were made ineligible for personal assistance. As there was no chronological age limit, this restriction left room for interpretation. This age-related restriction and other age-related confusions in the application of the Act have spawned many correction requests to higher governing and legal bodies that have had to clarify the practices (for example, Korkein hallinto-oikeus 2012: 60). The suggested age-related restriction in the disability legislation reform followed along the lines of the restriction in personal assistance, and discussion around it often referred to the experiences of personal assistance.

Before its (first) finalisation in 2023, the reform had been ongoing for many years. Regarding older persons with disabilities, the debate on age-related restrictions has been essential. In the discussion around the reform, understandings varied concerning what disability really is and whether age-related disabilities should be included (Era 2021). In a draft Act in 2017, persons whose impairments had originated, worsened, or increased because of old age or from deterioration due to old age were suggested to be made ineligible. In the 2018 government proposal, there was no age-related restriction, but the next draft proposal in 2022 introduced it again.

The draft of the new Act in 2022 suggested the same as the one in 2017: extending the beforementioned restriction to all disability services, including transportation services and home adaptations. This draft was introduced for public consultation in February 2022 and the government proposal was given to the Parliament in autumn 2022. However, the Constitutional Law Committee of the Parliament concluded that age-related restrictions were against the Constitution, and they were thus removed from the proposal. Instead of the age-related restriction, the scope of application of the Act now states that it will be applied if the person does not get required individual services according to any other law. The modified proposal was accepted in Parliament in the beginning of 2023. However, as mentioned, the Act has been now reopened by the new government, and there is no certainty of how its contents will change. The Act is planned to come into force in October 2024.

In Finland, the specific law that directs older persons' services is the Act on Supporting the Functional Capacity of the Older Population and on Social and Health Services for Older Persons (*Laki ikääntyneen väestön toimintakyvyn tukemisesta sekä iäkkäiden sosiaali- ja terveyspalveluista*, 2012, henceforth, the Older Persons' Services Act). The Older Persons' Services Act was introduced to tackle the gaps found in older persons' services at the time. However, it has been argued that it has had very little effect on the deficiencies of older persons' services (Hoppania 2015). Kröger, Van Aerschot, and Mathew Puthenparambil (2019) have stated that the Finnish long-term care system fails to fulfil the Nordic ambition for universalism, that is, to provide care to all older people who need it.

Although the legislation and services on the system level are separate, older persons with disabilities can acquire services according to disability

legislation (the Act on Disability Services and Assistance and the Act on Intellectual Disabilities) as well as the Older Persons' Services Act, as there are no chronological age limits in either. This was the case also with the previous disability legislation, but in practice the implementation of the Disability Services and Assistance Act by local authorities was varied. Before the disability legislation reform, Hoppania, Mäki-Petäjä-Leinonen, and Nikumaa (2017) identified weaknesses in the services regarding older persons with dementia and suggested that older persons with dementia ought to be accommodated in the disability framework and legislation instead of the Older Persons' Services Act. In their view, older persons with dementia remain in an unequal position compared to other people with different diseases or disabilities (*ibid.*). Even though the previous Disability Services and Assistance Act did not specify which disabilities were included in its realm, and only personal assistance had an age-related restriction, in practice, dementia in old age was often excluded. Other age-correlated disabilities faced the same issues.

The legislations regarding older persons and persons with disabilities differ in many ways, both with the previous and the reformed disability legislation: the Older Persons' Services Act does not provide specific rights to services but rather aims to ensure that services meet local needs and certain quality standards, whereas the Act on Disability Services and Assistance provides for enforceable legal rights (*i.e.* subjective rights) to a list of services. The most used disability service among older persons is transportation service (61 per cent of the service users were aged 65+ in 2020), whereas, for example, personal assistance (37 per cent) and service housing (35 per cent) are used more rarely by older people. However, it needs to be noted that personal assistance is the one disability service that previously has had an age-related restriction and the usage per cent of older persons might increase if the age-related restriction is lifted in 2025.

In sum, at the moment, there are no age-related restrictions in the Finnish disability legislation (except in personal assistance), and older persons with disabilities are included in both disability services and older persons' services. Although there is no general age-related limit, there has been support for such a restriction throughout the disability legislation reform process. Additionally, in practice, there has earlier been a tendency to exclude older people from disability services and provide them services only according to the Social Welfare Act (Hoppania, Mäki-Petäjä-Leinonen and Nikumaa, 2017) and/or the Older Persons' Services Act. However, the new disability legislation points clearer towards the inclusion of older persons with disabilities, and it remains to be seen how this translates into practice.

As noted earlier, the aim to exclude older persons with disabilities from disability services is not limited to the Finnish context but takes place in other countries as well (Jönson and Taghizadeh Larsson 2009; Mastin and Priestley 2011; Gibbons 2016; Leahy 2018). It has been suggested that one reason for such an exclusion is conceptual issues and especially the lack of the association

of the concept of disability with ageing (Leahy 2018). Molton and Ordway (2019) have suggested that disability studies and ageing research often speak different languages, as the conceptualisation of disability varies drastically between these two fields, and this can be a barrier to cross-network communication. There seems to be conceptual confusion at the intersection of disability and old age in research and in general discussion (Era et al. 2020; Era, Katsui and Kröger, forthcoming).

Conceptual gaps and bridges in the nexus of disability and old age

According to Priestley (2006, 85), disability and ageing both tend to be approached through health and functioning, whereas Molton and Ordway (2019, 55) point out that even within the nexus of disability and ageing there are divisions: the study of disability is scarce in ageing studies, and the same goes for ageing in the study of persons with disability. Yoshizaki-Gibbons (2018) has noted the same regarding critical disability studies and critical gerontology, with the former focusing on impairment/disability and the latter on old age. In ageing research, the health and functioning type approach to disability in old age seems to be mostly related to *disability with ageing*, whereas the more socially oriented conceptualisations intrinsic to disability studies often regard *ageing with disability* (Era, Katsui and Kröger, forthcoming). Accordingly, it seems that in disability studies, research in the nexus of disability and ageing focuses on persons ageing with disability whereas ageing research looks at older persons ageing into disability or acquiring disability with ageing. This difference in approach and concepts can further the division between ageing and disability research and respective policies.

In addition to conceptual issues surrounding the very concept of disability, there are conceptual differences concerning the use of the notion of in/dependence in the ageing and disability fields. In many parts of the world, self-sufficiency and independence are often portrayed as the preconditions of an ideal human being, and dependency is easily considered a failure (Kittay 2011). Therefore, those cast as ‘dependent’ are assumed to want to change that. According to Fine and Glendinning (2005, 602), ‘[autonomy and independence are] commonly promoted as the antithesis of dependency and, moreover, as unproblematic and universally desirable goals’.

The disability movement – and specifically the Independent Living (IL) movement – has challenged these assumptions with the argument that independence does not mean doing things by oneself physically, but rather that assistance makes independence possible (Barnes and Mercer 2006; Kittay 2011; Pearson 2013). Making independent decisions on how, when, where, and by whom the assistance is provided is independence rather than dependency, being ‘independently dependent’, as the activists of the IL movement call it (Barnes and Mercer 2006, 31). Looking at disability from within feminist care ethics, Kittay (2011, 51) has raised this notion’s risk of promoting

independence as the only way to dignified life and portraying dependence as ‘denigration of the person’. Similarly, Kelly notes (2013, 792) ‘[t]he IL movement revises common definitions of independence but it still maintains it as an important, if not paramount, social value’.

Even though there are differences in the conceptualisation of in/dependence, both disability studies and feminist care ethics have theorised (although with different premises and frameworks) that there is no independence without dependency: every human being is dependent at some point in their lives, and we all need others to be independent. It is a web of connections rather than a dichotomous, one-way flow of assistance. This conceptualisation of independence is concretely reflected in disability strategies in Finland as well as in the United Nations Convention on the Rights of Persons with Disabilities (UNCRPD) that Finland has ratified.

However, the conceptualisation of in/dependence can be different when viewed from the ageing sphere. For example, Phillips, Ajrouch, and Hillcoat-Nallétamby (2010, 131) have defined independence in the following way: ‘[independence is a] sense or state of physical, psychological and spiritual autonomy, self-identity, self-respect, control and degree of functional capacity’. This definition includes physical, psychological, and spiritual autonomy as well as functional capacity – the independence conceptualised in disability studies refrains from referring to similar requirements related to physical or psychological capacities.

Whereas in the disability field ‘Independent Living’ often refers to the ideology where individual autonomy can be achieved relationally, in the ageing field, ‘independent living’ or ‘living independently’ usually refers to the housing situations of older persons: living alone at home has been seen as a marker of independence (Portacolone 2011). Within housing for older persons, living independently often means living alone (or with a partner) in one’s home and not in any type of assisted living facility. According to Portacolone (2011), often the literature regarding independence has been closely related to studies on ‘ageing independently’ and supporting the ‘independent living’ of older persons. However, ageing research has argued for a broader conceptualisation of independence, for example, ‘relative independence’ (Hillcoat-Nallétamby 2014) as independence with intersecting dependency and independence (Secker et al. 2003).

As discussed above, ‘independence’, when used in an ageing context, typically means something rather different than in the disability field. Also, professionals’ views can differ from those of older persons or persons with disabilities. Writing in a disability context, Reindal (1999) has noted that professionals tend to view independence through self-care activities and therefore have a different meaning for independence than disabled people. Older persons’ services do not have the same kind of movement and involvement of activism as disability services do – and this can be expected to be reflected also in the professional understanding of in/dependence.

Data and methods

We collected 24 written accounts, gathered through Penna, which is a written data gathering website governed by the Finnish Social Science Data Archive. There we issued a call for texts that discuss the experiences older persons with disabilities have of the service system and of getting old with disabilities in general. We did not define ‘getting old’ or ‘disability’ in any specific way in the call, to permit people’s self-identification. In addition, we did not specify whether the acquired services were older persons’ services or disability services but encouraged the participants to tell us about the services in the text.

The call was open from October 18 to December 31, 2021. The length of letters was restricted to 10,000 words. The call was distributed through different social media platforms. We received 24 written responses of which we excluded one text that was submitted twice, one that did not concern Finland, one that was written entirely by a relative, and two that did not contain any text about respondents’ experiences, only answers to questions on the background of the participants. Hence, in the end, we had 19 texts from older persons with disabilities to analyse. Background information on the participants is presented in Table 3.1.

Our data collection is not without limitations. Since the call was distributed through social media platforms and emailing lists, it was restricted to persons who actively use the internet. We distributed the call with the help of disability organisations, but also through more general platforms (e.g., Facebook group for people born in the 1950s) in order to find persons who are not active in disability organisations. Writing about

Table 3.1 Background information of the participants

<i>Age, gender and service use</i>	<i>Number of participants</i>
Age	
55–59	1
60–64	4
65–69	1
70–74	8
75–79	3
80–84	1
85–89	1
Gender	
men	4
women	15
Use of municipal services	
yes	10
no	7
N/A	2

one's own life with its ups and downs may be strenuous both in terms of time and energy, and therefore, only persons who possessed these two responded. In addition, reflection on one's own life and its difficulties is cognitively demanding, and hence, this most likely influenced the data. The call was made accessible also in a PDF (Portable Document Format) form that was compatible with screen readers, and the assistance of another person with the task was allowed. However, the call was not available in other languages than Finnish, and therefore, potential participants from other language groups were omitted.

Men are underrepresented in the data: only 4 of the 20 participants were men, whereas the disability prevalence difference between genders in the EU is much narrower. In the EU, 26.8 per cent of women and 22.1 per cent of men report disabilities (Grammenos 2021, 15). However, the difference may be greater in old age, since women have a longer life expectancy and disability prevalence increases with age (*ibid.*). Still, our data have an overrepresentation of women compared to men.

We analysed the data using reflexive thematic analysis, developed by Braun and Clarke (2019), focusing on reflections around dependency related to impairments and old age. Reflexive thematic analysis is a revised or renewed version of the thematic analysis that Braun and Clarke proposed years before (2006), and their later reflections on the method have clarified their stance on thematic analysis (Braun and Clarke 2019; Clarke and Braun 2018). In their formulation of thematic analysis, the role of the analyst is recognised and kept in mind while doing the analysis (Braun and Clarke 2006, 2019; Clarke and Braun 2018). According to this method, themes in the data are not 'discovered', and they do not 'emerge' from the data, but themes are rather created and constructed during the process, with the analyst (with their abilities, knowledge, previous experiences, etc.) being an active actor in the creation. Hence, reflexive thematic analysis is a deliberate process, where the choices of the researchers and their effects are acknowledged. Even though the core of Braun and Clarke's thematic analysis has not changed throughout these years, we followed the latest formulation, which they call reflexive thematic analysis. Reflexive thematic analysis highlights the 'open, exploratory, flexible and iterative nature of the approach' (Braun and Clarke 2019, 593).

We took in/dependence as a starting point for our analysis, since dependency and independence are discussed widely in the ageing and disability fields, but just as disability in old age, they often mean different things in the two spheres. First, the accounts were read multiple times whilst taking notes. After that, the initial coding was performed, noting any relevant content in the data. Issues regarding in/dependence as well as conceptual differences within the disability and ageing spheres were familiar to us, and we chose to analyse the texts from the viewpoint of in/dependence, as it seemed to be relevant to the data as well. After a few rounds of reviewing and recreating, we presented the results in three themes. We focused rather on the

conceptualisations than the individuals, so each letter can contain multiple depictions of the conceptualisations. The analysis was performed by the first author but reviewed by both authors.

Findings: Navigating in/dependence

In general, the accounts included descriptions of how the participants' impairments had started, when, and what kind of medical encounters the participants had had in the past. The texts focused on the impairments, services, and the help the participants had received due to their impairments, and what they thought about the future. We did not separate those *ageing with disability* and *ageing into disability* as we wanted to categorise people as little as possible.

In our analysis, we focused on navigating between dependency and independence, and what kind of meanings they appear to convey. We noted that (1) fear of dependency was visible in the accounts; there were stories of how limiting it was to ask for help, and how scary it feels to become more dependent in the future. The second theme discusses (2) asking for help and justifying it: sometimes one has to be active and even make a demand in order to be helped. Some participants seemed to justify getting help as there were accounts emphasising reciprocity that allows one to be dependent: a long working career or caring for grandchildren can enforce a feeling of 'doing one's part in the world' and therefore deserving help in return. By contrast, the third section discusses (3) the independence that getting help brings: relationality in independence. The accounts indicate that independence can be achieved relationally, with the assistance of others. Here, however, problems with services through which independence could be achieved were raised.

In the following, we will discuss the different meanings of in/dependence reflected in the accounts. Some seemed to be related more to interconnected and relational independence, while others appeared to view dependency as an unwanted quality (although inevitable in old age), and therefore adhering more to the general perception of the ideal of self-sufficiency and self-reliance.

Fear of dependency

A great deal of fear was expressed in the accounts: participants feared getting old and dependent. For many, progressing impairments were inevitable, and even though the situation was good for now, the future was unknown and worrisome, as more needs could be expected to emerge. The next quote expresses the worry about the future:

As I age, I often wonder how I will survive as my physical strength begins to wane and my illnesses progress [...] it remains to be seen where I will find myself if my own strength fades so I can't cope alone.

(Woman, 70–74 years, uses services)

Dependency seems scary and not wanted. Being dependent, as Fine and Glendinning (2005, 605) noted, is regarded negatively: ‘dependency is cold and its connotations are almost entirely negative. Those identified as dependent are assumed actively to seek to reverse this status’. There were also accounts where participants did not currently describe impairments as difficult but expressed worry about the future with progressing impairments. The next quote expresses the feelings of loss when a person realises that something is no longer possible (without help):

It feels weird to write about limitations because I’m so used to ignoring them. I don’t think much about these things in my daily life. I run into a wall in situations where it happens – but it’s annoying just then, or even crushing – that’s no longer possible. That feeling of loss cuts deeply and reminds me of reality and the future.

(Woman, 60–64, no services)

Although not explicitly expressed, this quote can be interpreted to include worry and sadness about the future, and the feelings of loss of things that were previously possible: it ‘cuts deeply’ and is even ‘crushing’. The same participant continued:

All in all, ageing with this impairment is very challenging, even scary and degrading. At least I myself don’t know if I can get any help from my municipality or public health care. Now I can still be an independent disabled person living in my own home. Even though I can no longer take care of my home alone, I need the support of my spouse more and more.

(Woman, 60–64, no services)

The above participant described ageing with her impairment as ‘very challenging, even scary and degrading’, and continued by noting her unawareness of municipal services. She lives in her own home with the support of her spouse, who could be considered an informal carer – most likely unofficially, as she does not have knowledge of municipal services. This is common to many Finns: in the year 2020, there were over 50,000 ‘official’ informal carers who get receive support from the municipality (Sihto, Leinonen and Kröger 2022), but it is estimated that over 1.2 million Finnish people provide help to their close ones, many of whom are older persons with disabilities (Vilkko et al. 2014).

Asking for help can be difficult when dependency is seen in a negative light. One participant wrote that her children most likely would help if they had the time, but she thinks it is wrong to ask:

My children might help if they had time in their hurried lives. I think asking is wrong. I have had to cope on my own all my life, even in difficult

situations; I now realize that I will be asking for help at the last minute. That time will soon be around the corner.

(Woman, 70–74, no services)

The participant continued by writing that she has had to cope alone even in difficult situations: it is expressed in a negative way, as she *has had to* cope alone. This seems to indicate that she has not wanted to do it alone, and even now she does not want to ask for help since she thinks it is wrong.

The above quotes describe the fear of dependency and of having to rely on someone else to perform certain tasks. This relates to the larger picture depicted, especially in the context of ageing: the responsibility of staying active and healthy is shifted to the individual, hence enforcing the idea of dependency as the failure of an individual. Likewise, Timonen (2016, 45) has argued that, at the EU level, active ageing policies are ‘intended to maximize self-care and autonomy and push the “heavy lifting” of care from the public/policy sphere to the private sphere’. One downside of active ageing ideology can be the fear of admitting dependency and therefore delaying seeking help.

Seeking and justifying help

The participants also described difficulties related to seeking, asking for, and getting help. The accounts included descriptions of having to behave in a certain way in order to get help: one needs to be active, or one has to be brave enough to hold one’s ground, or one has to have a good sense of humour in order to navigate the services and society more generally. Perhaps because asking and getting help in a culture that emphasises independence as self-sufficiency is difficult, there were accounts that seemed to emphasise justifications for asking and getting help, for example, by describing help the participants themselves were providing for others, but also by underlining long careers before acquiring impairments. First, we will view the ‘requirements’ for getting help, and following that, we will move on to the ‘justifications’ for help.

First, there needs to be knowledge of the services one requires. As in the previous section, here too, the lack of knowledge and difficult bureaucracy, especially in a possible transition phase, were mentioned:

[...] access to information and communication with the disability service and the future care home unit has been cumbersome and bureaucratic. [W]hen, without knowledge, you cannot understand which services need to be applied from where, not to mention that the forms are difficult or impossible to fill out and send by computer in a way that would in any way fit their purpose.

(Man, 60–64, uses services)

As mentioned previously, getting help can be difficult due to many factors. Not only is it hard on its own because of the ideals of independence as

self-sufficiency, but surrounding barriers add to the obstacles. The task of seeking help becomes more strenuous as more challenges arise, and the requirements for the individual seem to increase:

In our welfare society you must be able and dare to open your mouth and hold your own, otherwise you are classified as 'toxic waste' and ignored in silence in the care service queue.

(Woman, 70–74, no services)

The above quote depicts a cold reality, where one needs to be active and daring to get help and not be regarded as 'toxic waste' in the society. This emphasis on a person's own activeness is visible throughout the data. Another participant briefly noted that 'who applies and wants, gets help, a lot of things depend on your own activeness' (Woman, 75–79, service user). The responsibility lies with the individual, who needs to find help and sometimes even demand it. As one participant noted earlier about her unawareness of available services, first there needs to be knowledge of the help and only after that, can one apply, sometimes assertively.

Asking for help can be difficult, and there were accounts that seemed to justify the services or the help the participants get from family and friends. The next quote indicates how dependency is negotiated through reciprocity:

I live alone; my children help as needed, and I have cared for six of my grandchildren myself since they were babies. Now two of them are in primary school.

(Woman, 70–74, N/A)

The participant described how her children help her when needed and immediately continued by describing her contribution to her grandchildren's care. It seems that she accepts dependency through reciprocity: one deserves help after helping others. In addition to reciprocity related to family and friends, working lives were described and seemed to be offered as a justification for getting (or deserving) help now – being a productive worker is important in the self-sufficient ideal. One participant explained how he had had a long career, and after getting injured tried to get back to work, and finally left working life:

I worked as a [title] in [working place]. After an accident at work in [around 20 years ago] ... [description of the incident], I returned to work after two months' sick leave and again [another similar incident]. Again, I had an endoscopic surgery like the first time. Now I was on sick leave for three months and returned to work, but my knee lasted no more than six hours. I told management that the leg could not last, so I would retire.

(Man, 75–79, N/A)

The participant described his injuries in detail, with specifics of the accident. He had tried multiple times to continue working, but due to his injuries, he had to retire. It seemed that this was not what he wished for; he would have wanted to continue working, but he had no choice. There seems to be a need to justify retiring and not working, that is, being a productive, self-sufficient human being.

The quotes above paint a picture of the difficulties of asking for and getting help. Dependency seems to be justified through reciprocity, but also through earlier productivity during a person's working life.

Being independently dependent

Whereas the first theme saw dependence as something highly negative and something to be feared and the second theme described the challenges of and strategies for acquiring help, the third theme focuses on notions of help as an enabler. This latter aspect of the in/dependence nexus seems to be closer to the principles and theoretical assumptions of the disability movement and care ethics: independence is achievable through help, as no one is truly and fully independent.

In many accounts, being independently dependent manifested in focusing the gaze on surroundings and services instead of individual impairments. For example, the following participant focused on the difficulties related to the assistance he was utilising:

However, getting around is always difficult and getting a taxi is uncertain, and the use of the taxi is inflexible, so that you may be late for a meeting or you may have to leave early due to the driver's schedules.

(Man, 60–64, uses services)

The participant described how he needs help moving outside the house, but that there are some issues with the assistance. The writer did not specify the difficulties with his mobility outside but instead focused on the problems related to the taxi service. It can be interpreted as meaning that the participant could be more independent if the taxi service worked more on his terms rather than according to the driver's schedules – the participant did not explicitly raise the dependencies caused by his impairments but instead raised the deficiencies in the assistance provided. This can be seen to reflect the social model of disability, as the *disabling* issue here is the problems related to the service and not to the impairment of the person.

Especially transportation services are used by older persons: 61 per cent of transportation service users in 2021 were 65+ years old (THL, 2022). There has been no age-related limit in transportation services, and a survey by THL, the National Institute of Welfare and Health, noted that many see a need for restricting the service, as it has been used widely among the older population and not only persons with disabilities (Sirola and Nurmi-Koikkalainen

2014). The age-related restriction in disability services has been the topic of a long-running debate (see, for example, Era 2021). However, transportation service is the most used disability service and does not currently have any age-related restriction, and the pressure to cut its costs can result in services of lower quality.

The above quotes describe the independence and autonomy that help brings. However, there was also fear of losing the services – and thus fear of losing independence:

Yet I am greatly grateful even for this support I have received from the city. Still, there is always the fear that these benefits can be taken away or made more difficult, for example, if the right to use your own taxi is lost. That fear is present also concretely, because the cuts always hit those of us that are the weakest, and these benefits can be taken away or otherwise limit our lives.

(Woman, 60–64, uses services)

The above participant was not the only one to be worried about losing services. Especially in relation to getting old, the transition to older persons' services seemed to represent a change for the worse:

The increase in functional limitations raises concerns, as I end up from being a client in Kela's rehabilitation services, to presumably a client of older persons' services, which do not sufficiently take into account the significance of disability in ageing.

(Man, 60–64, uses services)

Kela, the Social Insurance Institution of Finland, provides rehabilitation services for persons with disabilities, but most only until 65–67 years of age (*Kansaneläkelaitos* 2022). Municipal disability services do not have an age limit, but our participants seemed to be familiar with the discussion around this issue: after specifying her impairments, one participant wanted to add 'but nothing is age-related' (Woman, 70–74, service user).

It seems that many of the quotes on this theme were written by disability service users, as they described kinds of support that are only available through disability services. As noted before, the social model-guided disability services are based on a relational perspective on independence – an interdependent perspective, as Reindal (1999) noted – and perhaps these quotes demonstrate this. However, problems with disability services and worries about losing them with ageing were expressed.

Concluding remarks

In this chapter, we discussed the understandings of in/dependence through the experiences of older persons with disabilities in Finland. The participants

described their impairments, their lives, and the help they get in their day-to-day activities. Some wrote about disability services, and some noted older persons' services as well as the help they get from their children, spouses, and friends. In addition, peer support and activities provided by disability organisations were mentioned as important sources of different kinds of support. Financial resources can play a significant part in the availability of services, but in these data, there were almost no mentions of finances. However, some participants expressed fear of welfare cuts that may affect them, as it seems that the cuts 'always hit those of us that are the weakest'. When cuts are made from social services, public benefits are lost.

Even though the accounts present only a limited view, we can draw some preconditions to getting sufficient help, to be independently dependent: having knowledge of available services, and being willing to receive help, being active enough to apply for help, and sometimes being prepared to demand help. Of course, sufficient and suitable help has to exist first, and some problems with services were expressed as well. Discussions around in/dependence relate closely to getting help, be it assistance, care, or some other kind of support.

Especially the second precondition – being willing to receive help and being active enough to ask or demand help – seems relevant to discussions on in/dependence. We found that in/dependence presents itself in different ways in our data. First, fear was expressed about getting old and dependent, which was seen in a very negative light. Second, asking for help appeared to be difficult and negotiable in different ways: there was hesitation about asking for help from relatives, even though this could be negotiated through reciprocity. Justifying deservingness, most of the accounts described earlier participation in working life, only after which the respondents had started to need help. Also, a person's own activeness was raised: one needs to be active and assertive to get help. Third, help was presented as a vehicle for independence: the help, be it informal or formal, enabled being independent.

Conceptual difficulties have been recognised as one issue in bridging the two research and policy fields of disability and ageing (Leahy 2018). In this chapter, we discussed the conceptual confusion surrounding the conceptualisation of in/dependence. Our data indicate that in/dependence presents itself in varied and interconnected ways, where it is difficult to pinpoint where independence ends and dependence starts, or vice versa. In our data, there were relational manifestations of independence, but also notions of asking for help or being dependent as something very negative and undesired. The relational views of independence come close to the meanings of independence promoted by the disability movement and care ethics, whereas the negative approaches to dependence resonate with the ideal of self-sufficiency.

As seen in the accounts, having to ask for help is a difficult task: it requires admitting dependency. However, even after that step – as was noted in the accounts – receiving help requires activeness and sometimes help may not be available. In a sense, one needs to be self-sufficiently independent in claiming

dependence. In getting sufficient help, the ideal of independence as self-sufficiency seems to do harm.

Besides, or instead of, independence or dependency, several writers in disability studies as well as ageing and care research wish to refer to ‘interdependence’ (e.g., Shakespeare 2000). Interdependence recognises that all human beings are interdependent and vulnerable, as we all are connected and dependent on each other on some level. However, the conceptualisation of independence as used by disability researchers and the concept of interdependence are not poles apart: both support self-determination over self-sufficiency and recognise the connectedness of all humans (Kröger 2009). Nevertheless, in consistence with Kittay (2011), Fine and Glendinning (2005) have argued for the continuing use of ‘dependency’ in addition to ‘interdependence’ for its relevancy in, for example, recognising oppressive activities related to care.

In relation to disability, Reindal (1999) has argued that in/dependence as a dichotomy ascribes to the individual models of disability, where disability is seen as an individual (medical) issue and not as something created by the environment. Independence as interdependence, on the other hand, is more connected to the social models of disability, where disability is intertwined with the social and built environment, and issues related to disability are not individual but relational (ibid.). Many authors in the nexus of disability and old age have concluded that ageing research and policies reflect more the individual and medical models of disability, whereas disability studies and policies prefer the social models of disability (e.g., Era, Katsui and Kröger, forthcoming; Leahy 2021; Priestley 2006). Equally, many have argued for a ‘social model of ageing’ (Elder-Woodward 2013; Naue and Kroll 2010), a ‘social model of dementia’ (Thomas and Milligan 2018), or other socially oriented models to be applied to ageing as well.

Due to the demographic change among persons with disabilities, the need for research in the disability – old age nexus will only increase in the future. At the moment, there are still conceptual and theoretical divisions between ageing research and disability studies that need to be addressed in order to strengthen the research fields at their intersection. In our view, interdependence could be one concept that can be used to build bridges between ageing and disability. A unified framework for older persons with disabilities would be helpful to prevent anyone from falling through the service system’s safety net. Even in Finland, the happiest country in the world, there are many barriers for ageing people with disabilities to ask for and receive help. Adopting interdependence as a framework or underlying principle in disability and old age policies could help remove some of these barriers and lower the threshold to seeking and receiving necessary assistance.

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