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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 terveystalvveluista*, 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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