Article

Disability Tax in the Welfare State: Uncertainty and Resentment about Disability Services in Finland

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Abstract: This paper focuses on the uncertainty and resentment that many persons with disabilities feel concerning their disability services in the welfare state of Finland. This paper elaborates on the theme through the lived citizenship of persons with disabilities using the key theory of disability tax as an analytical tool. The empirical data were collected through an online survey (n = 541) and six group interviews (n = 41) of persons with disabilities in 2023. The disability tax experiences are elaborated through four aspects: (1) rejected applications, (2) uncertain realisation, (3) laborious complaint mechanisms, and (4) the psycho–emotional effect. The findings of this study establish collective experiences of multi-layered disability tax throughout the disability services process. It concludes that disability services, which were originally planned to specifically ensure equal opportunities to participate in society for persons with disabilities, are increasingly becoming the very sources of burden as austerity has silently grown deeper over recent years and has become the clear policy of the current government.

Keywords: disability services; lived citizenship; Finland; disability tax; welfare state

1. Introduction

The Nordic countries have been famous for their welfare states’ policies and practices being strongly based on the human rights framework, exemplified in their key concepts, such as equality and citizenship [1,2]. This is well known as the Nordic Welfare Model (see, e.g., Refs. [2,3]). All the Nordic countries once again occupied the top countries in the World Happiness Report, and Finland was selected as ‘the happiest country’ in the world for the seventh time in a row [4]. However, are ‘welfare’ and ‘happiness’ universally distributed among the population, especially among persons with disabilities? In their book, Katsui and Laitinen [5] shed light on Finland as a case country pursuing the Nordic Model and investigate it from the critical perspective of disability. According to the book, the answer to the question above is negative for persons with disabilities, as Finnish society is disabling to a large extent, both today and also in its history (see [6–8]).

In order to alleviate this situation, disability services have been developed to fill in some of the gaps. Finnish disability services are considered important preconditions for the equal participation of persons with disabilities in society and for their self-determination rights [9]. These disability services include many subjective rights for persons with severe disabilities who need daily and continuous support from others in their lives [10]. The Finnish disability movement has contributed to pushing the boundaries of these services over the decades (see Refs. [11,12]). However, the two laws relevant to this issue, which have undergone multiple revisions—the Act on Disability Services and Assistance (380/1987) (currently referred to as the Disability Services Act) and the Act on Special Care for the Mentally Handicapped (519/1977) (currently referred to as the Act on Special Care for People with Intellectual Disabilities)—are not without problems. This paper focuses on the uncertainty and resentment that many persons with disabilities feel concerning their disability services in the welfare state of Finland [13,14] and unravels some of the
mechanisms of biopolitics (see Ref. [15]) that are manifested in their daily lives. That is, power tends to be exercised over the bodies of persons with disabilities through disability service practices. As Finland is currently undergoing legal changes to merge the two laws into one to solve a number of identified institutional and structural problems [16], this paper is timely and relevant to the present discussion on disability policy.

This paper first presents the theoretical background, then the methodological choices made, and finally, the methods applied in the study [14]. It presents disability tax through four aspects: (1) rejected applications, (2) uncertain realisation, (3) laborious complaint mechanisms, and (4) the psycho–emotional effect. The empirical findings show that disability tax is established as the lived citizenship of many persons with disabilities in terms of their disability services. The concluding section also discusses the policy implications of the findings in this time of deepening austerity (see Refs. [17,18]).

2. Theoretical Background and Key Research Questions

This paper addresses some of the illustrated lived citizenship [19,20] of persons with disabilities in Finland today on the basis of collected data on disability services. Sepulchre [21] calls for closer observation of citizenship in the context of disability, as citizenship is not automatically granted to all citizens, and the concept requires constant negotiation, especially for marginalised groups such as persons with disabilities. Administrative rationality, in particular, including the practical realisation of citizenship, is an important aspect of understanding citizenship beyond the legal norms and rights [22]. Thus, this study used the concept of lived citizenship [19] as an analytical tool and conceptualised citizenship as a social construction (see Ref. [21]). In practice, this study focused on how the studied persons with disabilities experienced their citizenship, namely their rights and obligations, around disability services, including personal assistant services.

For the data analysis, the theories of minority tax ([23], p. 1123) and deaf tax [24] were useful. Minority tax and deaf tax are unique barriers, experiences, and responsibilities that disproportionately burden people in minority positions and deaf people, respectively. They form a significant disadvantage for people belonging to minority groups ([23], p. 1123). Holm, one of the keynote speakers at the Conference of the Nordic Network of Disability Research in 2023, presented the following example of deaf tax: when deaf people need to book sign language interpreters for their meetings at their workplace, they are the ones burdened by the extra task of having to book this service to be able to communicate with their colleagues, even though their colleagues also benefit from the interpreters. Thus ‘tax’ does not refer directly to the monetary tax for the government as such but encompasses other kinds of specific burdens in terms of time, energy, as well as psychological distress making it a metaphorical tax, especially attached to minority groups. This minority tax is also applicable to persons with disabilities in general; for example, when they have to arrange their disability services, which is specific to the group and an additional burden in their lives. Especially, when the service is rejected or poorly implemented, negative mental health outcomes form minority tax. In reality, disability tax can include an additional monetary burden to materialise their rights due to a disabling environment. Thus, in this paper, we refer to this phenomenon as disability tax in the welfare state (hereafter disability tax), which helps illustrate the daily reality of many persons with disabilities in terms of their disability services in Finland today. This paper answers the following two key research questions: (1) What kinds of disability tax do persons with disabilities experience related to Finnish disability services? (2) How is disability tax embodied through psycho–emotional effects?
3. Methodology

This study [14] was conducted between June and December 2023 to pave the way for the new national action plan to implement the United Nations Convention on the Rights of Persons with Disabilities (UN CRPD) [25]. A team from the University of Helsinki, including Hisayo Katsui, Reetta Mietola, Matti Laitinen, Juho Honkasila, and Alma Ritvaniemi, was commissioned to conduct this study in collaboration with the Finnish Disability Forum (the Forum). The team included researchers with and without disabilities, and their research was participatory [26,27]. This study focused on the daily lived experiences of persons with disabilities to determine the environmental factors that enable and prevent the realisation of their human rights on an equal basis with others. The scope was limited to their experiences during the period of the previous action plan between 2020 and 2023. This study originally aimed to determine how disability rights are realised in practice in Finland today; however, this paper focuses particularly on the lived citizenship concerning the disability services of the research participants.

We used two data collection methods: an online survey and group interviews. Both were targeted at persons with disabilities. The online survey (see Appendix A for some of the questions) was in three languages, Finnish, Swedish, and English, and was open from 19 June to 20 August 2023. The information about the survey was disseminated through national and local VANE (Advisory Board for the Rights of Persons with Disabilities) and their mailing lists and social media. Disability organisations were informed of this survey through the Forum. The researchers also shared information about the survey via their personal social media channels. The survey was divided into two parts: personal experiences and general views on persons with disabilities. The respondents could choose to answer only the first part if they so wished. Of the 22 questions, 12 were multiple choice and 10 were open. The second part of the survey had 27 questions, of which 13 were multiple choice and 14 were open. The questions coincided with the thematic areas of the UN CRPD, except for Article 32 on international cooperation, which would have been difficult for many individual persons with disabilities to answer on the basis of personal or collective experiences. A total of 541 people responded to the first part of the survey, and 81% of these also answered the second part of the survey on general views on persons with disabilities. Seventy percent of the respondents were persons with disabilities themselves, and 30% were individuals who helped persons with disabilities to fill in the survey, such as parents of children with disabilities and personal assistants. The majority of the respondents were working-aged people and aged between 25 and 64, more than the population on average. Sixty-two percent were women, 35% were men, 1% selected the ‘other gender’ option and 2% did not respond to the question on gender. Forty-seven percent of the respondents were from southern Finland, 26% from western Finland, 10% from eastern Finland, 9% from northern Finland, and 8% were from central Finland. Ninety-two percent responded in Finnish, 6% responded in Swedish, and less than 1% responded in English. Fifty-six percent were on a pension, 23% were working, 17% were at school, 6% were unemployed, and 10% chose ‘other’ and described their situations in different ways. As for types of disabilities, 42% were with physical disabilities, 37% with cognitive disabilities, 28% with sensory disabilities, 15% with social disabilities (such as autism spectrum), 10% with psychological disabilities, and 9% chose ‘other’ and described their situations in different ways. The total of 772 responses shows that some respondents had multiple disabilities.

Six group interviews were conducted with people who do not often participate in online surveys and people whose participation is legally obliged for matters related to them. These were (1) children with disabilities, (2) youths with disabilities, (3) deaf and sign language users, (4) persons with intellectual disabilities, (5) old people with disabilities, and (6) immigrants with disabilities. The majority of the group interviews took place in the Helsinki area, but a few were conducted elsewhere. The languages were Finnish, Finnish sign language, and Arabic through interpreters. Two group interviews took place online to enable interviewees living far from the Helsinki area to participate. The groups had
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between two and twenty interviewees; in total, 41 people. They were recruited through the researchers’ existing networks. The interviews lasted between two and three hours. The average time was slightly over two hours. The interview questions were similar to those in the online survey but adjusted for the different groups. For instance, we also asked deaf people and immigrants with disabilities questions related to the accessibility of services in their first languages. We similarly modified the interviews of children with disabilities to focus on relevant issues for their age. Prior to the interviews, the study information sheet, informed consent form, and privacy notice for scientific research based on the General Data Protection Regulation of the European Union were delivered and orally presented to the participants. They were informed that participation was voluntary, and that they were free to withdraw from the study, and we explained our privacy practice via pseudonymisation in the transcription and publications. Permission for the participation of the children with disabilities was given by both the children and their parents. One of the parents also came to the group interview for moral support of their child but did not intervene in the interview. We obtained all the interviewees’ permission to digitally record the interviews. We also consulted the university lawyer to ensure we adhered to the ethical guidelines, including appropriate data management. All the interviews were transcribed and thematically analysed using the key theories of lived citizenship [19] and disability tax for this paper. Four themes emerged from the data, which we will briefly discuss: (1) rejected applications, (2) uncertain realisation, (3) laborious complaint mechanisms, and (4) the psycho–emotional effect.

In order to protect the privacy of the study participants, only the information on the research methods and information on the group interviews are mentioned below after each citation by the study participants.

4. Rejected Applications and Falling through the Safety Net

The first and most evident disability tax concerning disability services was rejected applications for the services, which indicates that their genuine needs tend to be undermined. This has also previously been acknowledged as a burden and frustration for persons with disabilities [28]. One of the survey questions asked, ‘How well do the disability services you receive meet your current needs?’ with multiple choice answers, shown below. Table 1 shows the answers of people with different disabilities. The results indicate uncertainty about meeting their needs in terms of disability services, which is particularly true for the majority of persons with social and psychosocial disabilities. ‘In varying degrees’ is a clear indication of uncertainty and thus is analysed as a negative answer in the study.

Table 1. Multiple choice answers to the question, ‘How well do the disability services you receive meet your current needs?’ that are disaggregated by disability types (Source: Ref. [14], p. 116).

<table>
<thead>
<tr>
<th>Types of Disability</th>
<th>Poorly</th>
<th>Quite Poorly</th>
<th>In Varying Degrees</th>
<th>Quite Well</th>
<th>Well</th>
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<tbody>
<tr>
<td>Persons with sensory disabilities (%)</td>
<td>17.1</td>
<td>15.1</td>
<td>21.2</td>
<td>30.8</td>
<td>15.8</td>
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<tr>
<td>Persons with physical disabilities (%)</td>
<td>15.4</td>
<td>16.3</td>
<td>20.4</td>
<td>28.5</td>
<td>19.4</td>
</tr>
<tr>
<td>Persons with intellectual disabilities (%)</td>
<td>19.1</td>
<td>20.1</td>
<td>26.8</td>
<td>19.1</td>
<td>14.9</td>
</tr>
<tr>
<td>Persons with social disabilities (%)</td>
<td>30.6</td>
<td>24.0</td>
<td>22.7</td>
<td>16.0</td>
<td>6.7</td>
</tr>
<tr>
<td>Persons with psychosocial disabilities (%)</td>
<td>25.0</td>
<td>25.0</td>
<td>9.6</td>
<td>26.9</td>
<td>13.5</td>
</tr>
</tbody>
</table>
Many of the interviewees and the survey participants of the study pointed out this problem of rejection:

*Now I have followed the lives of persons with severe disabilities in [the name of the municipality], and they face barriers to living independently. They have difficulties obtaining services that they should be entitled to, like assistive devices. Too often social service officers neglect the needs that persons with disabilities genuinely have. Then there are so many rejections [rejected disability service applications], that can’t be complained about and have to be brought to court so that they get the justice, but that is too burdensome a way to get help and support for many, though they are legally entitled (to the services).*

(Group interview with old people with disabilities)

Rejected applications are problematic, as persons with disabilities apply for services on the basis of their individual needs. Many of the interviewees and survey participants felt that more and more applications of persons with disabilities had been rejected in recent years due to austerity measures. This means that disability services are increasingly being granted on the basis of a system-oriented approach instead of a needs-based approach [13].

Some interviewees and survey participants reported encountering difficulties and/or bureaucracy when trying to obtain information on available disability services and their applications. This was particularly pronounced in the group interviews of immigrants with disabilities as well as those of children and youths with disabilities. These barriers make persons with disabilities vulnerable, uncertain, and dependent on their friends and families.

*There have been big problems. The disability service social worker of [City A] for instance called me directly and offered me suitable services, but in [City B] I had to search for the information myself (when I moved to City B). I always have to ask friends or others to tell me about the services, as the social workers do not tell me about them. I have to suffer and beg friends for help or accidentally hear about some services, only then can I apply for them. (…) Also language is a big problem.*

(Group interview with immigrants with disabilities)

*In the beginning, they said that [the meeting of the services] they would decide who to take at the end of August and tell us (the result). Then it was extended to the beginning of September, and now when my parent called them a few days ago, they said they have the meeting sometime at the end of October.*

(Group interview with children with disabilities)

*I heard it is terrible that people can’t fill in the form. It is the classic situation, that the services are not granted because of this, as they can’t fill in the KELA forms. That’s really terrible in my opinion.*

(Group interview with youths with disabilities)

The responsibility for obtaining disability services lies largely with the persons with disabilities themselves, and it is a burden and disability tax to them. They also have to search for necessary information and ask for help, or even ‘beg’ their own social network for help, which makes their position even more vulnerable. Many of the persons with intellectual disabilities told us that they were automatically assigned to some option with no alternatives to choose from. Consequently, their self-determination right was violated. Many often have no freedom of choice due to a lack of services and/or human resources (see Ref. [29]).

*It is years since my vocational training, but when I graduated, I was immediately sent to the day activity centre. Nobody even thought about employment for me. It was the easiest (solution) because there are so few work supervisors. I could have done very well in property maintenance work, like sweeping, branch cutting, ploughing, if I had had supervision.*

(Online survey)
The number of staff decreased, and new people came, and then the [day activity centre] group was terminated. (Group interview with persons with intellectual disabilities)

Also there are good things, for instance, I went to a shop once (many years ago) with my supervisor and that was kind. (Group interview with persons with intellectual disabilities)

The last interview excerpt illustrates a rare opportunity for a free-time activity as human resources are lacking in housing facilities, and so even one visit to a shop over the years was greatly appreciated by the person with intellectual disabilities. According to many of the interviewees, the situations of many persons with disabilities are quite uncertain and depend on where they live and which social worker or other worker is in contact with them. Social workers are gatekeepers for these services for many persons with disabilities [13]. Decisions regarding applications also take too long, which means the applicants fall through the safety net while waiting for the decision, thereby becoming the disability tax itself.

Now that service application processes are becoming increasingly digitalised, they are ironically even more inaccessible, as many persons with disabilities cannot fill in the forms. Identification is impossible without bank IDs [for persons with intellectual disabilities]. Also, the mobile certificate requires identification using bank credentials. (Online survey)

The biggest problems are in the availability of accessible information, the accessibility challenges of websites and the inaccessibility of other information that is easily accessible to people with normal vision [that are not for persons with visual disabilities]. (Online survey)

Digitalisation is taking over in everything in the service sectors and in practical everyday life. There are no accessible or barrier-free service formats for digitalised applications. Nowadays, only a small number of citizens with disabilities have good digital skills. Many do not have financial or other opportunities to even acquire smart devices or learn how to use them. (Online survey)

The digital gap was also discussed in the group interview of old people with disabilities, as they also find it difficult to get used to the new, digitalised forms. Moreover, research findings show that some groups of persons with disabilities are clearly falling through the safety net of the disability services in the welfare state, such as persons with intellectual disabilities, persons with social disabilities such as the autism spectrum, immigrants with disabilities, and old persons with disabilities based on the findings of the research. Hömppi et al. ([29], p. 35) similarly present that the majority of disability service professionals also believe that some groups of persons with disabilities are falling through the safety net, for example, persons with neurodiversity. Many have also expressed inequalities among different administrative areas when the same rights and services are systematically refused in some regions, while in other regions, they are almost automatically granted to persons with similar disabilities. As mentioned above, we observed a series of disability tax experiences related to the rejections of applications for disability services in these times of austerity.
5. Uncertainty: Services Are Granted but Not Realised Properly in Practice

Another layer of daily realities for many concerning disability tax is that even after being granted, disability services are not realised. The research participants expressed their frustration at not receiving sufficient services even when their applications for these services had been approved.

*I am supposed to get 24/7 personal assistance services, but they are not available, and so my family helps in addition to their own work.*

(Online survey)

*My son was supposed to go to school every day with an assistant but he was often absent from school because the assistant had to take care of somebody else. (...) His application for the services was accepted, but the services were not realised into practice, as we were told that they are only given in urgent cases. A short stay service was also granted (...) but there were no available places for him. (...) So everything now depends on his mother managing to help him.*

(Online survey)

Thus, in addition to many rejected service applications and the long waiting time to hear whether or not the services are granted, the actual realisation of granted services is also a real challenge that a number of the study participants have to face, which hinders their independent living and planned daily activities. They claim that Finnish disability services are ‘not functioning’, ‘failing’, and ‘uncertain’, as they are poorly realised for many, especially personal assistant and transportation services. This uncertain realisation of disability services has negative consequences in the form of disability tax when persons with disabilities eventually give up on certain daily activities. Disability tax is also experienced by their families and friends, who fill the gaps of services that have been granted but not realised. According to some participants, this coerced dependency complicates the positionality of these persons with disabilities, particularly children and youths with disabilities, in their immediate social surroundings.

*Lack of support, lack of information, and limited resources. Children and youths with disabilities depend on the ability and support of their parents because personal assistant and support services are almost impossible to find and get.*

(Online survey)

The availability and accessibility of personal assistant services in general, and of obtaining a suitable personal assistant in particular, is a well-established problem [29] that was observed even before the COVID-19 pandemic [30]. During the pandemic, personal assistant services were even more significantly unavailable [31]. Our study [14] was conducted after the pandemic and revealed the difficulties experienced by many in attempting to access disability services even after receiving confirmation that the services had been granted to them.

*The barriers are structural and attitudinal. As a whole, disability rights are not seen as human rights, and so life is defined by [the lack of] services.*

(Online survey)

*Municipalities systematically violate the human rights of persons with visual disabilities through neglecting accessibility and forcing persons with disabilities to make their own decisions on their own issues.*

(Online survey)
In principle, the needs and voices of persons with disabilities are one of the central elements of the decisions regarding the granting of disability services [32]. Yet, their lived citizenship conversely implies a lack of self-determination, which is often due to multiple layers of structural and institutional barriers to accessing disability services. This contributes greatly to the mental health and well-being of many persons with disabilities, which is discussed later.

6. Laborious Complaint Mechanisms

In a welfare state, at best, disability services enable persons with disabilities to live independently [14]. We identified such positive experiential examples among the study participants. However, multiple layers of barriers hindered many from making their own independent decisions. They did not receive disability services for one reason or another and too often had to ‘fight’ for their services. That is, the disability services metaphorically became their ‘fight’ to negotiate their citizenship.

Even this kind of thing [service] nowadays can’t move forward without fighting. We have to be extreme fighters, if we want our rights to be realised.

(Group interview with old people with disabilities)

I have to fight for services. Everything has to be explained and well justified so that I can get any amount of [personal] assistant hours and transportation [services].

(Online survey)

Therefore, when applications are rejected or when the services are not realised properly, persons with disabilities and/or their families are faced with another layer of disability tax: making a complaint. There are several complaint mechanisms in Finland, such as a direct complaint to the service providers, social workers, social welfare board, the Chancellor of Justice, using the legal services of organisations of persons with disabilities, and filing a case to the administrative court. In Finland, social service customers are entitled to file a case to an administrative court without charge. Media coverage was also mentioned as a strategy to attract public attention and to indirectly bring about the desired change. Nevertheless, many persons with disabilities feel that the existing complaint mechanisms do not function properly.

It’s a small person against someone big, like KELA [The Social Insurance Institution of Finland, which is in charge of sign language interpretation services]. KELA has army-like lawyers who know exactly how to ‘extinguish fires’ pretty effectively (…) You get quite a rude attitude, until the fire is extinguished, and the process is over. We are not equal, when one person has to be against the whole system.

(Group interview with deaf people)

Many rejected applications for disability services can’t be rectified with an ordinary rectification request—you have to go to court in order to get justice for yourself. And again, it’s a very difficult route for many to get the help and support that they should get according to the law.

(Group interview with old persons with disabilities)

I feel that I can’t take (injustice) cases for instance to the newspapers or the court with my own face. We are really alone with the problem (of negative decisions).

(Group interview of deaf people)

[Name of the disability organisation] is moving forward very cautiously. Maybe they are afraid of the financial implications and of other things.

(Group interview of deaf people)
The Chancellor of Justice [33] has reported that the number of complaints made by persons with disabilities is increasing every year. Among the 300 complaints submitted to the Chancellor by persons with disabilities in 2021, 218 concerned social welfare services, of which 132, in turn, concerned disability services ([33], p. 70). Despite the option of also filing a case with the administrative court, many do not dare to do so due to, according to some who went through the legal process, the need of legal knowledge and the amount of paperwork this entails. The Non-discrimination Ombudsman [34] has also pointed out this problem and called for a low-threshold complaint mechanism. The resentment towards this part of the disability service process is obviously due to the time- and energy-consuming nature of the process of making a complaint as well as the uncertainty of the consequences even when one engages with the process. In addition, the ‘fight’ has to take place through asymmetrical power relations and against much more powerful actors and systems, and this discourages people from dealing with it. This powerlessness strengthens their feeling that they are alone and have no options to make the situation better.

Complaining is hard for many Finnish-speaking persons with disabilities, but it is even harder for many immigrants with disabilities, whose situation is much more precarious due to their specific conditions such as their lack of Finnish-language skills and information, and their ongoing resident permit process.

I have neither a residence permit nor Finnish language skills. I did not know how I could complain about this (...) I could do nothing, because I had no visa, did not know my rights, and did not know Finnish.

(Group interview with immigrants with disabilities)

Because I am an immigrant, I don’t know the Finnish language, so I obviously don’t know my rights and which services I am eligible for.

(Group interview with immigrants with disabilities)

The interviewed immigrants with disabilities believed they should not make any complaints if they wanted a resident permit and thus often chose to remain silent. In some cases, they did not even know that they could complain about the services, as it was not customary to do so in their countries of origin from which they had fled. The dysfunctional complaint mechanisms are a form of burdensome disability tax for many persons with disabilities.

7. Psycho–Emotional Impact of Navigating Disability Services

The purpose of disability services is to meet the disability-specific needs that cannot be attended to by general laws and their coverage, and thereby to enable persons with disabilities to participate in society on an equal basis with others. Yet, as has been discussed above, the disability services themselves often become the sources of disability tax for many persons with disabilities, which is contrary to their original objective. When persons with disabilities are turned down multiple times in relation to disability services, from applications to complaint-making, this tends to have a negative psycho–emotional impact on them [14]. That is, disability is embodied in the social and relational context of power [35]. Furthermore, it is noteworthy that the series of negative incidents related to disability services take place in a largely disabling society, which often creates additional burdens to already difficult situations among many persons with disabilities. This psycho–emotional effect of disability, which stems from disability-related social oppression, has been widely recognised and discussed (e.g., Refs. [35,36]). Next, we present and focus on the psycho–emotional effect of disability tax related to disability services.

We are bullied and we’re not accepted. And nothing is done. So we end up masking [meaning pretending to be ‘normal’]. That’s when we feel bad.

(Group interview with children with disabilities)
Intellectual disabilities can’t be rehabilitated, and so it’s hard to obtain rehabilitation services. The combination of intellectual disabilities and mental health issues is difficult, and I’ve been passed on from one care provider to another.

(Online survey)

When I don’t get the services and I have to manage to speak (about my needs), I’m bad at that.

(Online survey)

Above all, the ‘Do you have to get everything?’ mentality and attitude. (Social workers) belittle (my) accessibility needs.

(Online survey)

Many of the study participants talked about the belittling attitude of social service officials as being a problem related to the services in general, and rejections of the service applications in particular, and how they have a negative impact on the mental health conditions of many persons with disabilities. Similarly, a survey of people using personal assistant services in Finland [31] underlined that their loneliness, mental health problems, and health problems become much more pronounced when personal assistant services are not sufficiently provided.

As many as 88% of the respondents to the online survey felt unsafe and unequal in emergency situations ([14] p. 38), and in these circumstances, the lack of necessary disability services contributes to their vulnerability and uncertainty. The COVID-19 pandemic in particular is remembered bitterly, as many persons with disabilities feel they were neglected during it.

The COVID [situation] showed that disability services such as personal assistant and transportation services are not secured during crises at all.

(Online survey)

Persons with disabilities are at the mercy of officials (social workers), if we can’t get support from them, we can’t find any alternative ways to support ourselves. This was, for example, exemplified during the COVID pandemic.

(Online survey)

When the COVID pandemic hit us hard, persons with severe disabilities were left behind to die, because ‘life dependent on a (personal) assistant is sad anyway.’ I don’t believe that even one single government official seriously plans to do anything good for persons with disabilities.

(Online survey)

The negative emotions of resentment and frustration expressed above are experienced by many. Many also expressed ‘fear’ when talking about the future, as austerity is hitting Finland hard and security situations are escalating with the Ukrainian–Russian and Israeli–Palestinian wars.

I can’t deny that I have similar fears to [another group interview participant’s name]. I still want to believe in the law, though at the moment it looks quite hopeless in many ways.

(Group interview with old persons with disabilities)

During an emergency and when afraid, everyone takes care of themselves, and so only the fittest survive.

(Online survey)

The war in Ukraine brought [the issue of security] close to me and in a crisis persons with disabilities are the weakest of all.

(Online survey)
Thus, sadly, it is not surprising that the research participants described themselves as ‘second-class citizens’, ‘permanent children’, ‘invisible’, and/or ‘interlopers’ in Finnish society today. This psycho–emotional effect of disability tax on the identity and self-image of many persons with disabilities cannot be neglected when discussing disability services. The psycho–emotional effect is not only about the persons with disabilities of the current generation; it is also inter-generationally observed among persons with disabilities due to the long perpetuating history of eugenics and ableism in Finland [8].

8. Discussion

These aforementioned lived citizenships are also manifested in the statistics in Table 2. The European Union (EU) [37] compared social protection expenditure on disability by benefits in terms of percentage of Gross Domestic Product (GDP) in its latest statistics from 2016 to 2021. In 2016, it was 3.1% of the GDP in Finland, but it had fallen to 2.8% in the latest 2021 statistics. Expenditure is not drastically decreasing in Finland but it is falling steadily. In most of the Nordic countries, the percentages are higher than in Finland: 4.9% in Denmark, 4.4% in Iceland, and 4.1% in Norway (2021). Similarly, other statistics of the EU [38] show self-reported unmet needs for medical examinations for persons with disabilities. These figures were 9.5% in 2018 in Finland and increased to 12.5% in 2023. The statistics in the other Nordic countries were far better than in Finland: 4.9% in Denmark, 5.0% in Sweden in 2023, and even 1.6% in Norway in 2022 [38]. Medical examinations and reports are often the basis on which disability services are granted and thus are central to the lives of persons with disabilities [32]. The aforementioned Eurostat data are proxy statistics, but they support the findings of the research in terms of the trend of decreasing disability-specific benefits and increasing dissatisfaction and unmet needs of medical examinations among persons with disabilities in Finland.

Table 2. Social protection expenditure on disability by benefits (% of Gross Domestic Product).

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<td>Finland</td>
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<td>Norway</td>
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In a similar vein, as the Figure 1 shows below, the study of Hömpki et al. [29] found that 16% of disability service professionals felt that the realisation of personal assistant and housing services is problematic and 8% felt the same about transportation services. Seventy-one percent answered that the realisation of personal assistant service was somewhat problematic, 63% felt the same about housing services, and 44% felt similarly about transportation services ([29], p. 21). The percentages of those who answered that they saw no problems in the realisation of services were only 11% as regards personal assistant services, 15% as regards housing services, and 44% as regards transportation services. That is, the majority of these disability services are not realised properly to some extent or to a large extent, according to professionals. Furthermore, the recent survey study of the Finnish Disability Forum [39] already shows deterioration of disability services both in terms of quality and quantity after the administrative reform (SOTE-reform) in 2023. These studies underline the uncertainty and the worsening trend around the disability services in Finland, as our study findings also point out and elaborated further through the theory of disability tax.
9. Conclusions

In Finland, as it is a Nordic welfare state, disability policy has steadily developed towards personalised and needs-based disability services [13,40]. As a result, a minority of persons with disabilities do enjoy full citizenship when things work out well. Therefore, persons with disabilities should not be generalised and victimised [14,41], also because the sample is relatively small. The Nordic welfare states, however, are no longer seen as having a supreme framework that reduces inequalities (see Ref. [42]) but ‘as a fragile system encountering challenges of new public management, marketisation, austerity measures, lack of understanding of disability rights, re-medicalisation of social problems and re-institutionalisation.’ ([5] p. 4). That is, disability policy and practice do not exist in a vacuum; they are embedded in global neoliberalism [43–45] prioritising market principles in public procurement, such as cost-effectiveness rather than quality, on the one hand. On the other hand, the phenomenon of disability tax through the Finnish state’s actions and inaction concerning disability services is located in this context of biopolitics (see Ref. [15]). It is important that we remind ourselves that disability services are realised in a highly disabling context [5,34], in which women with disabilities and children with disabilities, especially those with psychosocial or social disabilities, tend to experience more inequalities than men with disabilities ([14] pp. 22 and 121).

This paper has elaborated on disability services in the welfare state through the lived citizenship of persons with disabilities using the key theory of disability tax as an analytical tool. The findings of the study are based on empirical data on the established collective experiences of multi-layered disability tax throughout the disability services process, from the application process to the complaint process. Moreover, the disability tax is much greater for those who lack privilege, such as immigrants with disabilities. In other words, disability services, which were originally planned to specifically ensure equal opportunities and possibilities to participate in society for persons with disabilities, are increasingly becoming the very sources of burden as austerity has silently grown deeper over recent years (see Ref. [37]) and has become the policy of the current government. Rejected applications for disability services [28], the lack of necessary resources, and the realisation of these services are highlighted [40]. Under these circumstances, an increasing number of persons with disabilities have to use their agency to defend their rights by themselves, which requires increasing awareness of disability rights among persons with disabilities during the UN CRPD era. At the same time, the fact that the responsibility to change disabling institutions and structures relies largely on the persons with disabilities themselves must be critically investigated as a serious burden and disability tax (see...
Ref. [18] for the impact of British austerity). The findings of this paper show that disability tax experiences are multi-layered and emerge at almost every step of the disability service process for many persons with disabilities. Many experience negative psycho–emotional effects of disability tax. As the psycho–emotional effect of disability tax is a sensitive and personal topic (see Ref. [46]), more in-depth personal interviews on this specific topic, in a safe environment, would be essential in future research. Especially, such a study focusing on children and women with disabilities and/or persons with social and psychosocial disabilities is needed. It would also be important to investigate the physical effects, including premature death under structural violence, of disability tax related to disability services (see, for example, the higher mortality rate among persons with disabilities during the COVID-19 pandemic in Ref. [47] and structural violence in Ref. [48]). In addition, behavioral science can be introduced in the analysis to understand the social and governmental responses to disability services (see Ref. [49]).

The current government of Prime Minister Orpo is undertaking major austerity measures in many sectors, exceptionally including disability services. At the time of writing this paper in April 2024, the drastic decision was made to cut between EUR 60 and 70 million from the annually budgeted EUR 100 million for disability services in the coming years. This makes the implementation of CRPD through the new disability service act extremely difficult. One of the policy implications of this study was to ensure sufficient disability services for persons with disabilities on the basis of their individual needs ([14] p. 1). The decision of the government is contrary to the policy implication and contributes to demystifying Finland as ‘the happiest country’ and reinforcing the perception that Finland is further deviating from welfare state principles. The lived citizenship of the studied Finnish persons with disabilities powerfully underlines the profound need for the government and Finnish society to reconsider its austerity policy and practices, especially concerning disability services. Disability services are not meant to require persons with disabilities to ‘fight’ to gain their citizenship. Disability services need to become a genuine entitlement that people can count on in this disabling society. Future research should look closely at the lived citizenship of persons with disabilities under the severe austerity of the coming years, as this study showed how profoundly biopolitics are embedded in disability services alone. The feeling of ‘fear’ of the future epitomises the unreasonably contested citizenship experienced by many persons with disabilities in Finland today.

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Institutional Review Board Statement: This study complies with the guideline of the Finnish National Board on Research Integrity (TENK) as well as the General Data Protection Regulation (GDPR). As we closely adhered to the guidelines, ethical review and approval were waived for this study. The Research Ethics Committee in the Humanities and Social and Behavioural Sciences of the University of Helsinki ensured that this compliance is a sufficient reason for the waiver.

Informed Consent Statement: Informed consent was obtained from all persons involved in this study.

Data Availability Statement: The data was collected upon permission from the research participants. They have not been asked to open the data beyond researchers. Therefore, we are not opening the data for others.

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Conflicts of Interest: The author declares no conflicts of interest.
Appendix A. Some of the Survey Questions

1. Have you experienced discrimination based on your disability in the last 12 months? Open question 1: In what situations or by whom does discrimination typically take place?
2. How well is accessibility realised in your daily life? Rate the areas below on a scale of 1–5. Open question 2: In your daily life, what are the most significant barriers to accessibility?
3. How much have you yourself influenced the choice of your place of residence, and how and with whom you live? Open question 3: What kind of factors have influenced your choice of residence, housing type, living partners and apartment (e.g., accessibility, services and support)?
4. How well are the different aspects of inclusion actualised in your personal life? Rate the areas below on a scale of 1–5. Open question 4: In your daily life, what are the most significant barriers to independent living and inclusion?

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