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Evaluating Digitalization of Social Services from the Viewpoint of the Citizen

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Abstract. Finland is known as a welfare state, which has small income gap and good ICT infrastructure. In recent decades, Finnish society has aimed to transfer public administration through digital services. They are nowadays available for different purposes including the social services such as unemployment benefits or housing allowance. However, digitalization have not yet expanded to all types of social services and one area of development is the services for people with disabilities. People with disabilities cannot be seen homogenous group of citizens; instead it includes people in different ages, and having different diagnoses. This study focuses only on one age group, the children, and on one type of diagnosis, the autism spectrum. While the children are the prime beneficiaries of the social services, their parents (or other care givers) are the ones responsible for applying and transferring these services to them. Hence, the unit of analysis in this study is the parents who have children with autism spectrum. Interviews with them represent the citizens' viewpoint through which the digitalization of social services is evaluated.

Keywords: Digitalization, Digital Services, Social Services, Social Sector, e-Government.

1 Introduction

Finland is one of the North European welfare states, where digitalization had advanced in private and in public sector. Digital services have expanded to social sector, where they cover different purposes such as applying accommodation support, unemployment benefits or child care services. However, all spheres of social sector have not advanced at the same rhythm and local differences exists. One example is the services for people with disabilities which are going through digital transformation. In this study, digitalization of social services for people with disabilities is evaluated from the viewpoint of the citizens. Citizens' viewpoint is represented by the parents of children with disabilities.

International studies have revealed that being a parent for children with disabilities is a challenging responsibility for multiple reasons. For example, caring for a child with disabilities requires more physical, emotional, social, and financial resources than caring for a child without disabilities [18]. In addition, parents must coordinate medical,

developmental, and educational interventions of their child [23], and they are responsible for carrying out exercises with their child as part of these interventions [21]. They also experience lack of information and they sometimes need to struggle for achieving suitable public services for themselves and for their child [2,17].

Research about the parents of children with disabilities living in the Nordic welfare states show that similar types of challenges also apply to Nordic context. According to Gundersen [5], parents of children with disabilities face different or greater challenges than other parents to give their children a dignified life. Studies in Finland demonstrate that situation in families, where at least one child has disabilities, vary greatly. Some families have found successful ways of coping [26] while others have problems with applying services [22] and caring for their child [28].

As these examples reflect, parents of children with disabilities face problems related to the social services they or their children need. Thus, this study aims to investigate further social services to support children with disabilities and their parents and their digitalization in Finland. While the social services have already been studied from the viewpoint of families, where at least one child has disabilities, the role of information systems within this service structure has got little attention from academia. Hence, the research question is: how parents of children with disabilities have experienced digitalization of social services? The answer to this question derives from qualitative study among the parents. Preliminary findings show that parents of children with disabilities are willing to use digital services for different purposes but the selection of digital services in the field of social sector is very limited.

2 Citizen's perspective on e-government

As a research topic, digitalization of social services fits in the field of e-government. e-Government is interested in the use of ICT to enhance the access and the delivery of public services for the benefit of citizens, business, governmental agencies and other stakeholders [1, 25]. Common theme for e-government research has been to study the intention to use and the utilization of e-government services and websites [1] while future re-search should place citizens at the center of e-government [24]. Helbig et al. [6] encourage researchers to ask, who benefits from e-government and how different groups are influenced.

Citizens' access to e-government relies heavily on their ability to access internet. In countries such as Philippines, citizens' access to e-government is hindered by the disparities to access ICT [29]. It is also important to study the accessibility of the available e-government services. Because e-government services are meant for the whole population, they should be designed according to the principles of universal access. The experiences citizens have for using e-government affect, how they interpret the behavior of public sector agencies [24]. Another aspect is the availability of e-government services. Fisher et al. [4] analyzed governmental websites targeted for people with intellectual and developmental disabilities. In these websites, some states did not include information on certain services, which were probably available. If these services were

available in these states, people needing them would not be able to find information on them through governmental websites.

Parents are one group of citizens whose use of e-government have been of interest to researchers. Especially new parents represent a group of citizens who are in the middle of life transition; hence, their need for governmental services is changing. Orzech et al. [19] have studied the use e-services offered by governmental institutions in the UK. They found out that new parents are willing to use these services, but governmental officials may underestimate their willingness to use them. In addition, governmental officials may overestimate the problems that citizens face while using digital services. Madsen and Kraemmergaard [14] have studied how single parents use different channels to access public service in Denmark. They noticed that citizens may change channels offered by a single authority which may lead to unanticipated problems in interaction between citizens and officials. Less research has been done on the use of e-government services among parents of children with disabilities. However, Zeng and Cheatham [31] have studied how Chinese-American parents, whose children have special needs, use internet to find information related to their child. They found out that the age of the parent was related to the frequency of searching information online.

To create useful and accessible e-government services, there is a need to engage citizens in designing e-government solutions. Millard [16] emphasizes that governments need to collaborate closely with non-government actors to take full advantage of e-government in combating challenges of the future. All e-government initiatives should be rigorously evaluated to ensure that they do not reinforce the exclusion of any marginalized group of citizens [13]. To prevent this, Wihlborg, Hedstrom, & Larsson [30] suggest to find out about users demands without being biased by specific interest or certain norms. However, the willingness of citizens to participate in the development of e-government services is an under researched area [7].

3 Digitalization of social services

Digitalization of social services have been studied to some extent in prior e-government literature – usually from the perspective of professionals and policy makers. There are hopes that harnessing big data would transfer social sector more transparent, effective and accountable [3]. However, there are many challenges that needs to be solved. Social workers as well as beneficiaries do not always have sufficient digital skills [15]. Citizens might also face barriers of accessing social services through digital mediums while digitalization changes the modes of interaction between professionals and beneficiaries [20].

In Finland, responsibility for different social services is dispersed between municipalities and the Social Insurance Institution of Finland called Kela. Municipalities organize social care for citizens and certain service can be produced by public or by private organization. Social services for people with disabilities include e.g. assistive technologies for children, home adjustments, supported living and sheltered work. Kela has

vast funding responsibilities in different spheres of wellbeing among citizens. For people with disabilities, Kela pays e.g. disability allowance, medical rehabilitation, and assistive technologies for education.

Digitalization of social services is ongoing process that have advanced at different pace in Kela and in the municipalities. Most of the allowances offered by Kela can be applied electronically but municipalities vary in their digital service structure. In 2014, the most common online service offered by the social service providers, was an informative website and possibility to give feedback online [8]. Although, the amount of online services offered by the social service providers have increased between years 2014 and 2017, only one out of five organizations offered online application services [12]. Hyppönen et al. [9] studied the use of digital services among citizens. In the case of social services, they found out that 54% of respondents experience some kind of barriers of using digital services and 15 % do not have internet and computer to access the services. Despite the challenges, one third of the respondents have experienced benefits such as saving money and time.

One of the biggest e-government projects in Finland is Kanta services, which produce digital services for the healthcare and which is currently expanding to social care. In the first phase, social service providers can participate by transferring their client information to national archive. This archive will facilitate the integration of client information from the social sector to the Kanta services [27].

4 Research setting

4.1 Research methods

This study employed participatory approach to evaluate digitalization of social services through the experiences of parents, whose children belong to autism spectrum. The study was conducted by one researcher, the author, who first presented the research plan in the parental peer groups ($n=2$) to give parents opportunity to share their views on the importance of the research topic. Participants in the peer groups found the research topic important and some of them were willing to join the study. Later more participants were found through recommendations of other participants or through parental peer groups in Facebook.

The main research method is semi-structured interviews, which were conducted among 13 parents living around Finland during 2016–2018. All interviewees were women. Most of them had good IT skills and were under 45 years old. Each interview lasted 40 to 90 minutes and most of them were recorded ($n=12$). In addition, author organized a focus group which had five participants (four of them were also interviewed personally) all living in the same municipality. One of the participants was a man who joined the focus group with his wife. Focus group lasted 116 minutes and it was recorded.

4.2 Research context

In Finland, children with disabilities are entitled to universal health care and social services. Health care includes care for acute health problems and rehabilitation, which aims to improve and maintain patient's abilities to function. In the case of children with disabilities, social services focus on funding their medical rehabilitation and their daily care. Social services are organized by Kela and the municipalities, where the child is living.

Kela offers disability allowances for the children under 16 years to cover the cost and the effort of their care. There are three levels of disability allowances: basic, heighten, and highest. Basic level is suitable for children who have continued health problems such as allergy for dairy products. Heighten level is suitable for children whose daily care is demanding due to their illness or their impairment, while highest level is meant for children who need to be cared round-the-clock due to their illness or their impairment. The decision about the allowance is usually made for certain period of time even if the disability is not assumed to disappear. This is justified according to the possible changes in the need of care, while the child grows [10]. If the child receives heighten or highest level of disability allowance, the cost of their medical rehabilitation is covered by Kela. Otherwise the municipality needs to pay for the child's medical rehabilitation.

Parents, who care for their children with disabilities at home, may be eligible for care allowance. The municipality, where the child with disabilities lives, is responsible for deciding and paying the care allowance. The decision is based on the parent's abilities to care for their child. If a parent is found suitable for caring their child at home, a contract can be made between the municipality and the parent. This contract resembles work contract and the parent is seen more as an employee than a client. The parent receives care allowance and they have a right for two monthly vacation days. During the vacation days municipality has to organize another care option for the child. Social services also supervise parent's abilities to care for their child. If the child is transferred to a long-term care outside home (e.g. in hospital), the payment of the care allowance is cancelled.

5 Preliminary findings related to digitalization of social services in Finland

Thematic analysis of the research data indicates that parents of children with disabilities cannot access most of the social services they or their children need through digital platforms. Instead, many service providers, such as municipalities, have webpages where one can download an application form to apply their services. Some of the interviewees have used these websites to download the application forms to apply needed services. In some cases, they have first printed the form and then filled it instead of filling it on their computer. Some parents told they did not use the computer, because they preferred writing by hand. After printing and filling the form, parents sent the application through regular mail, because there was no option to send it digitally.

All interviewees have applied disability allowance from Kela and they have been able to receive heighten disability allowance, even if this had sometimes required sending an official complaint about the initial decision. Some parents had received very good guidance for making the application from the social care workers who worked in their local hospital. As one of the parents said¹: ‘The hospital had social care worker who told everything that could be applied. Great service. Otherwise we probably haven’t had energy at that time.’

Conversely, parents were not able to use the digital platform offered by Kela to apply different type of allowances for their child because they “cannot use the e-service to handle their child’s affairs” [11]. Hence, the parents needed to send the applications by post. However, one of the parents remembered that she had applied allowance for her child’s therapy through it. She recalled that she had used her own credentials to complete the application. ‘In that point, I think I did it electronically. During past years I have applied electronically’. It is unsure, why her experience differs from the ones related to applying disability allowances. Perhaps, procedures are different for different type of allowances, although such exceptions are not mentioned in the context of disability services in the website of Kela [11]. Another possibility is that she did not recall all the details correctly.

Most of the interviewees had also applied for care allowance, and received it for their child with autism spectrum. None of the interviewees reported about any digital platform, which they could use to apply care allowance.

In addition to disability allowance and care allowance, children with disabilities are entitled for short-term care and personal assistance offered by the municipalities. Such services could include assistance for a child with disabilities to play outside home or to visit shops without their parents. To apply these services, one municipality had first introduced service vouchers which parents were able to use for receiving the required services from their preferred service provider. Later this municipality implemented a digital platform, which parents ought to use for spending the vouchers and choosing the service provider.

One of the interviewees had experiences of the vouchers and the digital platform. She explained that her child have had personal assistant before the introduction of the digital platform. However, she found the digital platform difficult to use and stopped applying personal assistance for her child. She said: ‘They became electronic. I didn’t have energy for it.’ Other interviewees who lived in the same municipality have not used the vouchers nor the digital platform. Hence, they were not able to agree or to disagree with her experience.

6 Discussion

This study found out avenues for improvement in the digitalization of social services in Finland. However, these problems represents only part of the challenges faced by the parents of children with autism spectrum. For example, many interviewees experience

¹ Translated from Finnish to English by the author.

fatigue, because they feel overloaded in their daily lives where they were the main carer for their children. In addition, some interviewees were single parents or did not have relatives who would help them by caring for their child with autism spectrum.

One reason, why parents feel overloaded, is the negative experiences they have for applying social services for their child. The first problem is to know about suitable services. Parents do not always learn about suitable services from professionals who work in social care, health care or education. Instead, they might have learned about the suitable services from other parents either through direct communication or through online discussion groups in Facebook. When a parent knows that certain service exists, they have to apply this. Some parents feel that applying for services takes a lot of their energy, but parents are usually content with any service they have received after applying. Understandably, they are unsatisfied when certain service is declined. Those parents, who have decided to complain about the negative decision(s), feel exhausted by this process.

Although, digital services cannot solve all problems that parents of children with disabilities experience, they have opportunity to be helpful. Many interviewees hoped that allowances offered by Kela could be applied online. Some of them suggested that new services would be created for mobile environment. At the time of the study, the opportunities promised by e-government were not fully realized – instead digital services were sometimes part of the challenges parents of children with disabilities need to cope.

Improving the existing digital services would be technically possible but it would require collaboration with social service providers and IT developers. Future research on this topic would benefit from finding partner who is ready to change its practices and invest in digital transformation to complete the improvements suggested in this study.

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