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ASSESSING SOCIAL CARE WORK

**The Service Satisfaction of People with Intellectual Disabilities
in a Helsinki Service Unit**

ABSTRACT

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Assessing Social Care Work: The Service Satisfaction of People with Intellectual Disabilities in a Helsinki Service Unit

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This thesis was made in order to find out about the service satisfaction of people with intellectual disabilities in the City of Helsinki's disability services social care work (northern service unit). The goals of this study included what the service user experience has been amongst the people with intellectual disabilities, and how the service users would want to develop the service itself. The reasons behind this paper were a lack of similar studies and the motivation to hear the opinions of the service users regarding the service.

Social care work for people with intellectual disabilities in the northern service unit is essentially assisting independently living adults with intellectual disabilities in their daily lives. In practice, for example instructing and assisting people with daily tasks, such as domestic work, nutrition, healthcare and service visits.

In this study satisfaction meant satisfaction with the content, availability and quality of the service, as well as its effects on the welfare of the service users. The developmental part focused on the sufficiency and possible future hopes regarding the service. There was also one direct question about the use of technology (assistance over a remote video connection).

The data was collected through interviews using questionnaires that were developed in collaboration with social work professionals. Interviews were conducted with one respondent at a time, and in an engaging and relaxed manner favouring dialogue. The same order of questions as they are found in the questionnaire was not always followed. The material was collected during spring and summer 2019. Participation was voluntary.

Results of the study revealed considerably high satisfaction with the service, suggesting that the service has been a very valuable help and form of support for the individuals who participated in this study. Clearly negative or critical comments concerning the service were not made or observed during the interviews.

Keywords: Intellectual Disabilities, Social Care Work, Disability Services, Service Satisfaction.

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1 INTRODUCTION

The City of Helsinki provides guidance and support for people with disabilities living in Helsinki. Disability services social work (Finnish: Vammaispalvelujen sosiaalityö) currently (as of 2019) consists of five different service units located around Helsinki. These are the northern, southern, eastern and western service units, as well as Itäkatu Family Centre. The City of Helsinki (2018) states that the aim of municipal disability services social work is to promote the ability of people with disabilities to cope on their own and seek to diminish possible restrictions and obstacles caused by the disability.

The purpose of this thesis is to provide more information about the service user satisfaction in social care work for people with intellectual disabilities (Finnish: Kehitysvammaisten sosiaaliohjaus). The focus is specifically on the work of social care workers. Their work is described as assisting over 18 years old independently living people with intellectual disabilities in their daily lives (City of Helsinki, 2018). This study intends to find more information about the satisfaction of the service users. The results will help to evaluate the service and can potentially help to develop the service. Also, they might help to develop and improve the effort of social care workers who work with people with intellectual disabilities. The working life partner is the City of Helsinki's disability social work, northern service unit.

This thesis is research oriented. The research question is how satisfied the service users are with the (northern service unit) social care work. The goals are finding out what the service user experience has been in the service and how service users would want to develop it. This will be achieved through interviews. Each respondent will answer to the same questions and there are no limitations regarding their age or gender. Therefore, the inclusion criteria are that the respondent is part of the social care work for people with intellectual disabilities and the exclusion criteria is being in the service for less than 12 months, so as to ensure that the respondent has been able to have sufficient experience of the service. However, the ability of the interviewee to comprehend and respond to questions was considered in planning and conducting the interviews.

2 KEY CONCEPTS

Definitions have been changing along with terminology and the term 'intellectual disability' has largely replaced various earlier terms which might nowadays sound outdated or even insulting, such as mental handicap, mental retardation, mental subnormality, feeblemindedness and even older Latin- or Greek based terms oligophrenia, idiocy and moronity among others (Westerinen, 2018). The currently recommended term intellectual disability (ID) highlights intellect but leaves out the word mental, which refers to mind (Westerinen, 2018). As a concept, mind is broader than intellect and cognitive functions (Scheerenberger 1983, cited in Westerinen, 2018).

In the Finnish language, the word 'kehitysvammaisuus' is the established dominant term. Direct translation of this term is developmental disability as abbreviated from 'älyllinen kehitysvammaisuus', meaning intellectual developmental disability. The established term 'kehitysvammaisuus' refers solely to ID in Finland. (Westerinen, 2018.)

2.1 Definition of Intellectual Disability

The term intellectual disability (ID) is currently defined by the World Health Organization (WHO) as "a significantly reduced ability to understand new or complex information and to learn and apply new skills (impaired intelligence). This results in a reduced ability to cope independently (impaired social functioning), and begins before adulthood, with a lasting effect on development." (WHO Regional Office for Europe, 2018.)

Previously, the WHO had defined ID somewhat differently with less emphasis on cognitive aspects: "as a condition of arrested or incomplete development of the mind, which is especially characterized by impairment of skills manifested during the developmental period, which contribute to the overall level of intelligence, i.e., cognitive, language, motor, and social abilities." (World Health Organization, WHO, 1992, cited in Ke & Liu, 2012, 2.) The first and newest definition above is more in line with the current definition from the American Association on Intellectual and Developmental Disabilities (AAIDD). The AAIDD have defined ID as a disability "characterized by significant limitations

in both intellectual functioning and in adaptive behaviour, which covers many everyday social and practical skills.” (The American Association on Intellectual and Developmental Disabilities, 2019.)

The AAIDD have highlighted the need to consider additional factors when defining and assessing intellectual disability. These additional factors are, for instance “the community environment typical of the individual’s peers and culture” and it is reminded that “professionals should also consider linguistic diversity and cultural differences in the way people communicate, move, and behave.” (The American Association on Intellectual and Developmental Disabilities, 2019.) Finally, limitations often coexist with strengths in individuals and life functioning of individuals is something that should improve if appropriate and personalized ways of support are provided long term without letting them get weaker (The American Association on Intellectual and Developmental Disabilities, 2019).

2.2 Epidemiology of Intellectual Disabilities

It can be argued that intellectual disability is neither a disease nor a disorder. The epidemiology of ID, however, is vital when it comes to planning services. There is a need to know how many people present intellectual disabilities, where they live, and what services are likely to be needed now and possibly in the future. (Emerson et al., 2012.)

People with intellectual disabilities may have problems with mental abilities that affect intellectual functioning (for example learning, problem solving and judgement) and adaptive functioning (daily life activities such as independent living and communication) (Parekh, 2017). The various needs and abilities for support of people with ID necessitate well-organized service systems and the detailed, up-to-date information concerning prevalence of ID in different age groups is vital information because of this (Westerinen, 2018).

The prevalence of ID across the world estimates from 1% to 3% according to several surveys (Harris, 2006, cited in Ke & Liu, 2012). There is variation between countries and income; the prevalence is higher in low- and middle-

income countries and significantly lower in richer countries, where it is only half compared to former (Maulik et al, 2011, cited in Ke & Liu, 2012). Also, prevalence is higher in males in both adult and child populations (Ke & Liu, 2012). In Finland, The FAIDD (The Finnish Association on Intellectual and Developmental Disabilities) claims that there are around 40 000 people with intellectual disability in Finland and this figure amounts to 0.8% of the population (The Finnish Association on Intellectual and Developmental Disabilities, n.d.).

The exact number of people with ID in the whole population in Finland is extremely challenging to determine. Administrative reports from different decades show the number of people with ID is around 0.6% of the population. However, higher estimates have been found in Finnish population sample studies. (Westerinen, 2018.)

In his PhD thesis (Prevalence of intellectual disability in Finland, 2018), Hannu Westerinen has explored the prevalence of ID in the whole of population at various ages using different sets of register-based data. From the prevalence estimates in four different age groups, the calculated total estimate is of around 53700 people with ID, what means an average prevalence of 0.97% for the population structure in 2017 (Westerinen, 2018). Nevertheless, it has to be remembered that there are many uncertainties also in this estimate and due to the uncertainty, the given estimate represents a minimum (Westerinen, 2018). Figure 1 below shows the number of people with ID in Finland in comparison with the whole of population in different age groups. It is notable that this represented minimum total estimate is significantly higher than the estimate made by the FAIDD.

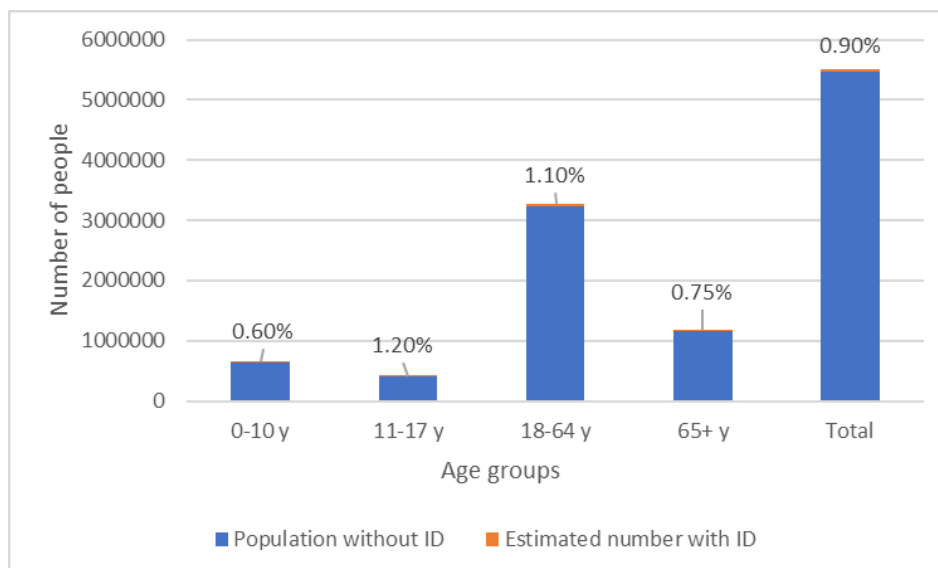


FIGURE 1. Estimated number of people with intellectual disabilities in comparison with the whole population in 2017 by age range and in total (Data extracted from Westerinen, 2018).

These estimated figures are lowest in the first (0-10 y) and in the last (65+ y) age groups. Several possible reasons may have affected the difference and the quick increase in the prevalence of ID by age. Improvements and increase in screening and arranging of diagnostic assessments in specialist care is likely to be one of the main explanations. After the age of 65 years, people with ID cannot be found effectively in registers and as a result there was a sudden drop in prevalence of ID after 65 years. However, this was corrected mathematically resulting in the estimate of 0.75%, which is significantly higher than previously thought. Inconsistencies concerning the age-specific prevalence distribution along with other findings have also pointed out the possibility of a hidden population of elderly people with ID (not recognized by the services but with difficulties in coping). (Westerinen, 2018.)

2.3 Common Causes

According to The Finnish Association on Intellectual and Developmental Disabilities (2016) the cause of disability remains undetermined in about 30 percent of the mild and about 50 percent of the profound cases of intellectual disability. Of those cases in which the cause is known, there are many possible factors contributing to the development of ID. The most common ones are: genetic

factors, problems during pregnancy and other causes, such as childhood injuries and illnesses, and lack of oxygen at birth, as well as use of alcohol during pregnancy (The Finnish Association on Intellectual and Developmental Disabilities, 2016).

Several factors have been associated with ID or have been confirmed to cause ID, and these factors which influence the child's development and function prenatally, perinatally or postnatally can be divided into three groups (Table 1.a. and 1.b.). These are organic, genetic and socio-cultural. However, it seems unlikely that all ID would fit neatly into these three groups due to overlapping genetic, socio-cultural and environmental factors (Ke & Liu, 2012).

TABLE 1.A. Common causes of intellectual disability (Ke & Liu, 2012).

Common causes of intellectual disability		
Category	Type	Example
Prenatal (before birth)	Chromosomal disorders	<ul style="list-style-type: none"> • Down's syndrome* • Fragile X syndrome • Prader Willi syndrome • Klinefelter's syndrom
	Single gene disorders	<ul style="list-style-type: none"> • Inborn errors of metabolism, such as galactosemia* • Phenylketonuria* • Mucopolysaccharidoses • Hypothyroidism* • Tay-Sachs disease • Neuro-cutaneous syndromes such as tuberous sclerosis and neurofibromatosis • Brain malformations such as genetic microcephaly, hydrocephalus and myelo-meningocele* • Other dysmorphic syndromes, such as Laurence-Moon-Biedl syndrome
	Other conditions of genetic origin	<ul style="list-style-type: none"> • Rubimstein-Taybi syndrome • Cornelia de Lange syndrome
	Adverse environmental influences	<ul style="list-style-type: none"> • Deficiencies* such as iodine deficiency and folic acid deficiency • Severe malnutrition in pregnancy* • Substances use* such as alcohol (fetal alcohol syndrome), nicotine and cocaine during early pregnancy • Exposure* to other harmful chemicals such as pollutants, heavy metals, abortifacients, and harmful medications such as thalidomide, phenytoin and warfarin in early pregnancy • Maternal infections such as rubella*, syphilis*, toxoplasmosis, cytomegalovirus and HIV • Others, such as excessive exposure to radiation* and Rh incompatibility*

TABLE 1.B. Common Causes of intellectual disability (Ke & Liu, 2012).

Perinatal (around the time of birth)	Third trimester (late pregnancy)	<ul style="list-style-type: none"> • Complications of pregnancy* • Diseases* in mother, such as heart and kidney disease, diabetes • Placental dysfunction
	Labour (during deliv- ery)	<ul style="list-style-type: none"> • Severe prematurity, very low birth weight, birth asphyxia • Difficult or complicated delivery* • Birth trauma*
	Neonatal (first four weeks of life)	<ul style="list-style-type: none"> • Brain infections such as tuberculosis, Japanese encephalitis, and bacterial meningitis • Head injury* • Chronic lead exposure* • Severe and prolonged malnutrition* • Gross under stimulation*
Postnatal (in in- fancy and childhood)		<ul style="list-style-type: none"> • Brain infections such as tuberculosis, Japanese encephalitis, and bacterial meningitis • Head injury* • Chronic lead exposure* • Severe and prolonged malnutrition* • Gross under stimulation*
*Definitely or potentially preventable.		

The most common causes behind ID are prenatal (before birth) and of genetic origin, either non-preventable chromosomal or single gene disorders or other conditions of genetic origin (Ke & Liu, 2012). However, adverse environmental conditions or influences, such as deficiencies and substance use, are definitely or potentially preventable causes. There are also several perinatal (around the time of birth) and postnatal (in infancy and childhood) causes that are definitely or potentially preventable.

3 SERVICES FOR PEOPLE WITH INTELLECTUAL DISABILITIES

The service system for people with intellectual disabilities has seen some major structural changes over the latter half of the twentieth century in Western countries. The term 'deinstitutionalisation' has been used to describe these changes. It is a process, during which institutional care has been widely replaced by other forms of support which may enable people with ID to live in the community with more freedom and independence. Furthermore, in the development of community-based provision, there has been emphasis on people with ID to have greater control over their lives and the possibility to make self-directed choices. (Miettinen & Teittinen, 2014.)

3.1 The Deinstitutionalisation Process

The first institutions in Finland that were built for people with ID, appeared at the beginning of the twentieth century. The 1958 Act on Mental Retardation accelerated the building process of these institutions. The number of people with intellectual disabilities in institutions was growing continuously until mid-1980s. The highest number at that time was nearly 8000 people in institutions. (Miettinen & Teittinen, 2014.)

Still, it has to be remembered that the majority of people with intellectual disabilities were not in institutions, but instead they lived with family members who were their parents in most cases (Tarvainen, 1966, cited in Miettinen & Teittinen, 2014). This could suggest that the institutions were essentially meant for those with disabilities whose families could not deal with their caring duties (Miettinen & Teittinen, 2014).

The process of deinstitutionalisation is still ongoing (Miettinen & Teittinen, 2014). At the end of 2016, there were close to 800 people in long-term care institutions (National Institute for Health and Welfare, n.d.), but this number has been being reduced gradually (Figure 2). For instance, in 2006 this number was still above 2100 people (National Institute for Health and Welfare, n.d.). In 2010, the Finnish government made a decision-in-principle to take this number down to zero by the year 2020 (Finnish Ministry of Social Affairs and Health, 2012, cited in Miettinen & Teittinen, 2014).

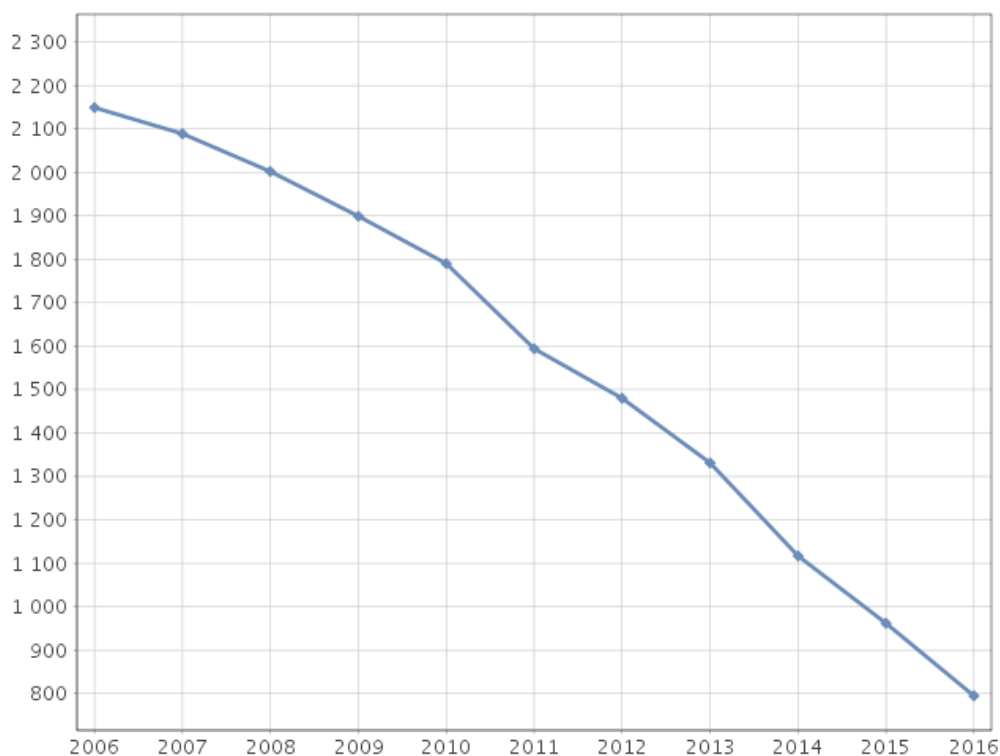


FIGURE 2. People with intellectual disabilities in long-term institutionalised care in Finland from 2006 to 2016 (National Institute for Health and Welfare, n.d.).

The impact of fairly recent deinstitutionalisation is shown by the significant reduction in the number of institutionalized patients before and especially after the decision-in-principle was made by the government in 2010, triplicating the reduction after it. Currently (as of 2019) the latest numbers from the National Institute for Health and Welfare are from 2017 and show that there were 622 people with intellectual disabilities in long-term institutionalised care in Finland, which is more than 1150 less than in 2010 (National Institute for Health and Welfare, n.d.).

3.2 Current Service System and Legislation

In the Finnish service system the municipalities manage the provision of services for people with intellectual disabilities. Generally, disability services are mainly the responsibility of municipalities in the current service system (Ministry of Social Affairs and Health, n.d.-b). However, changes have been

planned and they are discussed more in the subchapter 3.4 The Health, Social Services and Regional Government Reform.

There are laws that regulate the main services, such as the Social Welfare Act (Sosiaalihuoltolaki 1301/2014). Others include, for example, the Act on Special Care for the Mentally Handicapped (Laki kehitysvammaisten erityishuollosta 519/1977), as well as the Disability Services Act (Laki vammaisuuden perusteella järjestettävistä palveluista ja tukitoimista 380/1987). (Ministry of Social Affairs and Health, n.d.-a.) These acts “will be consolidated into one act on special services for persons with disabilities that would apply to all persons with disabilities equally” (Ministry of Social Affairs and Health, n.d.-a). This new act is due to come into force on 1 January 2021 as a result of the regional government, health and social services reform (Ministry of Social Affairs and Health, n.d.-a). The purpose behind this is that Finland would have one law which should secure equal services for all people with disabilities (The Finnish Association on Intellectual and Developmental Disabilities (FAIDD), n.d.).

The rights to equality and participation, and the necessary services and support, are the principles of Finnish policy concerning people with disabilities (Ministry of Social Affairs and Health, n.d.-b). In case that general public social services under the Social Welfare Act are not sufficient, special services needs to be arranged (Ministry of Social Affairs and Health, n.d.-b). These general public social services are “social services and related support services as well as other measures social welfare professionals adopt to promote and maintain the functional capacity, social wellbeing, safety and inclusion of individuals, families and communities” (Ministry of Social Affairs and Health, n.d.-c). Special services can include services concerning housing, interpretation, assistive devices and transport among others (Ministry of Social Affairs and Health, n.d.-b).

All these services are meant to support the individual autonomy and functional capacity of people with disabilities. The different needs of every person and their situation are considered in order to provide comprehensive assistance through developing a personal service plan with the needed services and support. (Ministry of Social Affairs and Health, n.d.-b.)

A personal service plan is a written plan concerning the services and ways of support that the person requires in order to cope with his or her daily life (Inclusion Finland, 2017). The services, organised by municipalities, are meant to help people with disabilities to cope with their daily lives (Ministry of Social Affairs and Health, n.d.-b). The Ministry of Social Affairs and Health (n.d.-b) has listed special care services arranged for people with intellectual disabilities, including housing services, work and day activities, and family care or institutional care.

Service housing or housing services is arranged by municipalities for people with disabilities who need help and support in housing. This could be due to the persons illness or disability, which means needing help in coping with everyday tasks. For people with intellectual disabilities, housing services could mean that they can live in an apartment where they can get help and support. Municipalities organise work and day activities for people with intellectual disabilities. The difference between them is that work activities include light work whereas daytime activities are meant for those with severe disability who are not able to participate in work activities. These daytime activities may include, for instance, exercise, discussion and cooking. (InfoFinland, 2016.)

Family care or care in family surroundings is a suitable way of housing for a person with an intellectual disability who needs treatment. It can be a temporary or a more permanent arrangement. It means that the person's treatment, education, upbringing and care happen in a private home outside the person's own home, although, it is possible that care in family surroundings is provided in the home of the person who requires treatment. Institutional care, as already mentioned, has been intentionally reduced and will be removed, but still exists. It can be arranged if a person with an intellectual disability requires care at all times and cannot be given care at home or in a service apartment. Institutional care can also be temporary solution. (InfoFinland, 2016.)

3.3 Social Care Work for People with Intellectual Disabilities

The social care work for people with intellectual disabilities is part of the City of Helsinki's disability services social work. The aim of social care work for people with intellectual disabilities is to support people with intellectual disabilities in their life-management, as well as in their independent acting and living. The service is intended primarily for adults who live independently. The social care workers can instruct and assist their customers in daily tasks, such as, domestic work, nutrition, healthcare and service visits. In addition, they can arrange other services to customers as needed. As part of the service it is also possible to receive sexual counselling, therapy or education concerning sexuality, body, feelings or relationships. The way to apply for the service is through contacting the social worker of disability services in the person's own residential area. A written application is not required as part of the process. The service is free of charge. (City of Helsinki, n.d.-a.)

Social workers working in disability services cooperate with other service providers and institutions, such as, home care, hospitals, and different associations (City of Helsinki, 2018). They also work together with social care workers who are often working with the same service users.

Social workers in disability services can be contacted if the disability or illness causes issues with living, mobility and coping at home. The workers are usually also contacted when a child is discovered to have a disability and in cases where an adult with disability is needing services concerning work, living or something else. The disability service staff, together with the customer, will work to determine the service needs of the customer. When preparing a service plan an evaluation of the need is utilized. (City of Helsinki, 2018.)

3.4 The Health, Social Services and Regional Government Reform

"The health, social services and regional government reform will establish the new counties and reform the structure, services and funding of health and social services as well as transfer new duties to the counties" (Finland's council of state, n.d.-a). The reform will gradually bring changes to social and health sector and will have an impact on the disability services. The responsibility for

organising health and social services will be transferred from the municipalities to 18 new counties (Finland's council of state, n.d.-b).

With disability services the idea is that the new act will ensure needs-based services for people with disabilities. This means that the new act “would safeguard all persons with disabilities access to services in accordance with their individual needs in situations where services based on other acts are not sufficient or appropriate (Ministry of Social Affairs and Health, 2018).

Diagnosis would not be determining eligibility for services. People with disabilities would maintain their right to similar services as those currently provided for them and the services for people with disabilities would remain free of charge. Still the reform is not simply reformation of the content of the previous acts, but it is aimed at achieving savings. Nevertheless, the message is that services should not be weakened but the savings would be the result of changes in operating practices. (Ministry of Social Affairs and Health, 2018.)

The reform has raised some concerns over disability services and already before the reform competitive bidding, in particular, has been criticised by citizens as it has been seen having negative affect on the quality of services for people with disabilities. Citizens' initiative (KAA 2/2018) was made on 12th June 2017 and it was signed by over 72000 people because there was a wide public concern about the effects of these changes on people with disabilities. More precisely, the initiative was asking for a law change in order to protect the necessary disability services supporting the daily living of people with disabilities from the competitive bidding on disability services. Debates in the government recognized the issues but there were doubts regarding the effectiveness of any law change or law addition as a solution to the problem and whether the fault was the law or its interpretation. It was then hoped that the Parliament would try to fix the issue regardless of any potential changes in law and whether they would improve the situation or not. (Parliament of Finland, 2018.)

The managing director of Service Foundation for People with an Intellectual Disability, Markku Virkamäki, has claimed that there is no research evidence suggesting that using competitive bidding with disability services would be the

most affordable way to arrange services. When it comes to competitive bidding and disability services he has suggested that it might in fact increase the costs in specialized medical care instead of achieving any savings. He claims that this is because people with disabilities who are needing and using disability services have been treated only as objects. This has led to constant changes with the different providers of disability services and the personnel, resulting in frequent big changes in the daily lives of the service users. Virkamäki suggests that if the service users cannot impact their situation concerning the services, the situation is chaotic for them. Disability services with less quality could result in increased illnesses and, therefore, increased costs for specialized health care. (Sullström, 2018).

However, in March 2019 the government resigned just some weeks ahead of new elections (14th April) and the reform, as it was planned, fell. Reportedly the government collapsed over its failed social and health care reform (YLE, 2019). Changes are, therefore, not taking place as they were planned, and it will remain to be seen what changes the new government(s) will make concerning disability services, and social and health care services overall.

3.5 The Right for Services

The ideals of Nordic Welfare Society have shaped the development of rights of people with disabilities. Besides, Finnish social policy and practice has benefited from the strong disability movement in Finland and largely as a result of the above mentioned the Finnish development policy recognizes the importance of rights of people with disabilities. Therefore, investing in equality and in the rights of people with disabilities are seen as cross-cutting objectives for all development. (Department for Developmental Policy Ministry for Foreign Affairs of Finland, 2018.)

Finland has also ratified the UN Convention on the Rights of Persons with Disabilities and its Optional Protocol in 2016. During the same year, they entered into force in Finland. (Parliamentary Ombudsman of Finland, n.d.) By ratifying the UN Convention Finland had signalled its commitment to fulfil the implementation of the Convention. The UN Convention on the Rights of Persons

with Disabilities views “persons with disabilities as “subjects” with rights, who are capable of claiming those rights and making decisions for their lives based on their free and informed consent as well as being active members of society” (United Nations, n.d.).

The Convention has many articles highlighting the right and access for services. For instance, article 5 Equality and non-discrimination mentions that States Parties will have to make sure that reasonable accommodation is provided for people with disabilities. It also states that necessary specific measures to accelerate or achieve true equality of people with disabilities shall not be considered discrimination under the terms of the present Convention. This should help to promote equality and eliminate discrimination. Also, article 20 Personal mobility focuses on the rights for services in trying to secure that effective measures are taken to ensure personal mobility with as much independence as possible for people with disabilities. Other articles such as 25 and 28 particularly highlight the right and access for health related services and overall support for wellbeing, as well as social protection for people with disabilities. (United Nations, n.d.)

In 2018, Ministry of Social Affairs and Health published a publication called Right to social inclusion and equality – The National Action Plan on the UN Convention on the Rights of Persons with Disabilities 2018–2019. It “determines the measures that will be taken to promote the implementation of the Convention in different administrative sectors during the first action plan period 2018–2019” (Ministry of Social Affairs and Health, 2018b).

Representatives from disability organizations have been involved in the making process of the Action Plan together with representatives from labour market organizations, as well as the key ministries regarding the rights of people with disabilities. The action plan has 82 measures which have been divided into those that will be implemented during the 2018-2019 period and those that are implemented over a longer period of time. These concrete measures are based on the information received from disability organizations and people with disabilities, who have been consulted about the matters that should be

promoted in the Action Plan according to the UN convention. (Ministry of Social Affairs and Health, 2018b.)

In particular, The Action Plan has put importance to the social inclusion of people with disabilities and to the importance of accessibility. These are seen as preconditions for the realisation of all the other rights. A person with a disability should have the right to get the services and support necessary for living independently as part of the community. The Plan also tries to increase awareness concerning the rights of people with disabilities. The idea is that these rights are effectively followed and respected widely in the society and not only in various administrative sectors. (Ministry of Social Affairs and Health, 2018b.)

4 BACKGROUND OF THE RESEARCH

Previous projects or research specifically about the social care work for people with intellectual disabilities in Finland has been limited. In fact, it was difficult to find any study or project related to the particular service (social care work for people with ID) this study is focusing on in Finland. Although, regarding the disability service system overall, a study has been made exploring the experiences of people with ID in the Finnish service system. The master's thesis conducted by Kristiina Keppo suggests that people with ID can assess their needs for services fairly well in case they have sufficient information about them (Keppo, 2012). Therefore, health and social service professionals should view the people with ID "as autonomous service users, whose opinions can be made to be heard through efficient planning and guidance" (Keppo, 2012).

The shortage of any official feedback or developmental wishes from the service users of the service themselves was perhaps the most important reason why this study was conducted. Nevertheless, when it comes to intellectual disability and disability services overall, interesting studies could be found. Selected studies that are somewhat similar to this study in measuring a particular service and service user satisfaction in Finland are briefly introduced in this chapter. This is followed by taking a look at some more research about service user satisfaction in disability services overseas.

4.1 Studies in Finland with Some Similarities

In her Bachelor's thesis, Hiekkamäki (2006), looked into the customers' experiences of the transport services in the Jyväskylä area using a questionnaire made by the Jyväskylä Council for the people with disabilities. Overall, 325 questionnaires were sent and 224 returned. All the respondents were receiving the service at the time. The aim was to find out the most popular transport service, the using rate of given journeys, and how people had experienced joint rides. In general, respondents were quite satisfied with the transportation service. Results were mostly positive in every section despite some criticism and comments especially concerning joint rides. Drivers' behaviour and safety devices also received a lot of attention in the results. (Hiekkamäki, 2006.)

Another example of disability services is the daytime activities for those with a severe disability who are not able to participate in work activities. Huttunen, (2010) (Bachelor's thesis) explored the customer satisfaction of daytime activities of the City of Vantaa. The study was comparing some differences between satisfaction results from 2008 and 2009. The purpose was to provide information concerning service user satisfaction for the administration of social and health care in Vantaa about the development during 2008 and 2009 (Huttunen, 2010).

In the study, service meant easiness of getting contact, professionalism of personnel, individuality of the services, and satisfaction with the content and schedules. There was intention to find out how the daytime activities affected in a positive way the customers' ability to function, feelings, communication with others and experience of meaningfulness. The material was collected through structured inquiries. The results of the report revealed positive answers towards the service. The customers were mostly satisfied and pleased with the daytime activities provided by Vantaa and had also many suggestions regarding the service. Positive feedback was given especially for the personnel and the service was considered important as it had decreased loneliness and increased the feeling of meaningfulness. Some disagreement was around the topics of the price and the content of the service as well as the timetables. (Huttunen, 2010.)

4.2 Research About Satisfaction in Disability Services Outside Finland

Research from abroad concerning customer satisfaction in disability services offers more interesting studies. Parent, Kregel and Johnson (1996) explored the satisfaction of individuals with severe disabilities who received supported employment services in Virginia, US. The study was conducted to evaluate the effectiveness of the supported employment model from the point of view of the people with disabilities whom it serves. 110 people with disabilities who were randomly selected from the total population of 3,431 of people who participated in supported employment in Virginia between July 1988 and August 1992 participated through face-to-face interviews. (Parent, Kregel and Johnson, 1996.)

The Consumer Satisfaction Survey (CSS) that was used, contained both open-ended and multiple-choice items that were generally divided into eight categories. Results showed that most of the consumers did like their jobs and most were happy with supported employment services. However, close to half of the consumers would have wanted to change some aspect of their job to make it better. Also, more than half felt their job was not the career they would have on a permanent basis. Based on the findings it was suggested that it would be useful to have more consumer involvement in all supported employment service delivery phases. (Parent, Kregel and Johnson, 1996.) The CSS developed by individuals with disabilities was “found to be a valid and reliable instrument” (Parent, Kregel and Johnson, 1996).

Another example from the US during the 1990's is a study that focused on client satisfaction with developmental disabilities services. In the study a representative sample of 312 clients of Florida's Department of Health and Rehabilitative Services was analysed to find out “the characteristics of the clients and to determine the extent to which the clients are satisfied with various services, reasons for any dissatisfaction that exists, and the factors which are related to satisfaction with services” (Weller, 1991).

It was found that service users were most likely to be less satisfied with the received caregiver support services and the vocational and rehabilitative services. In all the included categories the most common reasons for dissatisfaction with the services were inappropriateness and insufficient amount. Satisfaction with services was most strongly affected by age, living arrangements, and number of services received. In more detail, interesting findings included adolescents being less likely to be satisfied with the services they receive than people at other ages, and persons living in a family setting being more likely to be satisfied with services than individuals living in nonfamily settings. The results also showed that greater number of services received lowered the likelihood of satisfaction. (Weller, 1991.)

5 METHODOLOGY

The following chapter explains the data collection and data analysis. The chosen methods are justified, followed by subchapters providing more information concerning the process and challenges of this study.

5.1 Data Collection

This study is a qualitative research using face-to-face interviews to gather the material. The term qualitative interviewing might be used due to the use of some open-ended questions. Also, due to the blend of both closed- and open-ended questions used in this study (some of them accompanied with follow-up why questions), it could probably be described as semi-structured interviewing (Adams, 2015, 492-493).

These interviews were conducted with one respondent at a time, and in an engaging and relaxed manner following the structure of questionnaire or interview guide. However, this was not a standardized survey. The order of questions as they are found in the questionnaire (Appendix 1 and 2) was not always strictly followed with all of the interviews. The idea was to give respondents enough time to think and try to receive also as many answers as possible to follow-up why questions, and perhaps some additional comments that could reveal more information. Qualitative methods were used largely due to the fact that the sample was not that large. Moreover, and most importantly, there is no intention to generalise findings to a wider group.

Semi-structured interview can be a great method when asking probing open-ended questions and when wanting to get to know the independent thoughts of an individual. It can be useful when asking questions on topics that respondents might not be comfortable or willing to answer truthfully if sitting with others in an interview situation. (Adams, 2015, 494.) For the above-mentioned reasons, these interviews were conducted in a semi-structured manner.

The northern service unit in social care work for people with intellectual disabilities has approximately 40 service users (as of 2019). With this study the

aim was to receive at least 5 or 6 service users as was recommended by the leading social worker of the time at the northern disability services unit. This number, although fairly small, seemed big enough to get a decent understanding about the satisfaction towards services, opinions, and possibly hopes of different service users. Besides, it also seemed realistic in terms of workload and the completely voluntary nature of participation, combined with the somewhat small number of potential interviewees.

It should be noted that some of the service users are not receiving or needing so much support or do not want or require regular agreed meetings or home visits, for instance every week or fortnightly. Still, all of the people who are part of the service were considered eligible for interviews if they had been in the service for at least 12 months, which in most cases should be enough for having sufficient experience. Therefore, when participants were searched, the only criteria was that they had been part of the service for more than one year because the sufficient experience from the service was important in order to value it. Other factors, such as age and gender were not considered important, but it was hoped there would be both men and women from different age groups. This would make the somewhat small group of participants fairly diverse.

Questionnaires or interview guides, that included altogether 14 questions, were prepared. The number of questions was calculated so that it should be appropriate for finding out about the service user satisfaction with the service without repeating similar questions or adding anything irrelevant concerning the study and its goals. Some of the questions and a rough version of the interview guide was tested once with a service user who had agreed voluntarily to assist and answer to test questions. This also served as interviewing practice as it happened one-on-one with a service user. The same final interview guide was then used with all of the respondents because they all represented the same target group. Overall, seven people had agreed to participate at first.

Finally, being present when the structured interviews were being conducted was highly important as this gave the interviewer the possibility to explain and assist with the meaning of questions if needed. Although the questions were

written as clearly as possible, using clear and easily understandable language (Appendix 1 and 2), it was possible that some of the questions were not properly understood immediately.

5.2 Data Analysis

Qualitative content analysis was used to analyse the collected data. In qualitative content analysis, according to Bengtsson (2016), data are presented in words and themes which should give the possibility to draw some interpretation of the results. The manifest analysis was used to describe what the participants answered. It is a way to describe what the participants actually say by using their words and describing the visible and obvious (Bengtsson, 2016).

All the answers from the participants were written down during the interviews. After the data collection, the data was then read, organized, reviewed and explored carefully. This helped in achieving a better and deeper understanding of the data. Themes were combined and these and all the findings are presented in the chapter 7. A spreadsheet program, Microsoft Excel was useful in storing and interpreting data. It was also used to visualize some findings.

This study remains true to the participants and their voice so that the information they give can be shared as they have wanted it and reported on for others to read and learn from (Sutton & Austin, 2015). In qualitative research being true is “the most important part of data analysis and management” (Sutton & Austin, 2015).

5.3 The Study Process

This thesis work needed permission from the City of Helsinki before beginning the interviews and collecting data. For this, official research permission form (for the City of Helsinki Social and Health Department Disability Services) had to be filled correctly with all the necessary attachments included. These attachments were a written research plan that had to clearly describe the purpose of the study, the way of collecting data, and how the findings would be kept, as well as what would happen to them when the work is analysed. There was also need to include a written permission letter, as well as information letter which

informed the participants about the study, using clear and easily understandable language. All these documents were written in Finnish and if necessary, they would have been translated into a different language according to the need of participants.

The application was delivered to the Social and Health Department Disability Services. Processing the permit application will take some time. Exact information or estimation on the time usually needed to receive the permit from the Social and Health Department Disability Services could not be found. However, the Education Division of the City of Helsinki, for example, informs that it is better to submit the application well in advance, because it might take from four to six weeks of their arrival to process the application (in case that the application is not filled adequately, or some attachments are missing, the process may take longer) (City of Helsinki, n.d.-b.). With this study, it took close to two weeks before the (positive) answer was received.

After securing the official permission from the City of Helsinki, the voluntary participants could be chosen from the service users. The participants were chosen with the support of the service professionals. The participants agreed verbally first and then signed the written consent after having been explained clearly all the required information concerning the study and their rights. The interviews took place at the homes of the service users or somewhere else if agreed so. This way the interviews could be conducted in a way and in a place where the participants feel most comfortable and at the same time so that unexpected intrusions are minimised.

It is important to reserve enough time and always present the questions as clearly as possible and if needed explain them more in detail. The author was the only person present during the interviews and this was because wanting to minimize the impact of any other person affecting the answers. The interviews took place in spring and summer 2019. On average, the interviews lasted from 15 to 20 minutes, although some lasted longer.

In this study six individuals (three men and three women with ages ranging from 30 to 76 years with an average age of 49 years) who fulfilled the criteria

participated. They took part on voluntary basis and were chosen by professionals in the service according to the mentioned criteria. Each participant signed the written agreement paper after having been explained more information about the study and their rights. All of the interviews took place at the homes of the service users, except for one which was arranged in a public library according to the wishes of the participant.

The interviews were not recorded but all the comments were written down exactly as they were given. The major reason for not recording the interviews was that it was thought that it could have impacted in some way some of the respondent's willingness to participate and answer to questions without hesitating. All the given comments were then translated into English by the author.

The researcher was responsible for appropriate use and storage of the data. The confidential data in paper forms were stored securely and privately behind locked doors. The same data was also stored in electronic form and was protected by passwords. Only the researcher had access to these. After the work was finished, all the paper documents were destroyed by shredding them and all the electronic files were permanently deleted.

5.4 The Challenges

One interview was cancelled at the last moment due to the absence of the interviewee who had agreed to participate at first. Finding and interviewing participants one by one also took considerable amount of time and eventually lasted longer than what was first expected. The author was not allowed to arrange these interviews alone but had to receive participants through the service from professionals, as was mentioned earlier.

Limited data and its analysis was an expected challenge due to the somewhat small number of potential participants. Yet, it should be remembered that this is a qualitative research and although six participants out of approximately 40 is not ideal, it should be enough to get a decent understanding about satisfaction towards the services. Also, all of the potential participants did not fill the criteria that was set to ensure they would have sufficient experience from the

service. This reduced the actual number of potential participants. The six participants represented both men and women, as well as different age groups making it possible to compare potential differences. Nevertheless, the limited data affected interpreting the data and comparing differences.

Another issue or challenge related to the process was trying not to affect or guide the respondents in their answers in any way, but at the same time be leading and conducting the interviews efficiently and ethically with people with intellectual disabilities. As mentioned before, the questions were written and presented to the interviewees in a way that was easily understandable. This is particularly important when providing material for participants with intellectual disabilities (National Disability Authority, 2009). However, this can be challenging and planning the interview guides was a considerable challenge. Hence, assistance from experienced social service professionals in disability services was much appreciated in planning the interviews.

Another factor behind the significantly high satisfaction ratings could be the possible hesitation in answering all of the questions without trying to please anybody else. Although all of the participants were told as clearly as possible and exactly what this research is about and what it aims to achieve, it is possible there may have been, for example, some fear concerning the possibility of receiving punishments from clearly critical answers and opinions or even the fear of losing the right to service. Despite the best efforts to guarantee that the participants' responses would remain confidential and that it would not be possible to trace their responses back to them, it is possible that some answers may have been influenced by these above-mentioned reasons. Still it has to be underlined that all the previously described necessary steps were taken to ensure that participants could be honest and open when responding to questions.

Additionally, some of the participants might have been somewhat familiar with the author due to work experience as a student intern in the northern service unit during autumn and winter of 2018. However, most likely this had very little or no impact at all on the answers. Therefore, explaining the study, and the

aims and purposes of the study clearly to the participants, was extremely important in several ways.

Using questionnaires in face-to-face interviews with people with disabilities is one way to collect data and it was chosen for this study. The use of something else than questionnaires or surveys in measuring service user satisfaction with a service is a possibility. Whether this could produce somehow better or more reliable results is unclear. The most important thing is that the process is planned and conducted well so that it considers the target group (National Disability Authority, 2009). Considering accessibility, for example, is always important. According to the National Disability Authority (2009) the researcher should always in practice accommodate any specific information and communication needs related to the disability.

Preparing the right questions is a key issue and expertise in survey design can ensure the questionnaire is valid (Australian Government the Office for Disability, n.d.). The questionnaire used in this study was mostly developed by the author but there was collaboration with the professionals in the service when preparing the questions. The questions and the final version of the questionnaire were ultimately approved by the professionals in social care work northern service unit, before the interviews began.

6 RESEARCH ETHICS

“Research ethics govern the standards of conduct for scientific researchers. It is important to adhere to ethical principles in order to protect the dignity, rights and welfare of research participants” (WHO, 2015). This chapter will explain more about research ethics especially considering this study.

6.1 Ethical Norms in Research

There are many good reasons why following ethical norms in research is important. These norms promote the aim of research that include, for instance, knowledge, truth and avoidance of error. Research often involves a great deal of collaboration and there is need to have mutual respect, trust, and fairness. Following research ethics will help to promote these values that are highly important for successful collaboration. The ethical norms can also ensure that the researcher can be held accountable to the public. When people know and trust that the norms are followed and respected in research, they are also more likely to support it. (Resnik, 2011.)

6.2 Disability Research Ethics and Considerations Regarding this Study

“Disability research ethics are located within the wider research ethics framework” (National Disability Authority, 2009). Any research involving human beings has to respect the human rights of the individuals who are involved (National Disability Authority, 2009). When it comes to disability research, the UN Convention has specified what this should mean. The most important things to consider in disability research include respect for the inherent dignity, individual autonomy and independence of persons (National Disability Authority, 2009).

Some other core values found in Article 3 of the UN Convention on the Rights of Persons with Disability from 2006, are equality, respect for difference, full and effective participation and inclusion in society, as well as accessibility. In practice this can mean, for example, respecting people with disabilities as active participants in research by involving them in an appropriate way, including making sure they are properly informed about the research. It is important to

ensure that participants in the research who so require, are provided with the necessary communication aids making it accessible for them. (National Disability Authority, 2009.)

“The practice of requiring consent from next of kin for a person over 18 years to participate in a survey interview is open to question, on the grounds that the person is an adult and should be able to make such a decision for themselves” (Australian Government, 2000). Gaining appropriate consent for participation is a must. Unless demonstrated otherwise, adults with disabilities should be able to decide about voluntary participation (Australian Government, 2000). In this study all the potential participants (service users) are adults and not those with severe or profound ID. Instead, they are individuals with mild to moderate ID and who are living independently (alone or with a partner). Therefore, consent was asked directly from them and not from their families. Besides, there were potential participants without any close relatives or any information about them.

As the National Disability Authority (2009) has stated, a key issue in research with people with disabilities is that there is informed consent. Apart from verbal consent, written consent was necessary before taking any other action. Prior to that, official research permit was requested to the city of Helsinki and the positive decision was obtained on 14th February 2019. Finally, as part of properly informing the participants about the study, a clearly written information letter was given to the participants before the interviews were conducted.

The National Disability Authority (2009) has reminded that accessibility in research with people with ID means that easily readable and understandable information should be provided, and simple instructions and illustrations should be used. In this study these were considered throughout the process in planning and conducting the interviews. Therefore, both instructions and questions were as clear as possible.

In this study, the anonymity of the interviewed participants was protected by anonymisation. At the end of the study, all the notes, as well as any written documents containing information from the interviewees were destroyed.

Voluntary participation and self-determination of the participants was respected throughout the process. By listening to the participants and letting their opinions and voices to be heard, the study promotes social justice and equality. Ideally results will provide and reveal useful information about the service, and most importantly, the satisfaction of the service users, as well as perhaps some developmental help for the future.

Finally, it has to be mentioned that all the respondents should be told exactly what the research is about and what it aims to achieve. The respondents must be assured that their opinions are valued. Furthermore, at the same time it should be underlined that their responses will remain confidential and that it will not be possible to trace their responses back to them. Following these steps should help in encouraging individuals to participate and be honest and open when responding to questions. Responses should be given without any fear of retribution. (Australian Government the Office for Disability, n.d.) The participants in this study were reminded of the above mentioned verbally and in written form.

7 FINDINGS

This chapter presents the findings of the study. Overall, four participants told that they had been part of the service for 5 or more years while two others said for 3 to 5 years. Thus, they can all be considered somewhat experienced as service users. All the comments presented here in this chapter have been translated from Finnish to English by the author because all the respondents gave their answers and comments in Finnish.

7.1 The Sufficiency of Assistance

The feeling of sufficiency is a very important factor when it comes to the satisfaction with the services. As mentioned in the chapter 4, Weller (1991) found in his study that most common reasons for dissatisfaction with the (developmental disabilities) services were inappropriateness and insufficient amount. All the participants in this study had answered yes to the question whether assistance had been personally enough for them. When asking why, four of the six participants gave additional comments saying:

- "I have had sufficient guidance"
- "Satisfied"
- "Yes, it has"
- "Every fortnight has been good. Mother thinks more often would be good".

The answers and short additional comments suggest that the participants had all been satisfied with the sufficiency of the service. Words, such as satisfied and sufficient were used by two individuals. Another participant had replied simply yes, it has. These three have confirmed clearly their satisfaction with the sufficiency.

The last comment was particularly interesting, although the purpose was to only hear the participants own thoughts regarding the service. This respondent also shortly confirmed verbally to have been satisfied with the sufficiency in telling that (every fortnight) has been good for the respondent. Sometimes

additional comments, such as these, can reveal something interesting for the study and even indirect criticism, even if not from the participants themselves. The comment made by the mother of the individual as told by the respondent can be interpreted as criticism and perhaps simply concern for the mother's child.

Regarding the need for assistance according to the participants themselves, it varied. Only one replied once a week and two said fortnightly. Other two thought once a month was suitable and one felt the need was less often than once each month (Figure 3).

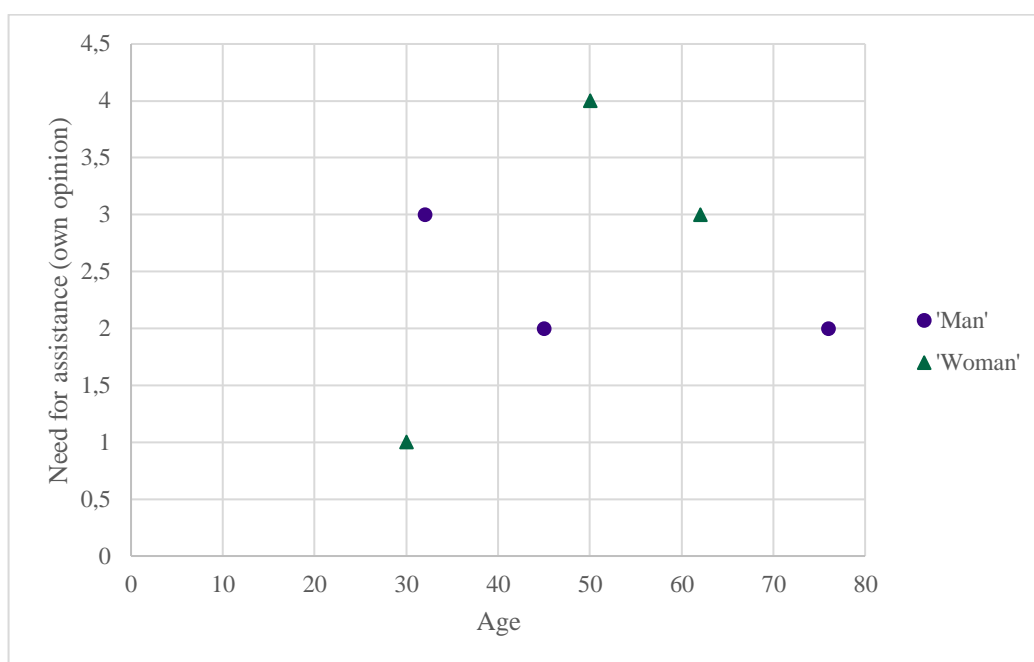


FIGURE 3. The need for assistance with gender and age of participants.

It could be expected that age would matter when it comes to the need for assistance (their own opinion), but interestingly results do not really support this expectation. This can be also because of the fact that those who are older and might have more health-related issues, might receive other services, such as home care services, that help to maintain their health and functionality and allow them to live independently, instead of living in supported housing units or nursing homes. Gender did not seem to matter much either. However, there were only six participants and three individuals of each gender. The findings seem to support the idea that the need for assistance has more to do with the

individual's life situation, as well as various needs and abilities of the individual, rather than their age for instance.

7.2 Service Satisfaction of the Service Users

The results showed that every single participant had been satisfied with the overall assistance the service has provided. Every participant answered yes to the question whether they have been in general satisfied with the assistance they have received. Additional reasons to follow-up why question about general satisfaction with the assistance included these four following comments:

- "Everything is alright now"
- "Workers are friendly and keep things confidential. It is always possible to call if there is something important"
- "I can't think of any reasons"
- "Sufficient assistance."

These comments did not truly reveal many reasons apart from the second one which is thanking the social care professionals and highlighting their role in the individual's satisfaction with the service. The word sufficient was repeated again in the additional comments. One individual simply stated not being able to think of any reasons to the follow-up why question despite answering yes to the question and two of the participants struggled once more in providing reasons and as a result there was four comments from the six possible. The same happened with the first follow-up why question regarding sufficiency with the service.

Rating the service numerically, five participants wanted to give the best possible grade (from lowest, 1, to highest, 5) and only one participant gave a four (at first this participant also gave a five but at the end added a comment which meant the final grade was four). This means the average of 4,83 out of 5 was given when rating the whole service overall. This average is considerably high and suggests that the satisfaction of the participants is indeed high concerning disability services social care work.

When it comes to the four welfare questions at the end of the interviews, the results were similarly very positive. All the participants gave the highest agreeable rating for the parts of receiving help when needed, being heard by the workers, and with the feeling that the service has been an important form of support for them personally. Only the question asking about the assistance and its positive impact on the welfare of the service users received numbers 3 (not sure) and 4 (somewhat agree) apart from the fives (completely agree) that were given. The answer 3 (not sure) shows uncertainty which can be the consequence of not really understanding the question properly or because of being unsure how much the service and assistance has really had positive impact on the person's wellbeing. The answer 4 (somewhat agree) also suggests some slight uncertainty over the services and assistances impact on the respondent's wellbeing, although it is still a mostly positive answer towards the service.

The findings are, therefore, showing that the participants are most satisfied with the (northern service unit) social care work. The service's content, availability, quality and its effects on their welfare have all been at a high level according to the people who participated in this study. It seems that these factors have all together resulted high ratings of satisfaction among service users. The feeling of sufficiency with the service is one of the key factors when it comes to satisfaction and each respondent claimed to have been personally satisfied with it.

7.3 Developmental Questions

When asked about the possibility to meet social care workers online (assistance over a remote video connection), only two participants said yes to readiness for online meetings (Appendix 1 and 2). In any case, with some people online meetings are unlikely to be a realistic possibility or even impossible with some tasks. This heavily depends on the individual and the task.

Based on the results of this study, there are many service users who are not, by now ready for online meetings. Also, if there are service users who simply refuse to accept online meetings, it would be entirely wrong to force them into

it. Still it is certainly good to offer various ways to aid and use ways that are seen useful with those are willing and wanting to try them. Exploring new and effective ways to assist is important but the opinions and possibilities of the service users should be considered. When it comes to the hopes for the future question, it was similarly to all of the interview questions apart from the follow-up why questions, answered by each participant and the results included all the following comments:

- "Help has been given when needed. Now there are no hopes in particular."
- "Feels that all hopes have been realized by now. What I have hoped has been fulfilled. Nice people are looking after things."
- "I can't think of any."
- "It has gone quite well. Help has been always given when asked. I will let know when it is needed. During (home) visits things are looked at together."
- "Nothing in particular."
- "There could be more activities outside home."

Among these answers there was only one concrete developmental wish, which is quite general in wishing for more activities outside home. This wish might suggest the individual would like to spend more time outside home and perhaps the individual is hoping and wanting to be more active in some ways. It is clear that most of the other comments are merely confirming satisfaction with the service or simply stating that they do not or did not have any particular wishes or ideas for the service when the interviews were conducted. Two have stated directly that they could not think of any suggestions to make. Two others have highlighted that help has always been given when needed or asked and they had, therefore, no suggestions or wishes to make during the interviews. It is probable that more concrete wishes and suggestions would have been made if the satisfaction with the whole service and assistance had been lower.

The message about satisfaction with the service seems clear though based on the findings. The participants claimed to have been most satisfied with it

overall. Their ratings and short comments about their experiences as service users support this.

7.4 Limitations of the Findings

It may have been better and easier for the participants to rate the service, using numbers from 1 to 10 instead of 1 to 5. This suggestion is made because there was one participant who first wanted to give 5 when rating the service from 1 to 5, but then later on during interview made a comment stating that 8 would be suitable. Still, this might not be true with every participant. Depending on the person with ID, it is possible it could have been also more useful or practical to use pictures in rating the service instead of numbers. This, however, might not again be significantly easier, better or suitable for every participant and using both numbers and pictures could complicate analysing results. The use and amount of both open-ended and closed questions is debatable. Combination of both can be productive.

At the end one important issue with this study was the lack or shortage of comments which may have been more the result of the content of the questionnaire used rather than anything else. Perhaps having still more open-ended questions would have been beneficial as the final questionnaire contained many closed questions as well (Appendix 1 and 2). However, two of the participants in particular found it difficult to answer to follow-up-why questions and open questions in general during the interviews. Open ended questions might have not been alone the answer to the issue of limited data, at least it might not be significant for the outcome with some individuals.

The modest number of participants affected the data analysis and comparing differences, but the main issue is likely to be the shortage of relevant data from the interviews. It is possible that the interviews might have been at times too straightforward at least for some of the participants, although dialogue was favoured, and accessibility was always considered throughout the whole process. Collecting still more relevant data concerning satisfaction with the service would be useful.

8 DISCUSSION

As argued before, the epidemiology of intellectual disabilities is vital when it comes to planning services. Up-to-date information from a specific region or an area should make it easier to understand what resources are really needed. Certainly, this does not mean treating people like numbers (objects) or trying one-size fits all kind of approach with services for people with ID. That would not only seem wrong, but it is against the rights of these people, and is, without a doubt, doomed to failure.

8.1 Services and People with Intellectual Disabilities

As mentioned in the chapter 3, the managing director of Service Foundation for People with an Intellectual Disability, Markku Virkamäki, has claimed that there is no research evidence suggesting that using competitive bidding with disability services would be the most affordable way to arrange services (Sullström, 2018). Constant changes with the service providers of disability services and personnel can result potentially big frequent changes in the daily lives of the service users. This would be a result of treating people with disabilities as objects only. Instead service users should be able to impact their situation with the services in order to prevent the situation becoming chaotic for them. (Sullström, 2018.) This should be done in order to respect their rights too. What could be required are services like the social care work for people with ID, where the disability services staff, together with the customer, work to determine service needs of the customer. This is based on the personal service plan which is made with every single service user.

The social care work for people with ID seems like a good example of this approach. Accordingly, with The UN Convention on the Rights of Persons with Disabilities viewing people with disabilities “as “subjects” with rights, who are capable of claiming those rights and making decisions for their lives based on their free and in-formed consent as well as being active members of society” (United Nations, n.d.).

Furthermore, as the number of people with ID in long-term institutionalized care has rapidly reduced in Finland due to deinstitutionalisation process, it is

most likely that other forms of support, such as the social care work for people with ID are now ever more important. The Action Plan (Ministry of Social Affairs and Health) put special importance to the social inclusion of people with disabilities and to the importance of accessibility, the preconditions for the realisation of all the other rights. The idea is that people with (intellectual) disabilities should have the right to the services and support needed for living and acting independently as part of the community (Ministry of Social Affairs and Health, 2018b).

8.2 Assessing Findings

The purpose was to find out how satisfied the service users are with the (northern service unit) social care work. Satisfaction with the service included satisfaction with the content, availability and quality of the service, as well as its effects on their welfare. The developmental part of the interviews focused on the sufficiency and possible future hopes regarding the service. There was also one direct developmental question about the use of technology (readiness for online meetings over a video connection).

The results showed clearly high ratings of satisfaction with the service. This seems extremely positive, although there might be some doubts over the highly positive results (see subchapters 5.4 The Challenges and 7.4 Limitations of the Findings) . The most important thing is that the questions are easily understandable for the target group and relevant for the study in finding out about service satisfaction.

It is known that older people (over 45 years) provide higher satisfaction ratings with services and this has been also the finding with the Victorian and Western Australian surveys (Australian Government, 2000). The results of this study do support this as the older participants showed clearly high levels of service satisfaction. However, the sample was fairly small and the younger participants (under 45 years) also gave similarly high ratings of service satisfaction, although the only ratings which did not give highest rating possible, came from the younger participants.

Generally, it was quite difficult to hear or notice any clear criticism during the interviews. At the end participants did make some interesting comments though, which are all found in the results section, and which supported the high ratings of satisfaction and perhaps explained better why. Social care workers, for instance, received very positive feedback for their work. These comments praising the workers confirmed that good professionals in the service was one of the major reasons for their high levels of satisfaction with the service. In the comments, the professionals received praise for their confidentiality, friendliness and 'niceness'.

It also appears that everyone was most satisfied with the amount of help they have received. The ratings and comments from the participants, such as "Help has been given when needed", "Sufficient assistance" and "I have had sufficient guidance" most clearly confirm this. The sufficiency is, as might be expected, one of the significant factors concerning satisfaction with services. As mentioned earlier, Weller (1991) found in his study that inappropriateness and insufficient amount were the most common reasons for dissatisfaction with the (developmental disabilities) services. The high results suggest that the participants have been happy with both the amount (availability), as well as quality and content of the service.

The last section with the four welfare questions similarly suggests that the social care work for people with ID, at least the northern service unit in Helsinki, has been successful with its aim to support people with ID in their life-management, and in their independent acting and living. Certainly, the six individuals who participated all gave most positive feedback for the service and how it has helped them.

As showed in the Figure 3, age or gender did not seem to really affect the need for assistance in a sound way. The fact that gender did not have much impact on the need for assistance was expectable. Although, it is known that the prevalence of ID is higher in males in both adult and child populations (Ke & Liu, 2012), it is not clear whether there are significantly more male service users in the northern service unit. Nevertheless, it was probably useful to have both males and females among participants thus making the group more diverse.

Somewhat surprising was that the youngest participant, who was 30 years old when the interview was made, was the only one who choose to answer once a week to the question about the need for assistance. Still these results can be expectable because of the participants' different life situations, needs and abilities, where age is not necessarily a big factor or affecting at all.

The possibility to draw interpretation of the results and compare possible differences was made more difficult due to the somewhat limited data that was caused mainly by the lack of relevant data, which was probably linked to the content of the questionnaire or interview guide and also to the modest number of participants. However, as has been mentioned before, the minimum number of recommended participants (at least five) was fulfilled with six participants and although the service has approximately 40 service users, they were not all considered eligible for this study due to a lack of service experience. Therefore, it is possible to get some sort of overall understanding about the service satisfaction of the service users. Also, it was positive that the six participants represented equally both men and women, as well as different ages.

8.3 Developmental Thoughts

It was difficult to get concrete developmental wishes or ideas, but comments were nevertheless interesting, though only one participant gave a concrete wish saying there could be more outside home activities. Could be that it was always going to be a difficult question to answer all of a sudden, or it was not written or presented in a right way. The high satisfaction generally may have resulted less reasons and motivation for the service users to give any concrete developmental wishes or needs regarding the service.

When it comes to developing the service, it is difficult to make any clear suggestions based on the results. They merely confirmed that the service has been most useful for the service users. The comments and ratings from the service users made this very clear.

The willingness towards online meetings over a remote video connection was modest since only two of the six people said yes to readiness for meetings

online. Depending on the individuals, professionals can already use, for instance, WhatsApp and possibly other applications and social media sources to communicate with the service users from distance, apart from SMSs, phone calls and emails. All these options can certainly be most useful when communicating with the service users.

Even if meetings online (over a video connection) would become more common with those who are willing and who have the necessary skills and devices, it is unlikely that the need for face-to-face meetings and home visits is going to reduce significantly with people with ID. This is because of the nature of the social care work; instructing and assisting people with ID in their daily lives with daily tasks, such as, domestic work, nutrition, healthcare and service visits. Instructing and assisting with these tasks forms a big part of the social care work. Some of these tasks are and will be difficult or even impossible to instruct and assist from distance depending on the task or need and the individual.

9 CONCLUSIONS

The idea for this study was created together by the author and social care professionals in the northern service unit during autumn 2018. There was good collaboration throughout the process always when needed and also a clear need for the type of research, especially because really similar studies could not be found.

9.1 Summarizing Findings

Based on the results, it is fair to state that the service has been a very valuable help and form of support for the service users who participated in this study. The six participants (men and women of different ages) all showed very high levels of satisfaction when it comes to the service and how the assistance has helped them in their everyday life and well-being. All these participants were, as mentioned before, somewhat experienced, having been as service users for at least 3 to 5 years or more. Undoubtedly some changes in the service, for instance with personnel, have taken place during those years, but the service satisfaction was, nevertheless, very high. Changes in the service, therefore, have not had any clear negative impacts, although not any clear positive either, on the service satisfaction of these people.

Although dialogue was favoured with the interviews and the interviews could perhaps be described as semi-structured, the comments received from the participants were usually fairly short. Without guiding anyone with their answers, it was at times difficult to receive comments for some of the questions. Help was given with the meaning of the questions when it was necessary. It is possible that including more open-ended questions could have been a good decision. Collecting still more relevant data will be useful.

Necessary steps were taken so that the participants could respond to questions openly and honestly without fear of retribution, as was mentioned in the chapters 5 and 6. Clearly negative or critical comments concerning the service were not made during the interviews, although with couple of the answers there was perhaps very slight criticism which was neither clear nor direct. In any

case the results are very positive regarding the service satisfaction of the service users.

The results were largely positive in all aspects. Firstly, all of the participants claimed that assistance had been personally enough for them. On a general level all were very pleased and their answers and comments suggested that the service is indeed easily accessible, useful and necessary for them. It has had a positive impact on their lives. Based on the results, it clearly has had some positive impact on their well-being. Moreover, everyone gave highest agreeable rating for the parts of receiving help when needed, being heard by the workers, and the feeling that the service has been an important form of support for them personally. Each participant, therefore, appeared to value highly the support the service has provided for them. Therefore, special thanks must go to the workers in the City of Helsinki's social care work northern service unit for people with intellectual disabilities.

9.2 Professional Development

This study started from an idea that was created during internship at the City of Helsinki's disability services. Personally, I had some experience from work with people with disabilities and intellectual disabilities already before the internship, and also plenty of experience in personal life. However, I was not that familiar with the service system or legislation before the internship and this study. Besides wider knowledge about the services and specific legislation, as well as more theoretical knowledge, I have further developed several important skills. These include at least enhanced interviewing, professional communication, and organizational skills. I also feel that my perseverance has increased and my ability to work under pressure has somewhat improved during all this time.

I have learned plenty of information and most importantly for the purposes of this study I have listened and learned from the people with intellectual disabilities. With this paper I have done my best in trying to transmit all this information and in communicating the opinions and thoughts of the participants clearly and truthfully.

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APPENDIX 1. Questionnaire (in Finnish)**Palvelukysely asiakkaiden tyytyväisyydestä****Helsingin kaupungin kehitysvammaisten sosiaaliohjaus (2019)**

Jokaisen kysymyksen kohdalla valitaan se, mikä vastaa parhaiten vastaajan mielipidettä. Joissakin kohdissa voi halutessa tai pyydettyäessä myös antaa vapaasti palautetta.

1. Vastaajan sukupuoli: Mies Nainen Muu

2. Vastaajan ikä: _____ vuotta

3. Kuinka kauan olet ollut sosiaaliohjauksen asiakkaana?
a) Noin vuoden b) 1 – 3 vuotta c) 3 – 5 vuotta d) 5 tai enemmän

4. Kuinka usein koet tarvitsevasi ohjausta?
a) Vähintään kerran viikossa
b) Kerran kahden viikon aikana
c) Kerran kuukaudessa
d) Harvemmin

5. Oletko kokenut saaneesi ohjausta riittävän usein?
 Kyllä Ei

Perustelut: _____

6. Oletko yleisellä tasolla tyytyväinen saamaasi ohjaukseen?

Kyllä Ei

Perustelut: _____

7. Minkälaisia toiveita sinulla olisi ohjaukselle tulevaisuutta varten?

8. Olisitko valmis vastaanottamaan ohjausta jossain määrin myös videoyhteyden kautta etänä?

Kyllä Ei

9. Minkä arvosanan haluaisit antaa ohjaukselle? (Arvosanat 1 – 5 siten, että 1 tarkoittaa huonointa mahdollista arvosanaa ja 5 parasta mahdollista arvosanaa)

• _____

10. ⊕ Palvelun vaikutus hyvinvointiin

- Arvioidaan seuraavien väittämien toteutumista käyttäen arvosanoja 1 – 5 siten, että
- 1 = täysin eri mieltä
- 2 = jokseenkin eri mieltä
- 3 = en osaa sanoa
- 4 = jokseenkin samaa mieltä
- 5 = täysin samaa mieltä

Olen saanut ohjauksesta apua tarvittaessa

1 2 3 4 5

Ohjauksella on ollut positiivinen vaikutus hyvinvointiini

1 2 3 4 5

Koen, että ohjaajat kuuntelevat minua

1 2 3 4 5

Koen, että palvelu on ollut minulle tärkeä tuki

1 2 3 4 5

APPENDIX 2. Questionnaire (in English)

Survey about the satisfaction of service users

The City Of Helsinki's social care work for people with intellectual disabilities (2019)

For each question, the one that matches best the respondent's opinion is selected. At some points there is a possibility to freely give feedback if wanted or when it is requested.

11. Gender of the participant: Male Female Other

12. Age of the participant: _____ years

13. How long have you been a service user in social care work?

a) About a year b) 1 – 3 years c) 3 – 5 years d) 5 or more

14. How often do you feel you need assistance?

e) At least once a week

f) Every fortnight

g) Once a month

h) Less often

15. Have you experienced assistance often enough?

Yes No

Why: _____

16. Are you generally satisfied with the assistance you have received?

Yes No

Why: _____

17. What wishes would you have for social care work in the future?

18. Would you be ready to receive some assistance over a remote video connection as well?

Yes No

19. What grade would you like to give to service? (Grades 1-5, with 1 representing the lowest possible grade and 5 being the best possible grade)

20. ⊕ Impact of service on well-being

- Evaluating the following statements using grades 1 – 5 so that
- 1 = completely disagree
- 2 = somewhat disagree
- 3 = not sure
- 4 = somewhat agree
- 5 = completely agree

I have received help when needed

1 2 3 4 5

Guidance has had a positive impact on my well-being

1 2 3 4 5

I feel the workers are listening to me

1 2 3 4 5

I feel the service has been an important support for me

1 2 3 4 5