Decision-making, Participation, Self-Determination and Empowerment of People with Intellectual Disabilities in Community Care

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Laurea University of Applied Sciences   **Abstract**

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This thesis was conducted in collaboration with an organization for people with intellectual disabilities in Finland. This research aims are to promote of awareness on the key issues: decision-making, self-determination and participation in the work with people with special needs. On the one hand, it focuses on informing the workers about these issues and getting feedback on the current situation. The service users are also being asked about their opinion on the current situation and if they are involved enough. Another focus is to determine possible challenges and difficulties which can hinder empowerment within the organisation. Furthermore, this thesis will discuss possible solutions to these occurring problems and find ways to improve the services.

The background of the study includes a section on the current legislation, an introduction of disability services in Finland as well as historical context. The theory behind this study is based on four main topics. The main topics are decision-making, self-determination and participation which are all part of the big concept of empowerment. Besides, the theory chapter will include possible obstacles of these concepts and explore the meaning of critical practice.

This research uses two methods for the collection data, focus groups and semi-structured interviews. The two focus groups took place with a selected group of workers from the working life partner who discussed decision-making and self-determination in the first focus group and participation in the second. The second method used is personal interviews with service users to get their viewpoint on issues such as work, leisure, spending money, trips, contact with people outside the organisation, being part of decisions and possible areas for improvement.

The main results are that even though the organisation is seen as a good place to work in which the service user's voices are heard, there are still areas for improvement. Key areas for improvement include meetings, communication, planning and motivation. The service users show an overall satisfaction and see no need for improvement.

Keywords: decision-making, self-determination, participation, empowerment, intellectual disability

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1   Introduction

"Aina mun pitää" is a song from Pertti Kurikan Nimipäivä, which translates to "I always have to". The band members are having special needs and are famous in Finland, even representing the country in the 2015 Eurovision Song Contest. In the song, the band describes tasks, they need to do during the day such as always having to take medicine, shower, go the doctor, doing the dishes, going to bed, have a rest, get up again and that they are not allowed to eat candy, drink soda, see their friends or not allowed to use the television nor computer.

This all sounds like people with special needs are facing many restrictions in their lives and being told what to do. Theunissen (2013) says that persons with intellectual disabilities are often perceived as not being capable of make decisions on their own due to their cognitive abilities. The workers often don't know about teaching meaningful choice-making is another problem (Brown 1993).

"toward autonomy and self-determination" was the topic of lasts year world autism awareness day 2017 (UN Web TV 2017). So, is it still a long way to go before until people with special needs are seen as equal and given the chance of making decisions on their own?

On the other hand, more legislation is introduced in favour of people with special needs. In 2008, UN convention on the Rights for Persons with Disabilities was established and many countries introduced law reforms in effort to recognize "that everyone –with or without disabilities – is equal before the law" (OHCHR 2018). Finland is describing their own approach as "nothing about us without us", meaning that it recognizes the importance of participation of people with special needs in processes of development.

Even though the emphasis lies more and more on the empowerment of people with special needs, how well is it implemented in real life?

This thesis is going to discuss whether people with intellectual disabilities are given the chance to make choices and participating in issues concerning their own lives, how self-determined they are and whether or not being empowered. This will be achieved by reflecting on the current situation of people with special needs in Finland followed by a dive into the topics of choice, self-determination, participation and empowerment. After the theoretical part, methods used in this research will be introduced. The methods hereby used are personal interviews with the service users as well as focus group sessions with workers. In the end, there will be a discussion which links the theory with the results of the interviews and focus groups.

2   Background

This part of the thesis is going to describe the background, meaning the starting point of this thesis and my personal learning goal. The name of the organization I have worked with will be kept anonymous. Therefore it will be referred to as the working life partner (WLP) in the following.

I have worked in the WLP organization for over two years, prior to my studies. Since I have gained quite some experience there, it was not far-fetched to write my thesis in cooperation with them. The clients are familiar with me and most of the workers as well. Few years ago, a women came to visit the organization and held a presentation about the right of self-determination. This was the first time I came in contact with this topic.

During my working time in the WLP organisation, I started to reflect on my working style. I realized that at times, especially when being in a hurry, it was easier to decide in favor of the service users and not always necessarily ask them. Sometimes there were just small decisions such as what clothes to wear in the morning. Other times there are decisions that are not only concern themselves but the whole village. For example, when it came to decide what program to have during the festivals. It felt like the service users could be more involved and part of the process. Other workers acknowledged this issue and said it is important to talk about, also to remind. This is how the idea of the thesis was born.

Therefore, the purpose of the thesis is to remind the workers to let the clients be part of the decision-making, may the decision seem small or concern more people. The idea is to reflect on how decision-making, self-determination and participation can be put into practice. It is important to me that the workers can discuss, reflect and share their experiences. So, in the end it is not just me holding a presentation to them.

One of my personal learning goals is to get more insight into the discussion. The thesis will be helpful in my later working life because I hope to learn how to discuss important issues with colleagues. I would like to keep on working with people with disabilities and hopefully reflect on how I work.

3   People with intellectual disability in Finland

This part is going to focus on the situation of people with intellectual disabilities in Finland and will start with a definition of the term intellectual disability. Before describing the legislation and services people with special needs are entitled to in Finland, it is interesting to introduce some facts about people with special needs in Finland and find out about the history of the disability movement in order to give some context to the research.

In the beginning, it is necessary to define the term intellectual disability because the service users in the WLP organization have intellectual and developmental disabilities. According to WHO (2010), a person with intellectual disability is someone who has a reduced ability to comprehend new or complex information. The person 's intelligence is impaired leading to difficulties in acquiring new skills and using them (WHO 2010). Furthermore, intellectual disability is linked with an impaired social functioning visible in regards of the ability to cope independently (WHO 2010). The upbringing, inclusion in society and other environmental factors can have a big influence on the abilities and health of children with intellectual disabilities (WHO 2010).

Around 0.8% of the Finnish population has an intellectual disability (FAIDD 2015). It is estimated that there are around 25.000 people with intellectual disability in the working age but only around 500 earn wages, more than 2000 are employed in communities (FAIDD 2015). The Finnish Association on Intellectual and Developmental Disabilities (2015) sees a need in employing more work coaches in the municipalities to help people with intellectual disabilities to find a fitting workplace.

The most recent report by THL in 2017 show that 920 people with intellectual disabilities are living in institutions which is 16% less than the year before. The number of service users in supported living (tuettu asuminen) increased by 7% (THL 2017). In Finland around 1.954 with intellectual disabilities live in housing with part-time assistance (ohjattu asuminen), and around 1.684 in supported housing. Most people with intellectual disabilities live in sheltered housing (palveluasuminen) (THL 2017).

3.1   Historical context

In order to give some context, it is interesting to have a short look on the history of people with special needs. For a long time, people with special needs were excluded from the society. A big step forward was the disability movement in 1960s and 1970s, by focusing on deinstitutionalization (Fleischer, 2011). Wehmeyer (1998) said that self-determination was the first time in the focus, next to independent living and normalization of disabilities. Before, people with serious physical impairments were excluded because of the ill-adapted environment, this situation sparked an activism (Fleischer, 2011). Also, more and more trials arose, in which persons with special needs were selected to leave the institution and become part of the mainstream by e.g. attending college. The institutions themselves changed as well, for example in the case of "Goldwaters", introducing council of residents, the personnel was not wearing a uniform, there was rock music and romance (Fleischer, 2011). Another new attitude arose in which the focus was on the strength of an individual and how it can be used, not anymore on its failure or lack of abilities (Theunissen 2013).

The next phase after de-institutionalization according to Schwalb et al (2009) was described as integration. It became more and more visible that people with disabilities have deficits but those are reducible and through adequate support it is possible to live under "normal living conditions" (Schwalb 2009, 12). The current phase is called inclusion and is defined by characteristics such as empowerment and autonomy (Schwalb 2009). Before there was a prioritization of the organization's interests and the workers often determined what would be best for the service users (Schwalb 2009). Nowadays power is divided differently, the service users themselves are seen as the experts who decide what is good, purposeful and helpful when it comes to making decisions (Schwalb 2009). The right for autonomy is being emphasized as well as the access to the primary job market and a living in community integrated housing (Schwalb 2009). According to the Ministry of Foreign Affairs (UM n.d.) the finnish disability movement had a strong influence on the policy.

It is also to be mentioned that Finland is also supporting people with special needs internationally. The main aim of the development policy in Finland is "reducing poverty and inequality and the promotion of sustainable development" (UM n.d., 9). Activists of the Finnish disability movement established two important organizations for the advancement of rights of people with special needs around the world. The first one was the Disability Partnership Finland (formerly FIDIDA) in 1989, created by eight different organization, it is therefore considered to be an umbrella organization. Its focus is the co-operation with NGOs, companies, public offices and education services by working together in the name of inclusion. The second important organization was funded in 1998 and is called Abilis Foundation. This organization emphasizes the importance of human rights and is sharing their knowledge about special needs and development in developing countries (UM, 2018). "Finland is also active in political dialogue to advance the attention and urgency to the disability rights agenda globally" (UM, 2018, 9)

3.2   Legislation for people with special needs

The following chapter is about the legislation and rights concerning people with special needs. The chapter will start with the European Disability Strategy which is related to the UN convention that is explained subsequently. The last part focus on the current legislation in Finland including the newest change in the national legislation.

Back in 2010 the European commission introduced their European Disability Strategy 2010-2020. For the purpose on the thesis it will be only focusing on the participation of people with special needs in this strategy. The commission points out issues people with special needs are still facing when it comes to the right of an equal participation in society (European Commission, 2010). "Those rights include the right to free movement, to choose where and how to live, and to have full access to cultural, recreational, and sports activities" (European Commission, 2010,5). In order to achieve this goal the European Commission (2010) planned to use funds to

support community-based care and develop a better accessibility of leisure activities. Furthermore, the European Commission (2010) implements the strategy by raising awareness. For this purpose, so-called awareness campaigns will be supported which aim to make sure that the people with special needs are aware of their rights (European Commission, 2010).

Finland signed the convention on the rights of persons with disabilities which entered force on the 10.06.2016, according to a press release by the Ministry of Foreign Affairs (Finnish Government 2016). It was seen as an important step towards strengthening their rights, furthermore the minister points out the significance of engaging people with special needs in issues which are of concern for them and hearing what they have to say (Finnish Government 2016). The whole convention contains 50 articles and it would not be possible to mention them all. In the following will be an introduction of four articles which are of concern for this thesis.

In article 3 of the convention are eight general principles listed (UN 2006). For this research the first six principles are especially important and listed in the following:

> *"Article 3- General Principles. 1. Respect for the inherent dignity, individual autonomy including the freedom to make one's own choices and independence of persons; 2. Non-discrimination; 3. Full and effective participation and inclusion in society; 4. Respect for difference and acceptance of persons with disabilities as part of human diversity and humanity; 5. Equality of opportunity; 6. Accessibility;"(UN 2006)*

The convention also acknowledged the importance of awareness-raising in article 8. It states that the awareness concerning rights and dignity of people with special needs throughout society (UN, article 8, 1A). It also aims "to promote the awareness of the capabilities and contributions of persons with disabilities" (UN 2006 article 8, 1.C) The ninth article is focusing on accessibility, including the access to appropriate support to ensure access to information (UN 2006, article 9, 2f). The last article, which will be referred to, is about the right for participation in recreational and leisure activities (UN 2006, article 30). The 30th articles ensures the possibility of taking equally part in cultural offers. The second section of the article mentions the necessity of giving people with special needs the "opportunity to develop and utilize their creative, artistic and intellectual potential, not only for their own benefit, but also for the enrichment of society." (UN 2006, article 30, 2).

In the following will be an introduction into the Finnish legislation concerning people with special needs. It will again focus on those laws that fit the purpose of the research. According to the ministry for foreign affairs in Finland, already back in the 1980s, Finland promoted changes in order to "guarantuee equal access to public services and equal human rights for persons with disabilities" (UM n.d.). The main legislation for people with intellectual disabilities in Finland can be found in the special care act (Finland 1977). It is visible that this law was

changed in 2016 in accordance with the UN convention mentioned above. There are some minor changes but also new parts were added, such as the chapter 3 which is aiming to strengthen the right of self-determination and defining the use of restricting measurements in special care (Finland 1977). According to § 42 (Finland 1977), the right for self-determination is strengthened by treating the person with intellectual disability in a way that the dignity is not violated, and that his/her beliefs and privacy are respected (Finland 1977). According to the law (Finland 1977) it is important that the person 's wishes, opinions, interests and needs are taken into account, when implementing special care. A person in special care must be given the opportunity to participate and influence in his/her own affairs (Finland 1977). The well-being, health and safety of a person with special care must be maintained and promoted (Finland 1977). Besides, the new chapter describes what the service- and care plan that is made by the service provide which has to contain. The third chapter includes information on (1) measures to support and promote the independent performance of a person and to strengthen self-determination; (2) reasonable adjustments to ensure full participation and involvement of the person; (3) communication methods used by a person; (4) a person's care is primarily carried out without restriction measures; and that (5) restriction measures are the last resort and need to be evaluated (Finland 1977). Furthermore there is chapter aiming to ensure that the workers are familiar with the support and promotion of independent performance, self-determination of the service users and are trained in preventing situation which may require restriction measures (Finland 1977).

In 1987, the Disability Services Act was set into force in Finland, obligating the municipalities to be responsible for the services of people with special needs (Finland 1987). According to §1 (380/1987), the purpose of the law is to promote the person with special needs and give the conditions so they can be an equal member of society and prevent obstacles and disadvantages (Finland 1987).

The non-discrimination act (Finland 2014) has the purpose of "promoting equality and prevent discrimination as well as to enhance the protection provided by law to those who have been discriminated against" (Finland 2014, section 1).

The latest reform in the Finnish legislation concerning people with intellectual disabilities according to the Ministry of Social Affair and Health (STM b n.d.) is the combination of the Disability Services Act and the Special Care Act for People with Intellectual Disabilities (STM b n.d.).

> *"The Government submitted a proposal on the matter to Parliament on 27 September 2018. The act is due to come into force on 1 January 2021. The new act on services for persons with disabilities would safeguard all persons with*

disabilities access to services in accordance with their individual needs. Diagnosis would not determine eligibility for services." (STM b n.d.)

As a result of this new law, more people will be able to make use of short-term care as well as the access of coaching and support (STM b n.d.). Already back in 2014, there have been complaints about the issue of having the two laws separated. (Finnish Government 2014).

3.3   Services for people with special needs in Finland
"There have to be services when they are required, in other words when a person cannot manage in every-day life without assistance. Different needs naturally require different forms of assistance. For some it is support in doing certain things, for others it is about communicating or understanding,"

says Huhta in a news article from 2014, published by the Ministry of Social Affairs and Health (Finnish Government 2014).

In Finland, people with special needs have the right to make use of the necessary services and support (STM a 2018). The use of services is free of charge (STM b 2018). The services are provided by the responsible municipality (STM a 2018).

Each person with special need will get a personal service plan which describes their support and services required (STM a, 2018). Many of the services have the aim to ensure accessibility such as assistive devices, interpretation services and transportation services (STM a, 2018). People with intellectual disability have special care services which include "housing services, work and day activities, family care or institutional care" (STM a, 2018).

KELA is providing financial support so that people with special needs can take fully part in life and study (STM a, 2018). KELA support includes allowances, rehabilitation services, interpreter service, disability card and house benefits (KELA n.d.).

In conclusion of this chapter, it can be said that Finland is in the process of making changes for people with intellectual disabilities. The emphasis is more and more on the participation of people with intellectual disabilities when it comes to their own life. The inclusion is guaranteed by legislation and measures such as services ensure a life as independent as possible. So, after the overall situation in Finland is being described, it is interesting to scale it down to a specific organization and use it as an example. Therefore, the following will introduce the working life partner (WLP) with whom the research was conducted.

4   Introduction of the working life partner

Like mentioned before, it was decided to keep the name of the organization anonymous therefore it will only be referred to as the working life partner (WLP). The WLP organization is

a private organization which offers a place for people with intellectual disability to live and work. The three main aims of the WLP are to ensure the service user's well-being, support the personal life path and developing a balanced community life. The conversational exchange and an adequate support are rated as important.

The community is divided into seven houses which are mainly named after characters from the Kalevala. Currently it has around 40 service users with an age range from 24 to 80 years. Within the WLP organization, the service users are commonly referred to as villagers (kyläläiset). All residents have a certain need for support and are not able to live independently. Each service user lives in one of the seven houses. Everybody has their own private space. There is a common area where people can meet and join the activities in their free-time. Each house has a "house parent" who is responsible for all matters from the house. The houseparent is the superior of the workers in the house and takes care of the work shift plans, development discussions, the house budget and the maintenance of the house.

The service users go to work during the week. From Monday until Thursday the work starts at 8.30 am and ends at 4.30 pm. On Fridays, the work ends earlier at 4 pm. In between is a launch break in which the service users go back to their own houses. Each workplace is individually chosen according to the client 's abilities, skills and interests. The organization emphasis the importance of a fitting workplace. Possible workshops for the service users to participate are the garden (puutarha), herb garden (yrttipaja), forest group (puuryhmä), maintenance group (huolto), weavery (kutomo), cheesery (juustola), stables (naavetta) and the house workshop (talopaja). Persons working in the house workhop are not working in the house they live in.

In the evening and on weekends the clients have free-time. In this time it is possible to participate in free-time activities that are offered, such as swimming group, art therapy, eurhythmy, puppet making, music lessons and singing evening. Every Tuesday and Friday evening is Sauna.

There are currently 43 workers, including therapists and part-time workers. The workers have diverse professional and cultural backgrounds. The typical professions are nurses, practical nurses and social workers. Some of the workers come from different countries all around the world. Furthermore, the WLP organization takes each year a group of volunteers which complete their gap year.

There is a leading group as the highest instance to make final decisions concerning the WLP organization. It consists currently of four people who come from different areas from the organization and therefore bring diverse perspectives. The tasks of the leading group include ensuring the implementation of the main principles and values. They are responsible of several areas such as taking care of the houses, workshops, therapies and health care. Also the

safeguarding of resources and the operating conditions. This includes human resources such as training, professional development and developmental discussions with workers. Furthermore, the leading group is working in co-operation with the authorities. Other task are financial matters and the overall budget. The next lower instance are the house parents which are meeting weekly as well, to discuss urgent matter e.g. if help is needed in a house. Furthermore, in the house parent meetings issues such as seasonal celebrations and happenings, different journeys, trips, transportation are being planned. Three times a month is a worker meeting (henkilökunnan kokous). In this meeting workers from all houses meet to plan the coming weeks. It is important to have this exchange of information between the workers and communication in general. The participants of the meeting discuss current matters but the meeting also aims to further educate and plan the future together. Once a month, instead of a workers meeting there will be a calendar meeting in which the next month 's program will be organized. Every Wednesday is the village meeting (kyläkokous). Everybody is invited to join and share important matters with the community. Throughout the whole organization structure it is visible that matter are not only decided by one person but go through different groups.

The values and principles of the organization are based on the Rudolf Steiner philosophy which is called anthroposophy. Rudolf Steiner once said:" A healthy social life is found only, when in the mirror of each soul the whole community finds its reflection, and when in the whole community the virtue of each one is living." (Barber, n.d.). Everybody 's contribution within the community is appreciated and from importance (Barber, n.d.). Besides, the WLP organization has a list of principles which will be translated from the house map (unpublished sources) in the following. According to the house map the values of Sylvia Koti RY are based on an anthroposophical viewpoint. The first principles is stated as followed: the body, soul and spiritual growing is the base of each individual 's talents and one's own uniqueness. The next principle is the sense of community. Sharing the daily lives and celebrations are signs of a community. Everybody, regardless of age, gender, or status are working for a common goal and share their efforts with the community. Members of the community care about each other and grow spiritually. In general, the Christian belief is visible in daily life and holidays. It has an uplifting effect since celebrations are part of the human integrity and nurture the whole community. The WLP organization is a living and work community, meaning it is home to everybody living there. Everybody has their own tasks and freedom. Caretaker and people in the need of care are treated equally. Schooling is offered for the personal growth. Rehabilitation is an essential part of the organization. Next to the therapies, the service users learn to put their skills into practice in the daily life. Peer support is important because it gives a feeling of understanding and experiencing similar grow can make stronger. The last principle is collegiality, meaning that activities, planning, decisions are worked on by different groups, like mentioned above.

At the moment, the WLP organization is in the process of creating a support and care plan for each service user. The aim is to measure their need for support. The information is saved using the Hilkka program on the computer and is accessible in all houses. The service users are part of creating the plan together with a multi-professional team. It is important to take time, in order to discuss everything thoroughly and also to listen to the service user's opinion. The support plan includes information of the service user in different categories which aim to show in what situation the service user might need some help or support. It contains a variety of general information about their hygiene routines, what public services they use and their interaction skills. Furthermore, it has detailed information about the service user 's self-directing skills such as their ability to make choices, following schedules, how they ask for help and how they handle problem situations. The support plan also give information on their mental health, health risks like smoking, their social abilities such as the reaction towards others and the use of money. There is a segment which is rating their willingness and ability of participating and how regular they are part in daily activities. It also has a section about their knowledge and abilities in which can be for example describe if they capable of reading and writing, understand time and more skills and talents. It is also measuring the service user's ability to take care of their environment like e.g. cleaning their room. Like already mentioned it is still in the process, some houses have not yet filled the Hilkka program, meaning that there is no information available about the service user in some houses.

5 Theoretical framework

The theoretical framework is structure from smallest to biggest concept. It is going to start with an explanation of decision-making, in what areas people with intellectual needs can make decisions and how the choice diversity model is used. The second part of the first theory chapter will focus on the meaning of self-determination, the functional model and what effects it is proven to have on people with intellectual disabilities. The first theory chapter will be concluded by ways of measuring decision-making and self- determination that were used in research.

The second chapter of the theoretical framework is about participation an empowerment. It is going to explain the terms participation and empowerment and how those two concepts can be facilitated in organizations. Furthermore, it will point out the benefits and explain what empowerment evaluation is.

The biggest concept is empowerment like Theunissen (2013) said, decision-making, self-determination and participation are part of empowerment. Therefore, all concepts are related with each other. Decision-making is part of self-determination in that it is the act of choosing matters concerning the person 's life. Participation and empowerment are strongly connected because without participation there will be no empowerment and a person needs to be empowered in order to participate (Adams 2008). Wehmeyer (2013) states that

> *"choice opportunity and self-determination have become part of the demands by people with disabilities in the self-advocacy movement and these ideas have been incorporated into the disability right and empowerment movement. Clearly, efforts to promote community inclusion and quality of life need to include efforts to promote and support self-determination".*

After introducing all the concepts, there will be a chapter about the obstacles for implementing decision-making, self-determination, participation and empowerment.

The fourth theory chapter is going to describe the meaning of critical practice. Critical practice is important to describe because it explains what could be changed on the worker 's side and give some ideas how to develop a reflective working style.

5.1   Decision-making and Self-Determination

The liberal concept of autonomy defines that the freedom of choice is fully, well considered, independently and individually made by the person who make the decision (Hassan 2017). Fyson and Cromby (2013) point out that if a person with intellectual disability is making a meaningful decision, it is necessary that they know the range of options, its consequences and that the choice can be changed or even reversed in future. Many researches such as the one from Kishi, have shown that people with disabilities are making far less decisions during the day than their able-bodied counterparts (Brown 1993).

For service user who have difficulties in making choices, there are two ways of possible involvement, the first one being defined as substituted decision-making the other possibility is decision making (Devi et al 2011). Substituted decision-making means that a person is chosen to make a choice on behalf of another who is not capable of doing so (Devi et all 2011). According to Devi et al (2011) the person who will make the substituted decision should know the service user 's wishes, values and beliefs, often relatives are preferred over social workers or nurses. Another important aspect is that the proxy is not making the decision how they would personally like to but how the individual would act in the situation, so the service user 's best interest (Devi et al 2011). The proxy is usually decided in court (Devi et al 2011).

Devi et al (2011) defines supported decision-making as an alternative which respects the service user's autonomy and ability to be part in the process of the decision-making concerning their own lives, sometimes with help if needed. In a case of decision, the service user get support by a trusted individual to make decisions which are legally binding also for third parties such as financial institutions or service providers (Devi et al 2011). The support person will ensure that the service user understands the information given and if needed communicates in favor of them, by formulating their preferences (Devi et al 2011). The support can be different forms

such as reading to them, interpretation services or help the person to focus and give attentions to the decision which is being made (Devi et al 2011).

Even though no decision-making is perfect and can be influenced, supported decision making seem like the better option because it is closer to the service user 's preferences, wished and values (Devi et al 2011). Devi et al (2011) argues that through supported- decision making, the service users can use their rights for autonomy and self-determination, furthermore their decisions are less likely to be interfered by others. Moreover, in supported decision-making, the service user has the possibility of self-progression because they are being informed and learn about the issue (Devi et al 2011). Devi et al (2011) points out that the possibility of somebody taking advantage, abuse or discriminate is much lower than in substitutive decision-making.

In Finland, since the ratification of the UN convention of right for people with disabilities, supported decision-making is used regardless of the severity of the impairment (Vikkula, 2016). The decision is founded in the person 's will a preference, using different ways of communicating to overcome barriers (Vikkula 2016). Furthermore, the person with disability has the right to terminate or change the relationship to the proxy whenever they want (Vikkula 2016). Vikkula (2016) says that the state is required to ensure the support in decision-making, according to the signed convention.

There are many areas and situations in a service user's life which acquire to make a decision. The decision can range from basic ones such as choosing a drink for breakfast to more complex issues like choosing a workplace (Brown et al 1993). IN the following are three examples. One area of daily life decision-making for people with intellectual disabilities is choosing their free-time activities. Hassan (2017) conducted a research on how people with intellectual disabilities are engaging in recreational free-time activities. She points out that it is important to find a "meaningful, vocational, social, leisure or learning activity" fitting to their interests (Hassan 2017). In 2002, Reynolds made a survey in which she researched the most accessible creative leisure for people with special needs. As a result, painting was seen as the most accessible creative activity and drama the least (Reynolds 2002). Listening to music is a leisure activity at home in which nearly all participants of the survey were able to take part (Reynolds 2002). Hassan (2017) confirms this assumption by saying that in supported living scheme, music activities such as listening to music were enjoyed by all residents sometimes even shared with others. In practice, it is important to also consider people with lack of verbal communication or the lack of ability in using devices when playing music (Hassan 2017). Some service user might need help. Choice about the food consumption seems like an easy daily life decision at first sight (Hollomotz 2014). In a study, participants were asked about their food-related choices, 12 participants answered that they are able to have control what food they consume (Hollomotz 2014). Nevertheless, five persons in the interview reported that they are following

some diet because of health reason. Hollomotz (2014) noted that if the particpants were given the chance, they would eat something unhealthy (Hollomotz 2014). Consequently, one could assume that they are not voluntarily on that diet, therefore it might not be their choice (Hollomotz 2014). Hollomotz (2014) is referring to Brown and Brown who argue that food has a big impact on the person 's overall wellbeing and health, thus choices can turn into an ethical dilemma when it does not seem like their best interest to e.g. consume something unhealthy. Sometimes decisions such as the diet might even come from the family so the workers are only enforcing it (Hollomotz 2014). Another issue when it comes to the topic of food is the food preparation. One third of the participants told that they are not part of the food process at all because those preparing it, will ultimately decide what will be eaten (Hollomotz 2014). It is also possible for people with intellectual needs to be part of decision making at their workplace (Agran 2010). Decisions concerning where the person wants to work, what tasks need to be done, in what order the tasks are done, who is supporting and with whom to work (Agran 2010). The participants of the study said that it is important to make choices and that the staff recognized the importance by providing opportunity to make choices (Agran 2010). The study suggested that people which are more capable were often given more decision opportunities than those with more severe impairments (Agran 2010). More complex decisions such as choosing where to live can be decided with support (supported decision-making) if needed.

The choice diversity model was created to help the decision-making of people with severe disabilities and is better to use for more basic and routine decisions (Brown et al 1993). The choice diversity model is divided into seven categories related to decision-making in a daily routine (Brown et al 1993). The first category is the decision-making *within an activity*, meaning the ability to choose material (Brown et al 1993). For example, making a choice between drinking orange juice or apple juice for breakfast. The next category is called *between* activities (Brown et al 1993). So, it gives the person with severe disabilities the possibility to decide which activity to take part in (Brown et al 1993). It is also possible to *refuse* participation of an activity (Brown et al 1993). The next three categories give the opportunity to choose *where* the activity takes place, *who* is participating and at what time (*when*) it will start (Brown et al 1993). The final category according to Brown et al (1993) is defined as the possibility to *terminate*, meaning to decide when the activity should end. This model is a good to implement in the daily work with people with intellectual disabilities, not only the severely disabled. It is necessary to be aware of expanding the diversity of choices throughout the day (Brown 1994). If the diversity of decision-making possibilities is increasing, so will the self-determination, "making choices available within an activity is only a start" (Brown 1994, 324). Also Wehmeyer (1998) agrees by saying that "choice-making opportunity is a strong predictor of self-determination", which is a good transition to the next topic.

5.1.1   Self-Determination

According to Adams (2008, 352) self-determination means choosing for oneself. This includes the ability to choose what one wants to do, be or value (Adams 2008). Theunissen (2013) describes self-determination as being able to know, define and at the same time exercise power over oneself. Self-determination can be seen as a life-long developmental process, according to Polloway (Theunissen 2013). Self-determination is based on the "philosophical doctrine of determinism which suggests that all action (including human behavior) is in some way "caused.""(Shagron et al 2015). Wehmeyer (2013) defines self-determination as psychological construct which explains human agentic behavior. Agentic behavior, according to Little et al, means that a person is able to learn from failures, recognizes possibilities for action, is ambitious and has an overall sense of well-being (Wehmeyer 2013). The behavior is viewed as self-regulated and goal driven (Wehmeyer 2013). The person is able to make decisions with external interference or influence (Shagron et al 2015).

The process has specific characteristics such as a free and autonomous decisions, self-actualization through the use of one's strengths. Self-regulation is another characteristic (Theunissen 2013). Wehmeyer (1998) defines self-regulation as the ability of knowing which skills to use in a situation by examining the task and being capable of formulating, implementing and evaluating an action plan. The self-determination process also includes self-monitoring and self-evaluation (Theunissen 2013). It is linked with the capacity to set goals and act according to those, showing initiative in a self-realizing manner (Theunissen 2013). Self-realization means that a person knows oneself reasonably, including their strengths and limits (Wehmeyer 1998). A person is capable of using their skills helpful manner (Wehmeyer 1998). Theunissen (2013) adds that self-determination relates to interaction with others. Overall one can say that,

> *"Self- determined people are, in essence, actors in their own lives, rather than being acted upon." (Wehmeyer 2013, 399)*

In 2015 Shogren et al decided that there is need for change in the conceptualization of self-determination. Especially because of the rising of positive psychology, the focus on action-oriented behavior and volitional action. The model was created with a focus on special education (Shogren et al 2015).One reason for this change is that a "complex construct such as self-determination is not a static process" (Shogren et al 2015). It is a construct that is constantly changing because of new research and changing comprehension of human behavior (Shogren et al 2015).

The new model is partly based on self-determination theory. More exactly on the mini theory about "Basic Psychological Needs Theory: Satisfaction and Frustration of Autonomy, Competence, and Relatedness in Relation to Psychological Wellness and Full Functioning" (Ryan & Deci 2017). This theory "views all people as affected by the satisfaction of the basic

psychological needs for competence, relatedness, and autonomy" (Ryan & Deci 2017, 239). The satisfaction of these needs will lead to enhanced wellness (Ryan & Deci 2017).

In the following, will be an explanation of the new model using Figure 1 as a visual aid.
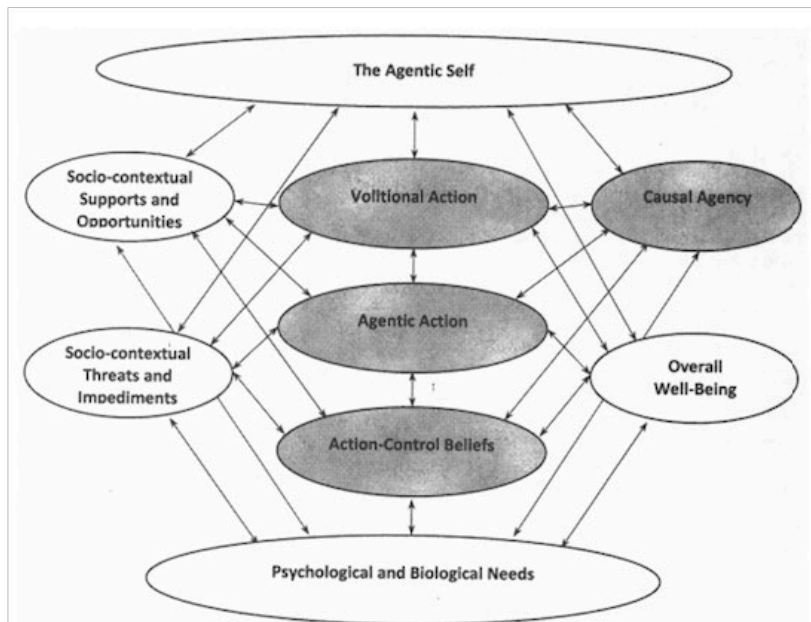

Figure 1: The Multiple Layers of Human Agency (Shogren et al 2015)

First all of, the three main layers between the agentic self and the psychological and biological needs will be explained. Starting with *volitional action* which means that a choice is made in a conscious and intentional way founded in the personal preferences (Shogren et al 2015). The choice is made without direct external influence and is self-initiated (Shogren et al 2015). Shogren et al (2015) adds that it involves causal capabilities, meaning the capacity to cause something occur in their life. The next term to be explained is *agentic action*. Agent is the person who act subsequently agency is a "self-directed-action in the service of a goal" such as creating change. (Shogren et al 2015, 259). The process of identifying pathways that lead to the freely chosen goal is purposive and proactive (Shogren et al 2015). There are three *action-control beliefs* (Shogren et al 2015). The first one is the connection between the self and the goal ("Control expectancy; When I want to ____, I can") (Shogren et al 2015, 259). The second belief is between the self and the means to achieve such goal ("capabilities belief; I have the capacities to do ___) (Shogren et al 2015, 259). The third belief is the utility and usefulness of achieving the goal ("Causality belief; I belief my effort will lead to goal achievement") (Shogren et al 2015, 259)

"The basic psychological needs […] are either supported or challenged by social context" (Shogren et al 2015, 257). The biological and psychological needs are on the bottom of the Figure 1, symbolizing them as the foundation upon which everything is built up (Shogren et al 2015). It is necessary first to achieve satisfaction in those needs before the progress to other

layers can start (Shogren et al 2015). According to Shogren et al 2015, social environments can harm or support the overall well-being.

The three layers (Figure 1 shaded boxes in the middle) guide to causal-agency (Figure 1, on the rights side on top) which is the result of the agentic self. In the three layers of human agency the social context can have the biggest influence and support or challenge the outcome of self-agency.

5.1.2 Effects and measurements of decision-making opportunities and self-determination

> *"Promoting self-determination and choice opportunities for people with intellectual and developmental disabilities has become best practice in the field" (Wehmeyer 2013)*

Brown (1993) points out that decision-making has an important impact on the social and emotional development of persons with intellectual disabilities. More opportunities for choice-making results in an increased independence and participation in leisure activities and may reduce aggressive behaviors, self-injury, social avoidance and tantrums (Brown 1993). Furthermore, it can help with the acquisition of new skills (Brown 1993).

In 1998 (Wehmeyer et al) a study, funded by the American department of education, explored the relationship of self-determination and the quality of life. The research focus was on the eight core dimensions of quality of life which are defined by Schalock (Wehmeyer et al 1998).

> *"(a) emotional well-being, (b) interpersonal relations, (c) material well being, (d) personal development, (e) physical well-being, (f) self- determination, (g) social inclusion, and (h) rights." (Wehmeyeret al 1998, 4)*

The results of the study show that there is a strong correlation between the satisfaction of live and self-determination. Thus it can be said that self-determination is a core dimension for the quality of one' s life (Wehmeyer 2013). Other factors such as age of the participants and IQ score did not seem to have a big impact on the results. Other studies with students with intellectual disabilities have already shown that there is a correlation between self-determination and quality of life. The students which were educated about self-determination lived more often outside home, have a savings account and are more likely to be employed as well as earning more money after they left school (Wehmeyer et al 1998).

There have been many researches which aim to measure the self-determination and choice possibilities of people with intellectual disabilities. The goals of such researches differ from each other. Some are researching on the choice opportunity other focus on who is making the choices (service user, staff or family) (O' Donovan 2017).

Kishi et al (1988) were one of the first to measure decision-making for people with intellectual disabilities. They used a ten item survey which included: what food to eat, what clothes to wear, leisure activities, what TV show to watch, how money is used, wether to participate in a group activity, with whom to live, calling friends or family, what time is bedtime and job choice. The answers were evaluated using Likert- scale (Kishi et al 1988). The clear result was that people with intellectual disabilities could make far less choices (Kishi et al 1988). Kishi et al (1988) pointed out that there is also a correlation between the severity of disability and less opportunities in decision-making.

Wehmeyer introduce one set of questions, when conducted the national consumer survey in 1995. The questions have some similarities with Kishi et al 's questionnaire. He conducted an interview concerning the issue of self-determination of people with disabilities in America. The questions were sorted into categories, including level of choice and control (Wehmeyer, 1995). In the first part, the participants were asked if they are able to choose the place they live, their work, activities in their leisure which include trips. In order to evaluate their level of control the participants were asked if they can decide where to spend money and how their room is decorated. A more recent consumer survey in America asked people with special needs about their community participation and their involvement in decision-making concerning their everyday lives in a similar way (NASUAD, 2015-2016).

The choice inventory scale, based on Heller, was extended on two items and was used for conducting a survey in Ireland which measured the choice of people with intellectual disabilities(O' Donovan 2017). The answer options were simplified, either that the participant can decide themselves or somebody else makes the decision for them, instead of using the Likert scale (O' Donovan 2017). It had nine items for determining every day choice possibilities. It included exactly the same items like Kishi et al used plus a question concerning their possibility to decorate their room themselves. Furthermore, O' Donovan (2017) had a category with key life choices. The questions aimed to find out if the service users can choose by themselves with whom they live, where they live, where they keep money, what support they get and what job they have (O' Donovan). Concluding, many researches which are trying to rate the decisions possibilities are based on the same principles and are roughly covering the same daily life situations such as measuring if the service users are given the chance to decide about their free-time activities. The next chapter will describe decisions which are not only regarding the service user 's daily life but which are also of concern for others, e.g. organizational policies.

5.2   Participation and Empowerment

In the beginning of the chapter, it is to be mentioned that for the purpose of this thesis, participation is only evaluated on an organizational level and not referring to the socio-political

nor societal level. Participation means that one is enabling service users to engage in everyday practice and policy (Adams 2008).

Adams (2008) states that the concepts of participation and empowerment are overlapping and sort of relying on each other. The service user becomes empowered through participation and the other way around, needs to be empowered in order to participate (Adams, 2008). This chapter will explore those two concepts further starting with participation.

5.2.1 Participation

> *"Participation refers to that part of the continuum of involvement where people play a more active part, have greater choice, exercise more power and contribute significantly to decision-making and management." (Adams, 2008, 31)*

Schwalb (2013) writes that it is necessary to support the service user in order to let him/her be an active part of the community. This can be done by collaborative involvement, participation and listen to their opinion concerning development, activities and other issues related to their living situation (Schwalb 2013).

The office of the deputy prime minister (Brafield 2007) states that participation can take place on four different level. The first level is information and dialogue, meaning that the service users are being informed about their services (Brafield 2007). The next, apparently higher level according to Brafield's book (2007) is defined as the day-to-day basis level. So, the possibility of the service users to make low-level decisions in their daily life such as decoration, rules and food (Brafield 2007). One level higher, the service user is exerting more influence and can take part in medium-term planning and policy. The office of the deputy prime minister states (Brafield 2007) that for example, the service user can be included in developing new policies and hiring staff. The fourth level is outlined as service management; it gives the service user the possibility to make decisions on how the services are run and managed. One way of including them would be to involve them at board level when it comes to e.g. questions concerning the future service development (Brafield 2007). Thus, a high-level participation is a necessary indicator of empowerment. Nowadays, empowerment is a topic that is being more and more emphasized within organizations as well. Therefore, the following chapter will introduce the concept of empowerment, explain how it can be used in organization and justify its importance.

5.2.2 Empowerment

Rappoport (Page, 1999) said that is it easy to recognize empowerment when there is a lack of it but hard to define in action because of its different forms depending on the people and contexts.When trying to describe empowerment, it is necessary to understand the idea power (Page,1999). Weber (Page, 1999) formulates power as the ability to make people do something

without considering their interests or wishes. It demonstrates that one person hast power over the other. Thus, power exists in the context of interpersonal connections (Page, 1999). According to Adams (2008), power can also be used in a positive context, such as protection. In order for empowerment to work, it is necessary to acknowledge that power can be changed and expanded, meaning that giving power to someone is not at the expanse of somebody one's own power and can even strengthen the power of others (Page, 1999). In social science, writers assume that power is not shared in an equal way within society (Adams, 2008). The aim is to share the power more equally and help people to find ways in which they can improve their lives (Adams, 2008).

Adams (2008), describes empowerment as becoming powerful and uses Thomas and Piersons definitions in the context of social work. Thomas and Pierson state that empowerment refers to the service user's participation in services and help them to achieve control over their own lives (Adams, 2008). Schwalb (2012) is naming four aspects of empowerment, the first one is individual strength and resources to control circumstances in their own life and living autonomously. The second aspect is the engagement for equality and fairness such as accessibility (Schwalb, 2012). Besides, Schwalb (2012) mentions empowerment in the context of self-determined action and learning process, in which e.g. parent with special needs children are learning about disability and forming self-organized peer support groups with others. The last aspect is encouragement of the people with special needs through practice to find their strength and discover their ability and trust within themselves and make use of it (Schwalb, 2012). In the following is a quote by Adams, defining empowerment as

> *"the capacity of individuals, groups and/or communities to take control of their circumstances, exercise more power and achieve their own goals, and the process by which, individually and collectively, they are able to help themselves and others to maximize the quality of their lives." (Adams, 2008, 17)*

5.2.3 Benefits of participation and empowerment

According to (Adams 2008) participation is important because it can help to change the services with the aim of a better quality. By involving the service users in more democratic ways both parties, the leaders and service user will learn how to work in a democratic way and also improve their interpersonal and social skills in the process (Adams 2008). They need to discuss about all issues and the workers need to ensure that the service users fully understand. Especially the service user will profit from the new interpersonal skills because they learn how their voices can be heard (Adams 2008). The services will change and become more inclusive (Adams 2008). Furthermore, Adams (2008) argues that this process can encourage even more and wider participation maybe into other areas as well.

Empowerment can have many benefits on a person such as building confidence (Adams 2008). Besides it can make the service user feel useful, especially when they are asked to give their opinion on topics (Adams 2008). There are also indirect gains from empowerment such as the extension of networks and the increase of mutual support.

> *"the more empowered people are and the more they participate, the more likely it is that the services will be relevant, quality based and effective"* (Adams 2008, 198).

5.2.4   Empowerment in organizations and empowerment evaluation

The goal of participation for the service user is, to see the results and achievements of their involvement. Therefore, the development of plans and structures needs the service user's contribution. The workers need to ensure that the service users understand the process (Brafield 2007). For ensuring an effective participation, the organization needs to have a certain structure, responsibility and culture (Brafield 2007). The organizational structure should make it possible for service users to articulate their demands directly and making sure their needs are met and monitor potential changes in need (Adams 2008). This can be seen as acting like a facilitator, meaning to help people find out what they want and need instead of deciding in their names (Adams 2008).

In order to create such a organizational strucute, the leader of the organization is responsible integrating participation effectively into commissioning (Brafield 2007). Furthermore, Brafield (2007) points out there should be a positive organizational culture, the workers must have the confidence and skills to design involving activities. There should be effective mechanisms to ensure that the service users voices are heard within the organization, therefore it is important to ensure that the service users are able to understand (Brafield 2007).

In the book "empowerment, participation and social work", Adams (2008, 147) has created a list of characteristics for empowering organizations. The list is comparing different aspects from a traditional organization perspective and an empowering one. It is visible that the main goal of an empowered organization is to benefit the service users by making sure that their needs are met and not only the fulfilment of the organizational requirements, thus the service users are the most important persons (Adams, 2008). The organization culture should be critical and self-aware as well as innovative (Adams, 2008). Furthermore, Adams (2008) mentions the importance of open attitude towards changes and innovations and flexible roles, thus making boundaries appear blurry. Another characteristic of an empowering organization is the distribution of power, which should be dispersed, this can be fulfilled by a democratic management style and a communication which is not only from top down (Adams, 2008). Also, Theunissen (2013) recognizes that a top- down communication is hindering the empowerment, he suggests concepts which take into consideration the voices of all people involved, when a development process is planned. The top-down communication is often related to a more

hierarchical system in an organization. Theunissen (2013) argues that there is a need to change the system by reducing hierarchy and bureaucracy and supporting a more democratic decision structure as well as deinstitutionalization.

There should be also a way to include the voices of people with more severe disabilities, the hard-to-reach clients (Brafield 2007). Their opinion is of great value, a possible way of involving them could be the formation of small groups which represent the views of other service users (Brafield 2007).

There are many ways oin which an organization can implement a more empowering approach. One example is the empowerment evaluation that was introduced in 1994 by Fetterman (Smith 1999). It is based on empowerment theory. In order to give enough context there will be first a short explanation of empowerment theory before continuing with the introduction of empowerment evaluation.

Empowerment theory is based on 6 main principles (Langer 2014). The first one is that personal issues such as suffering from discrimination or oppression is political because everyone is at the risk of experiencing the same (Langer 2014). The structural elements have to be identified and changed (Langer 2014). Marginalization is systematic because certain condition such as the political climate can lead to marginalization of vulnerable groups by causing an environment of oppression (Langer 2014). According to Langer (2014) there needs to be first the atmosphere for personal psychosocial transformation, meaning that the person ought to be empowered needs to be aware of their personal strength before social change can happen. Furthermore, it is important that the workers are treating the service users with respect and dignity in order to empower them (Langer 2014). The fifth principle suggest that non-hierarchical model needs to be used in order to support empowerment (Langer 2014). It also mentions the dual perspective which means that on the one side the larger environment needs to be acknowledged as well as the service user (Langer 2014). The last principle is to acknowledge that workers can have influence on different levels in order to promote change. So that "Empowerment leads to social action" (Langer 2014, 174)

According to Theunissen (2013) empowerment evaluation is an open and democratic group process which gives everybody involved the possibility to be listened, create an evaluation and actively participating in the creation of the development of new concepts or tasks. Empowerment evaluation can be seen as a bottom-up approach in which the service user help themselves to improve their services by self-evaluating and reflection (Theunissen 2013). So, it is based on the principle that solutions are more effective and stable if decided upon together with everybody (Theunissen 2013). The aim of empowerment evaluation is to foster self-determination, so people learn how to help themselves and create social change (Smith 1999).

According to Fetterman empowerment evaluation is based on four easy and effective steps (Theunissen 2013):

1. Formulation of a mission/vision

2. Gathering, evaluation and reasons of relevant aspects, also called "taking stock" (Theunissen 2013, 76)

3. "Planning the future" (Theunissen 2013, 76)

4. development of working strategies

These steps should be monitored by an external evaluator who is responsible to evaluate the process, ensure that trust an honesty are respected and all people involved are able to voice their opinion, views and interests (Theunissen 2013). The Evaluation can have different societal purposes such as producing knowledge or promoting social reform (Smith 1999). Empowerment evaluation can be seen as liberating from traditional roles and expectations, "find new opportunities, see existing resources in a new light, and redefine their identity and their future roles" (Smith 1999, 53). In the end the participants themselves are the judges if the evaluation worked their judgements can be harder than from an outside evaluator (Smit 1999).

5.3 Obstacles

Unfortunately, there are obstacles in the areas decision-making, self-determination and participation that people with intellectual disabilities often experience.

> *"clients may attach more importance to freedom and autonomy than professionals are aware of" (Janssen 2005, 66)*

Brown et al (1993) is referring to a study from Kishi that compared the range of choices non-disabled people can make during a day with the range of choice people who are having severe disability are able to participate in. As a result, people with severe disability were given far less opportunities to make decisions which the staff explained by referring to the missing ability to communicate preferences (Brown et al 1993).

Next to the lack of sufficient communication abilities, responsibilities to follow a tight scheduling and having certain objectives and aims, were reasons why the participants with severe disabilities were not given the possibility to make more choices themselves (Brown et al 1993). The workers are often not familiar or prepared to teach meaningful decision-making (Brown et al 1993). Hassan (2017) states that restrictions on choice are not only affecting fundamental aspects of the service user 's life but also in every day life such as in leisure activities or diet. According to Hollomotz 's (2014) research which indicates that the service users are usually presented a "restricted menu".

> *"The options on offer may be restricted and pre-agreed by staff, who remain in control, while an individual's selections from the menu are at times tokenistic."* *(Hollomotz 2014, 245)*

Hollomotz (2014) mentions that especially in the past workers felt the need to protect people with intellectual disabilities from bad choices. She refers to Beck who said that society is not about what is good but how to prevent the worst form happening, as a result self-limitation becomes the aim and not self-realization (Hollomotz 2014). In 2010, Dunn said that workers became negative feedback from the agency when supporting service users to take a risk (Hollomotz 2014). If the individual choices such as leisure activities are not reviewed regularly some might do the same activities for years and never try somethings different. (Hollomotz 2014)

People with intellectual disabilities are have limitations when it comes to acting in a self-determined way (Theunissen 2013). Theunissen (2013) has pointed out problems such as infantilizing behaviors by the care person, overprotection, constant control and regulations. Further identified problems include an ignorance of the wishes and interests or in general a life full of "stop signs" (Theunissen 2013, 42). Also Hollomotz (2014) argues that learned obedience towards the staff which might be rooted in disproportionate protection, can be restricting for the service users. It is important to be aware that decisions are influenced by social relations and dependency (Hassan 2017). Many times, people with severe disabilities only experience a limited opportunity to participate in decision-making and mainly in the more basic ones (Brown et al 1993). For people with more profound intellectual disabilities may not have the capacity to make meaningful decisions (Hassan 2017). Hassan (2017) refers to Van Loon et al which state that people with intellectual disabilities are not always capable of making free choices due to missing competence, rational ability and awareness therefore the liberal concept of autonomy cannot fully be applied. Fyson and Cromb (2013) raise concern that sometimes the decision a service user wants to make is not in their own best. He is referring to an example from Schelly in 2008 who was working with a service user that had mild to moderate intellectual disabilities. The service user if asked only wanted to sit inside, watch television and drink soda which would make him unhappy. Through promoting other possible activities and intervening that the outcomes have change for better.

"Other studies have suggested that 'choice' is invoked as a right only when it suits the needs of service commissioners and providers." (Fyson & Cromb 2013) If the organization aims to be more empowering the biggest problem occurring might be to find consensus between people that are involved in this process (Adams 2008). Empowerment is a subjective word which can mean different things to different people (Adams 2008).

The lack possibilities to make choices leads to a missing understanding for the connection between actions and environmental outcomes which can result in learned helplessness (Brown et al 1993). Learned helplessness means that people with intellectual disabilities are not used to make decisions on their own because they were not supported in that aspect in their upbringing (O'Donovan 2017). Hollomotz (2014) emphasizes that the act of making a choice should be active. The service user 's "passive acceptance or compliance should not be interpreted as choice" (Hollomotz 2014, 236). An obvious consequence may be learned passiveness, when the service user is not used to be active in the decision-making.

5.4   Critical practice

Critical practice is important for an empowering organization. It means that the workers are reflecting critically on their practice (Adams et al 2009). Critical in this context mean that different perspectives and choices are taken into consideration in order to find the most appropriate practice (Adams et al 2009). Glaister defines critical as considering different experience, viewpoints and assumptions, so having a certain open-mindedness in the approach (Adams et al 2009).

Adams et al (2009) views critical practice as a process that involves change, reflection and rethinking which is necessary in a changing world. Critical practice is a reflexive cycle in which the worker is using "the experience of action and its outcomes to inform further thinking [...] [they] put themselves in the picture by thinking and acting with the people they serve" (Adams et al 2009, 4).

It also involves questioning ideology and "entail[s] identifying and challenging injustice and power structures" (Adams et al 2009, 235). Critical practice is not emphasizing the results but reflecting on how it was done and if there is something that can be improved (Adams et al 2009).

6   Research Methodology and study design

Before describing the study design, it is important to point out why this research was conducted in first place. Therefore, the following part is focusing on the aims and research questions. After the objectives have been introduced, ethical considerations will be described. Later on, the used method will be explained. Furthermore, there will be a detailed description on how the data was collected and analyzed. Besides, this chapter includes justifications of the methods and will end with the reliability of this research.

6.1   Research objectives and questions

The aim of this study is to raise awareness about the topics choice, self-determination, participation and empowerment when work with people with special needs in the WLP organization. One of the goals is to be thought-provoking for the workers, so they might reflect

their way of working. Raising awareness by informing the workers about these issues might ultimately lead to change in the working attitudes towards a more participatory work approach. It is also important to have the service user 's voice heard. Therefore, another aim is to find out how the service user evaluate the current situation and how satisfied they are. Furthermore, this research is aiming to find areas in which improvements are needed and to help finding possible solutions.

The purpose of this research can be summed up in the following questions:

1. What is the current situation of choice and participation in the WLP organisation?

2. What are possible challenges facing choice, self-determination and participation in the WLP organisation?

3. How can the services be improved?

6.2   Ethical considerations

In order to conduct an ethical research the participant's rights need to be respected. It is important to establish an informed consent. In order to get the consent it is important to inform about the research's intention (Fontana 2007). In the beginning of the interview/focus group a brief introduction was given about the research's topic and purpose. Furthermore, all participants were asked for permission to record, to which all agreed. The record will not be published and only used as a reference.

Another issue is the right to privacy, meaning that the identity of the participant is protected (Fontana 2007). Before the interview and the focus group the author or the research started with a statement, guaranteeing total confidentiality and anonymity. The thesis does not include any names. Especially in the focus group all information are inherently shared with all participants (Morgan 1997). Therefore, the questions are limited to topics which are not of private concern (Morgan 1997).

The participation was voluntary and there was the possibility to withdraw any time. This is part of the protection from harm (Fontana 2007) which includes physical, emotional or any other kind of harm. If somebody would feel uncomfortable in a situation they were free to leave any time.

6.3   Study Design

The study design consists of three different phases (Figure 1). In phase one the emphasis was to get information from the clients themselves. Therefore, a semi-structured interview was used. The second phase entailed interviewing the workers on their standpoint of view. The gathering of information took place in two focus groups. Each focus group had its own topic, the first one focusing on choice and self-determination and the second one was about

participation. The two methods used in this study are qualitative. It is recommended to use more than just one method because using multiple ways of gathering data since it results in a wider spectrum of diverse viewpoints (Saldana 2011). According to Saldana (2011), qualitative research methods are characterized by their aim to study the natural social life, not predicting or controlling it. The last phase is the discussion of the results. This means that the results of this thesis will be send to the working life partner, where it will be discussed in different meetings.
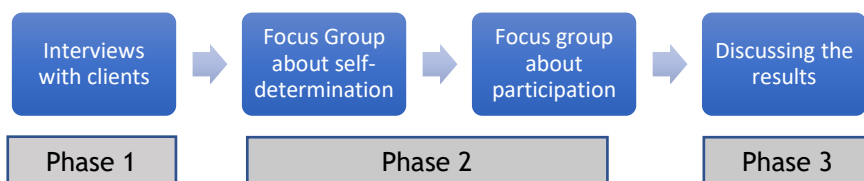

Figure 1

In the following, will be a description on how each method was used as well as a justification.

6.3.1   Semi-structured interview as a method

The first method used was a personal interview. The purpose of the interview was to find out what the service users think about the current situation in the WLP organization. The interview was chosen because of its privacy, as many clients may be too shy to speak out loud in a group setting or in general in an unfamiliar setting. Another aspect is that the majority is not able to neither read nor write, thus a written survey would not be possible.

Before conducting interviews the researcher needs to determine whether the questions are asked in a structured or flexible manner. Postmus referred to it as "The challenge of flexibility versus consistency" (Fortune et al. 2012, 244). In this case, it was chosen the best decision to conduct the interviews in a semi-structured manner, meaning that the participants received the same set of questions but the formulation during the interview might differ (Fontana 2007). Contrarily to the structured interview, it is not important to formulate the questions in the same way or have the same order for each interviewee (Edwards 2013). Semi-structured interviews support the answering on the participant's own terms, because of its flexibility (Edwards 2013). According to (Dörnyei 2003) in a semi structured interview

> *"the interviewer provides guidance and direction […] but is also keen to follow up interesting developments and to let the interviewee elaborate on the issue raised in an exploratory manner."* (Dörnyei, 2003,136)

The interviewees had different severities of intellectual disabilities. Some needed a more thorough explanation and therefore it was essential to make sure they understand the question,

in order to get a relevant answer. By giving supportive information, misunderstandings can be clarified. The semi-structured interview has a more spontaneous character.

The location where the interview takes place can be key for good results. Edwards (2013) mentions that when interviewing people at work they give different answers than asked in a public place or at home. They tend to share their opinion more freely. (Edwards 2013) The setting can make a big difference, so in the case of the interview it was important to guarantee privacy, avoid possible interruptions and make the participants feel at ease. Thus, the interviews took place in their own room.

Here are the questions of the interviews which are going to be described more detailed in the following. The questions can also be found in the appendix 6.

1. What do you like to do in your leisure? Who decides what you can do in your free-time?
2. Can you decide how your personal space is decorated?
3. Who decides to which trips the house is going (Are you going on trips and can you decide where? Are your wishes heard?)
4. Who chooses the place where you live and are you happy with the decision?
5. Did you choose your job?
6. How often do you have contact with people outside the WLP organisation? Who?
7. Can you take part in decisions concerning the house? Do you have the feeling that you are listened to?
8. What courses/activity would be interesting for you which are not currently offered in the WLP organisation?
9. Do you have a person to contact when you have a problem? Who? Do you tell when you have a problem?
10. Is there something you would like to improve?

Since the aim of this study was to find out about their possibility to make use of their right to self-determine in different areas, it seemed fitting to use the national consumer survey from Wehmeyer 1995 as orientation. Thus, the first six questions of the interviews in this study were focusing on the same areas and followed roughly the scheme like the consumer survey.

The second topic of this thesis is participation. Therefore, the questions seven until eleven were aimed to determine the current state of participation in the WLP organization from the service users perspective. Part of this is also to rate their level of integration. For example, if they go out to have trips (visiting cinema etc.) and how often they are in contact with other people. This idea came from the national consumer survey as well (Wehmeyer 1995). For the purpose of this thesis, the questions were extended. Question number 8 was inspired by the eight principles of participation by service users and carers which is a joint statement signed by general social care council, commission for social care inspection, skills for care and the

social care institute for excellence in 2005 (Adams 2008). The questions focus on the principle number 3 which states that the service user should be able to choose the way they become involved (Adams 2008). According to Brafield (2007), it is important that the service users are able to become involved in low-key decision-making as well as policy development. The question also asked if the service user have the feeling that they are listened to. This is the seventh principle which says, "value the contribution, expertise and time of service users and carers" (Adams 2008, 39). So, each feedback and suggestion should be listened to. The tenth question is having the same idea behind it. It is aimed to find out if there is a specific person the service user can trust when they have a problem, so again if they have somebody to listen to and trust when it comes to their problems. The ninth and eleventh question (Appendix 6) have a common main goal as well. It is about finding out what could be improved, like e.g. activities and hobbies that are missing or if there is something that could be done in a better way in general. According to Adams (2008), "what people desire from participating is being able to bring about improvements in their own service provision" (Adams 2008, 41).

Another aspect by designing the questions was to use open-ended questions. According to Folkestad (2000), acquiescence means a tendency of people with intellectual disability to answer "yes" whenever possible and that they have a certain affinity to please. For this reason, most of the questions were not easily answered with yes or no.

6.3.2   Focus group as a method

The focus group was chosen as a method because a survey would not be flexible enough with its pre-determined answers and questions. Individual interviews would gather information but don't give the participants the opportunity for new ideas and different point of views. The participants can inspire each other.

Focus group is considered being a group interview which is different in a few aspects (Fontana 2007). A focus group discussion is a group of people, usually around 6 to 8 participants, which discuss a predetermined topic for 60 to 90 minutes (Hennink 2013). The aim of such a discussion is to create an atmosphere in which the participants feel comfortable to freely share their views and opinions and do not have to worry about being judged by others (Hennink 2013). These group dynamics lead to a deeper range of data because of its social interaction than one-to-one interviewing (Rabiee 2004). They can build on something that was said before or change the topic. Another advantage according to Hannah Frith (Edwards 2013) is that focus groups can make people feel more comfortable, on the other hand "disagreement may lead to participants defending their views and provide further explanation" (Edwards 2013, 38). Since there is a focus on a specific issue it allows sufficient time to review it more detailed (Hennink 2013). The purpose of the discussion is to rather gathering a wide range of perspectives and experiences than finding a consensus between the participants (Hennink 2013). The discussion

is led by a moderator who stimulates a conversation (Hennink 2013, 2). The researcher is usually the moderator and provides the topics of discussion (Edwards 2013).

The discussion topics (Appendix 2) for the first focus group were based on the first six questions (Appendix 6) of the interview with the service users. So, the discussion topics included spending money, trips, choosing a workplace, leisure, place to live and contact with people from outside (Appendix 2).

The second focus group discussion had six questions prepared beforehand to bring more structure into the conversation. The first question was purposely quite broad because Hennink (2013) said that there should be a warm up question in the beginning. The structure of a focus group is comparable to an hourglass shape, meaning in the beginning the opening questions which are providing rapport are being quite broad. In the middle of the discussion are the key topics and specific questions which provides data. The closing question which, like the name suggest, provide closure is asked at the end of a session (Hennink 2013). Half of the questions used are related to the interview with the service users, such as question number 1, 2 and 6 (Appendix 2). The other three questions were more specific on the practice of the workers. The third question is specific to the WLP organization and aims find out how the service users could be more involved. The next question (Appendix 2) is about the ability of the service user if they are able to articulate themselves sufficiently. This question can be seen in connection with the second question because it indirectly asks if the workers are listening. The fifth question (Appendix 2) is about the system within the WLP organization and if the service users are able to have a say in it.

6.4   Interview

The following chapter will describe the selection of the interview participants, how the data was collected and analyzed as well as the feedback of the participants.

When picking the participants, the aim was to be able to represent the village as good as possible. The respondents had to fulfill certain requirements. For a participation in the Interview it was needed that the participant is able to communicate in a verbal manner and understand the questions. In order to hear different voices, the participants were picked from different houses. Each house has their own workers therefore the situation might differ. In the end the participants came from 5 of the 7 houses. Another important factor when choosing the respondents, was to have different ages represented. Along with the difference of age comes a different length of stay in the organization. The chosen participants had an age range from 24-65 years.

6.4.1   Data collection and analysis of the interviews

This subchapter will give an on how the interviews took place.In the beginning of each interview a small introduction was given. In this way it was possible to find out if they have some knowledge about the topics, e.g. what self-determination means. Afterwards, it was explained that the interview will be recorded and that the privacy will be respected by guaranteeing total anonymity. Then the interviews started and the researcher followed roughly the outline of the questions (Appendix 6). In accordance with Edwards (2013) suggestion for a good interview setting, it took place in their room.

The service users were quite short-spoken in the interview, therefore the material only comprised around 10 pages. This material was analyzed by sorting it into categories, which is a common way of handling interview data (Fontana 2007). For the first six questions (Appendix 6, 1-6), it was easy to divide them into two main categories. So, depending on how the service user answered, it was categorized into either "they are able to decide by themselves" or the second possibility as "somebody else decides" for them. This was inspired by the study conducted by O' Donovan (2017).

The second part of the questionnaire was harder to categorize, consequently each question was individually looked at. The categories were form in accordance with the given answers. So, when asked if the service users have contact with people from outside (Appendix 6, 7), the most mentioned answers were: not at all, friends, family, family and friends. The next question (Appendix 6, 8). was an estimation on their ability to be part of decisions, indirectly asking if they are listened to. The answers were either yes or rarely. The most common answers when asking about courses or activities that are currently missing (Appendix 6, 9), was either that they are satisfied the way it is or examples what they would like to join such as swimming, painting, cinema or studying. When ask to whom they go in case of a problem (Appendix 6, 10), most service user answered either, coworkers, house parents or coworkers/friends. The last question (Appendix 6,11) only needed one category because the service users answered unanimously that there is nothing that needs to be improved and that they are overall satisfied. The table with the answer will be in the result part of this thesis.

There was not a lot of feedback concerning the interviews. Right after the interview, the participants were asked on the level difficultness of the questions. Everybody that was asked answered that the questions were understandable. Even though sometimes during the interview it was necessary to explain a little bit more detailed what they mean. One of the participants told afterwards proudly to others about their participation in the interview, which can be considered as a good feedback. It means that they liked to participate and told others about it.

6.5   Focus group

This chapter will be about the conducted focus groups with the workers. It starts with an introduction of the participants, continues with the data collection which is followed by the feedback of the focus group. The same order of topics is used for the second focus group.

Both focus groups are analyzed in the same way, therefore only one subchapter on the focus groups' analysis is needed.

6.5.1   Participants of both focus groups

The participants of a focus group are selected beforehand and have share a common experience (Hennink 2013). In this case, all of the participants are working with people with special needs in the same place.

The recruitment of participants was purposive, meaning non-random (Hennink 2013). For the purpose of this study, it is important to invite people from different cultural and professional backgrounds. Overall 3/11 participants were not born in Finland, the professions ranged practical nurse, social workers and previous working experience in the social field. The participants came from different working places within the organization, meaning they work in different houses. Also, workshop leaders were invited and one person from the office joined. Another aspect that was influencing the choice of participants was the different period of time they have worked in the WLP organization. It can make a difference in their experience. Five participants out of eleven worked for more than five years in the WLP organization. The age range of the participants was 24 to over 50.

6.5.2   Data collection of the first focus group

According to Hennink (2013, 96), "there is no single way to conduct qualitative research or focus group discussions". It is important to describe what was done during the focus group session as well as reasoning why it was done in this way. It is called procedural detail. (Hennink 2013). In the following are different aspects which were taken into account before the focus group was conducted which continues with an exact description on how the group interview took place.

The setting of the group interview needs to be taken into consideration. The space should be convenient, accessible, private and adequate for recording the session (Edwards 2013). Following these tips, the focus group was conducted in the coffee shop of the village which was not in use at this time (Appendix 1). In this way, nobody was able to interrupt from the outside and it was private. Besides, it was possible to offer coffee, tea and cookies which enlightens the mood and made it easier for people to feel comfortable. A picture of the setting can be found in the appendix 1.

It is also important to determine beforehand the level of involvement by the moderator during the discussion (Morgan 1997). For the first focus group, the researcher decided to have the discussion in a less structured way and only having a minimal participation of the moderator. According to SAGE a less structured focus groups gives "the participants more opportunity to pursue what interests them" (Morgan 1997). They can start a discussion without much involvement on the moderator' s side (Morgan 1997).

The first focus group started with small talk. The session was planned to start at 13 o clock but some people had a delay, so people started to have small talks while waiting. Since the meeting took place in a coffee shop it was a nice possibility to share some tea and coffee. After 15 minutes every participant had arrived and it was possible to start the discussion. In order to make everybody's voice heard it was necessary to have a translator. Even though the most part of the conversation was in Finnish, sometimes the main points were translated to English as well to ensure that everybody can follow. The focus group started with a small introduction of the topic. It should give some more information about the discussion that follows, so everybody had the same base. After the introduction, the discussion started by letting the worker evaluate on the current situation in the WLP organization concerning the right of self-determination for the service users.

> *"Eli, ensimmäinen keskusteluaihe liittyy tähän [WLP organization's] tilanteeseen tällä hetkellä. Eli miltä työntekijästä tuntuu [miten] itsemääräämisoikeudet toteutuvat tällä hetkellä, mikä on hyvä mitä on huonoa. […] Semmoinen tilanne-katsaus." (FOCUS GROUP 1 2018)*

After the opening questions was asked, the initial idea was to have a few topics have been prepared beforehand. These topic cards (Appendix 2) should keep the conversation going and collect their views on different topics. The idea was to put the pile with topics in the middle and let everybody pick one. The person who picked a card could say something concerning the topic and then a small discussion would start. Unfortunately, this part did not go like planned. The first question was enough to get the discussion going for one hour. There was no time to bring up the topics even though they were mentioned in the introduction. The cards would have interrupted the whole discussion.

The overall length of the discussion was 75 minutes. The session was recorded using an audio-recording device. Additionally, the author took notes in English.

The feedback on the first session were positive. The discussion flow was rated as being good. Nevertheless, there was space to improve in a few aspects. It was mentioned that there should have been more structure. People kept on interrupting each other, which can be seen as a sign that they have been passionate but unfortunately not everybody had the feeling like they were given the possibility to speak as often as they would have liked to. This was the fault of the

moderator and who should have intervened more often. The rules should have been stricter and some kind of order been introduced. A positive aspect which was mentioned several times was the nice atmosphere within the group as well as the environment. One participants said afterwards that it was helpful to discuss the theory and relate it with the work practice, seeing how it overall works in the daily work situations.

6.5.3   Data Collection of the second focus group

After the feedback of the first session a few changes were made compared to the first time. The aims of the changes were to avoid interruption and bring more structure.

This time the moderator was more involved than the first time. The moderation was more central this time in order to give everybody the floor to express their views and avoid domination of individuals. The aim was to discuss more of the initial topics. According to Morgan (1997), a more structured focus group will keep the discussion focus on the issues of interests in accordance with the research aims.

The beginning was similar to the first time, meaning it started with a small talk because of some delays. The session was again held in two languages to make it easier for everybody to understand the topics discussed. The focus group took place at 13 o clock in the coffee shop again (Appendix 3). According to Hennink (2013) a good way to start a focus group is by having a short activity. So, in the beginning, a piece of paper was given around, asking to estimate the current situation in the WLP organization concerning the participation possibilities of the clients. The participants were asked to make a dot on a paper. This sheet can be found in the appendix 4.

During the discussion, everybody had a sheet of paper in front of them with the questions that ought to be addressed (Appendix 5). It should give the conversation a general order and ideas for conversation. Since people saw it beforehand a bit it was easier to make up their mind. Furthermore, they had the possibility to take notes in case they want to say something but somebody else is currently talking. This aimed to reduce interruptions which was criticized in the first focus group session. The discussion went quite smoothly this time and people listened to each other.

The overall length of the discussion was around 90 minutes, which were again recorded.

The feedback from the second session was better. This time there was more structure of conversation to begin with. The participants respected each other and there was no complaint that people were not able to join the conversations. Some feedback is more communicated in an indirect way. For example, several people heard of me conducting such a focus group and they showed interest by asking what the topic what and how it went. This can be seen as a sign that people are discussing and spreading the words. So, overall it can be said that the

participants were satisfied with the focus group and felt nice to discuss these issues and give their opinion.

6.5.4 Focus groups data analysis

The data of both focus group sessions was analyzed by using constructing categories.

Hennink (2013) described the data analysis of focus groups as a cyclic process that at times need to be repeated in order to understand the results.

> *"one begins to identify the study findings and the core message from the study, which inevitably generates further questions about the data, identifies clarifications needed, or gaps in the emerging study findings, and this leads back to the data for further analysis to refine the study findings." (Hennink, 2013, 129)*

First the data had to be prepared for the analysis (Rabiee 2004). The recordings of the sessions were listened to and written down in a transcript.

According to Rabiee (2004), in order to manage the data, it is necessary to get rid of irrelevant information. Therefore, the small talk in the beginning and other not usable parts of the discussion were sorted out. The data was reduced in accordance with the purpose of the study. During the focus groups, notes were made which were used in the process as well. There was a comparison between the notes and the transcription.

After the data was reduced, the papers were skimmed through to find patterns, for example topics which have been discussed during the session several times, so searching for the frequency as well (Hennink 2013). When the themes raised by the participants are summed up in smaller segments, marked and given a name e.g. time problem, is called a thematic analysis (Hennink 2013). So, the transcript was searched for key words. Afterwards, these themes were summed up into categories (Saldana 2011). Each category was then marked with a different color in the transcript.

> *"[…] particular categories during qualitative data analysis are not perfectly bounded. Category construction is our best attempt to cluster the most seemingly alike things into the most seemingly appropriate group" (Saldana, 2011, 91).*

A mind map helped to link the categories with each other and find their relation.

Parts of the discussion which can be quoted in order to bring across a point or give an example, were marked in the notes (Rabiee 2004).

6.6 Reliability

Concerning the interview, it is to mention that the small group of people asked cannot be representing the experience of the whole village. Some clients might disagree or have another

viewpoint. In regards of the interview it should be mentioned that there is still the possibility of acquiescence, even though it was tried to avoid by using open-ended questions mainly. The interviews were semi-structured, meaning that the participants received all the same set of questions (Fontana 2007). Using the same set of question has benefits, especially when it comes to reliability and validity (Fortune et al 2013). It can lead to a decreased chance of errors during the process. (Fontana 2007) The answers are easier to compare and less biased, since the questions for each participant stay the same (Fortune et al 2013).

During the second focus group the possible issue of interpersonal reflexivity needs to be mentioned. Interpersonal reflexivity means that e.g. power dynamics could influence the results. (Hennink 2013) At the second session two of the participants were part of the leading group. This means they have a higher status which could have influenced the discussion flow. Maybe people were too shy to speak out or did not want to say something wrong.

Rabiee (2004) mentions that the analysis of the focus group contains subjectivity to some extend. The researcher is the one deciding which data to use and how.

7   Results

The result part is divided into the three parts. First describing the results of the service user interview using a table. The questions themselves are put into two categories: possibility of choosing and participation.

This is followed by an individual description of the two focus groups. A mind map in the beginning is going to give an overview and quotes are being used to verify the results.

7.1   Results of the service user's interviews

The interview data consisted of around 10 pages.

The first 6 questions aimed to find out about their possibility to choose and had the following results.

	Topic of questions	Self-deciding	By someone else	Result
1	Leisure	9/9 100%	0/9 0%	Self-deciding
2	Personal space	10/10 100%	0/10 0%	Self-deciding (with support)

3	Spending money	6/9 66,6%	3/9 33,3%	Mainly by someone else but included in decision-making
4	trips	5/10 50%	5/10 50%	Half says self-deciding
5	living situation	1/10 10%	9/10 90%	By someone else
6	job	9/10 90%	1/10 10%	Self-deciding

The following questions were about the participation of the service users within the WLP organization and the society. For these questions, it was difficult to divide it into only two categories. Therefor each question is listed with the most common answers.

7	Do you have contact with people outside the WLP organisation? With whom?	Not at all 1/10	Friends 2/10	Family 4/10	Family and friends 3/10	
8	Can you take part in decision? Are you listened to?	Yes 9/10	Rarely 1/9			
9	Is there something you would like to learn e.g. participating a course?	Satisfied 3/10	Swimming 3/10	Painting 2/10	Cinema 1/10	Studying 1/10
10	Do you have somebody to contact if you have a problem?	Coworkers 5/10	House parents 3/10	Coworkers/ friends 2/10		

11	Is there something you would like to improve?	There is nothing to improve 10/10

It can be noticed that sometimes the number of people asked is 10 and other times 9. It does not mean that the number of participants change but that sometimes the given answers could not be used. For example, when one interviewee was asked if they can do what they want in their leisure, the person only describe what they are doing but did not mention if they can decide by themselves. So, the answer was not used in the analysis.

7.2   Results of the first focus group
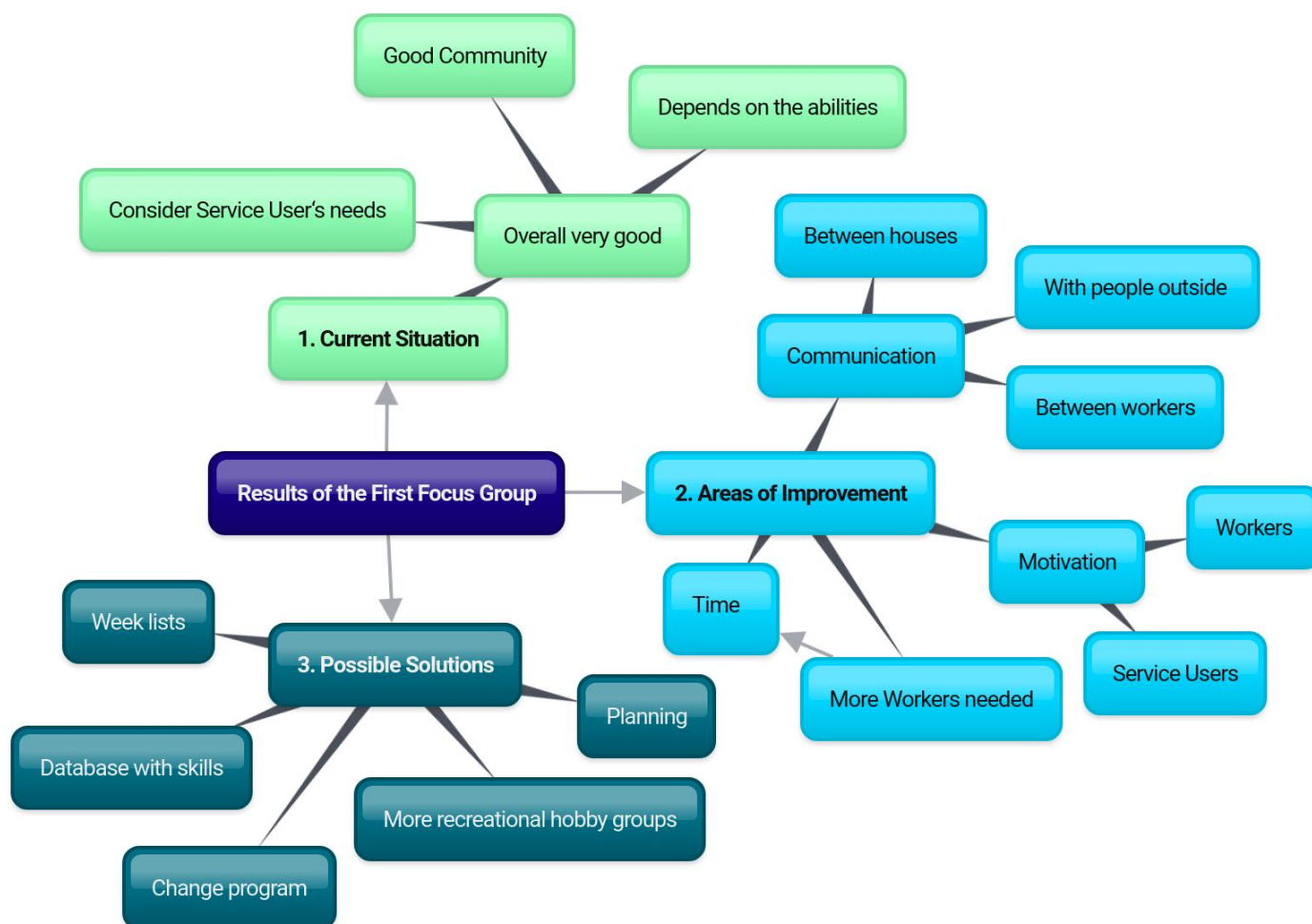
created with www.bubbl.us

Figure 2

The figure was created by sorting the topics which arose during the discussion into three main issues. It illustrates the structure of the results of the first focus group and gives a rough overview. The result part will start with an evaluation of the current situation, followed by areas of improvement and possible solutions for the occuring issues.

Concerning the current situation of self-determination, choice and participation in the WLP organization, the feedback of the participants was overall positive. It was mentioned that one can nowadays read from places which having it worse (Focus Group 1 2018). One participant complimented the working community and that the clients are having it very good. (Focus Group 1 2018).

> *"Periaatteessa täällä on asiat varmasti tosi hyvin. […] Hyvä työyhteisö […] ottaa huomioon just sellaiset kyläläiset […] must tosi hyvin" (Focus Group 1 2018)*

During the discussion, it was said that in the WLP organization, it is possible for the clients to do something and the workers try to make it happen, "usein se tapahtuu" (Focus Group 1 2018).

One aspect that has to be considered in the terms of how self-determinated the clients are and what choices they can make is their ability. Some clients are capable and do not need a lot of support from the workers whereas others are dependent more on help (Focus Group 1 2018).

Even though in the beginning of the conversation the implementation of self-determination and choice was rated as being very good ("tosi hyvin", Focus group 1 2018) currently there are still difficulties that were addressed during the discussion. In the following is a description of the different categories in which those difficulties were sorted. In the end is a chapter with possible solutions and areas of improvement that were mentioned during the focus group.

The first difficulty which arose in the discussion was communication. It can be further divided into three categories: communication between the houses, workers and with people from outside. The communication between the houses and workers is especially crucial when it comes to planning activities. The activities, like for example going for swimming and other trips, are usually only planned spontaneously within one house ("vaan talon sisällä", Focus Group 1 2018). The houses often don't know what is happening in other houses. So, the communication between the houses could be improved and more things planned together. Another issue arises when a worker is going to a different house to help out, when for example somebody got sick. They are not familiar with the service users in other houses and often the communication beforehand is not sufficient. The worker does not know what service users like to do.

"Siellä ei selviä mikään [...] ei ole kiva sitten" (Focus Group 1 2018)

Even within the same house workers are having different views of the service user's skills. During the discussion, it was said that they don't know how much help the service user need during the workshop when it comes to e.g. ironing. Whilst one worker described that he lets one service user iron clothes during the workshop time, another worker said that they never let him/her iron (Focus Group 1 2018).

Like mentioned before, the communication with people outside needs to be improved. There is nearly no contact at all. This issue is visible especially when there is disco or other festivities, which takes place somewhere else. The workers describe this situation with comments like, nobody is talking with others, even though the main idea is to get to know each other. It was also mentioned that they are just sitting down and nobody goes to dance, e.g. in the disco. They are only sitting and talking with the people they know.

"idea on varmasti tutustua […] muihinkin ihmisiiin […] ja sitten me istutaan ja ei kukaan lähde tanssimaan", "ei kukaan juttele vieraille", "omassa porukassa ollaan" (Focus Group 1 2018)

The problem of the communication with people from outside might be related with the next issue, motivation, that was discussed thoroughly as well. When the service users are for example asked, what they would like to do in the weekend, many service users answer that they don't know or have no ideas. (Focus Group 1 2018) The suggestions often come from the worker when the service users don't think of anything by themselves. For example, that they can go to the next city.

"Täytyy aina tulla se ehdotus henkilökunnalta, että me voidaan mennä [jonnekin] […] ei tule itse sellaista" (Focus Group 1 2018)

One participant said that even when you organize an activity, in the end only a few people participate (Focus Group 1). It is difficult to motivate people to come and join in.

"jos ajattelet järjestää jotain […] lopussa aika vähän osallistuu […] iso ongelma [on] saada ihmisiä mukaan." (Focus Group 1 2018)

In the focus group (1 2018) it was mentioned many times that food seem to be the main motivation in many situations for the service users to participate. For example, once a week is a coffee shop offered in where everybody is invited. Unfortunately, the people just go there and eat their cake and leave afterwards. So, overall it is a ten-minute gathering and there is nearly no conversation, especially between the service users. In the case of the disco it was said that the main purpose is more the eating of the pastry.

"Diskon tarkoitus on enemmän se pulla" (Focus Group 1 2018)

Another example which was mention was the volunteer farewell party. It was nice weather that they and there was grilling outside. There was given the possibility of joining board games or dance to the music. Unfortunately, the majority left right after the food was eaten (Focus Group 1 2018). So, maybe there needs to be a new way in which the service user can be motivated apart from food.

It is not only the service users which are lacking motivation, also the workers could do more in certain areas. It was mentioned two times that there should be more possibilities for the service users to do some recreational activities.

"I think this is also missing … more hobby groups. It is about recreation […] it means a lot of effort for the workers themselves […] to really give that time"

In the WLP organization, the hobby groups are often lead by volunteers, which change each year. This results in a change of leisure offers (Focus Group 1). Some years are more activities available to participate than in other years. It seems like the workers forget that these activities are important to keep up even though the volunteers leave. Especially when the new volunteers are coming and they are not capable to speak Finnish, a worker should be helping. It is hard for the service users as well when the things are changing all the time. (Focus Group 1 2018) one participant gave the example of the swimming group. Last year nobody of the workers was volunteering to go there and it was hard to find somebody.

> *"että ei kukaan halua [pitää uintiryhmää] […] eiks oo kiva mennä joka launtai kolme tuntia vaan uimaan [...] ja saunaan?"*

It is also plausible that the lack of hobby groups is not only connected with motivation but also with missing staff. This seem to be a big issue at the moment in the WLP organization, it was mentioned several times during the focus group (1 2018) that more workers are needed in order to give more recreational possibilities to the service users and also to help develop new skills. The participants complained that they have too many responsibilities and tasks to manage (Focus Group 1 2018). They need to take care of food making, laundry and cleaning during the workshop time and are also responsible for other duties such as participating in meetings, help in other houses when somebody is sick and other bureaucratical tasks on top (Focus Group 1 2018). The number of workers is probably a problem for many places in the social field. The participants said that it can be hard to teach the service users new skills when they have to lead the whole workshop, meaning at least 3 people at one time. It is difficult to squeeze in time for teaching new abilities. If there would be two workers in a shift it would be easier to divide the tasks

> *"[…] perunan kuorimisen opettaminen, sitten minun piti ohjata samaan aikaan imurointi […] ei oikeasti aikaa kahteen asiaan","must tuntuu, että ongelma on aina liian vähän henkilökuntaa", "työntekijämäärä se on varmaan ihan joka paikassa ongelma"* (Focus Group 1, 2018)

Also, when making a trip, one worker is not enough. First, it is hard to pay attention to all service user of one house which means at least 5 people at the same time. Secondly, when not everybody wants to join, it is a problem because they cannot be left alone in the house for a longer period without a worker close by (Focus Group 1, 2018). There need to be more workers outside the workshop time as well to support free-time activities and trips (Focus Group 1, 2018).

> *" […] mutta ei oo sitten mahdollista, kun ei koko talo lähde", "kun joku talosta ei halua. Mää en voi tässä yksin toteuttaa [toiveita] koska tämä yks henkilö ei*

> *halua", "Sää olet siinä välissä sitten", "tarvitaan myös henkilökuntaa vapaa-*
> *aikoihin" (Focus Group 1, 2018*

The missing of sufficient workers can be seen as one of the causes of another problem. There is not enough time. One of the participants said that "ei ehdit teke tätä" (Focus Group 1, 2018), meaning "you don't manage to do this". The comment was based on the time missing to teach new skills. One example was the teaching of peeling vegetables during the workshop time. It would take the whole work shop to explain and the schedules are so tight (Focus Group 1).

> *"jokaisen omassa työajassa täyty saada ruoka valmiiksi, kuka sitten opettaa kuorimista*
> *kun siihen menee koko työpajan aika", "aikataulut […] on niin tiukat" (Focus Group 1,*
> *2018)*

Summing up, the main problems can be seen in the areas of communication, motivation and number of workers which results in a not enough time. Furthermore, it may be necessary to offer more possibilities to help the service users to develop their skills further or offering new hobbies. Therefor the following part will focus on the solutions to this issues.

Even though issues arose during the discussion, usually they were accompanied with suggestions how these problems could be tackled. In the discussion, it was mentioned that the communication between the houses needs to be improved. One way in doing so is to plan better ahead. It was suggested to ask automatically from other houses when for example a service user wants to go to the cinema, to watch a hockey game or some other activity (Focus Group 1 2018).

> *"[…] kysyä muista talosta automaattisesti… onko teillä ketään joka halua lähteä?"*
> (Focus Group 1 2018)

The WLP organization has a week list, where all the happenings such as birthdays, trips and holidays are written down. Each house is send such a list in the end of the week for the upcoming week. At the moment, this list does not seem to work good enough (Focus Group 1 2018). During the focus group (1 2018), it was suggested to plan more in the workers meeting and go together through the happenings in the next time. In this way, it can be also planned who from the workers will go to the trip and who will stay home (Focus Group 1 2018). It is important that the people which will stay home have a nice program as well (Focus Group 1 2018).

In the focus group (1 2018) the importance of knowing the service user's skills was pointed out. For this purpose, it could be useful to create a data base to which people have access. In this data base, could be next to the skills, mentioned what the service user likes to do and what they don't like to do.

*"on myös hyvä jos kirjoitetaan se ylös, koska esimerkiksi jos uusi työntekijä tulee", "
[…] työntekijä ei tiedä että hän [kyläläinen] tykkää [käsitöistä]", "Se on helppoa jos
sitten tiedät" (Focus Group 1 2018)*

There was also a suggestion about how the communication with people outside the organization
could be improved. For example, when there is disco to which several organizations are invited
there could be more games or dancing together in a circle. Something that would stimulate a
conversation and aiming to get to know each other. (Focus Group 1, 2018).

*"[...] leikkiä, että pääset juttelemaan toisen kanssa. Tansseja missä tehdään kaks
rinkiä. Jotain vähän semmoista."* (Focus Group 1, 2018)

Another aim should be to create a program in such a way that the focus is not on the food. One
suggestion could be that dinner is eaten in the house before leaving. Another solution would be
to first have the program and then divide the food. (Focus Group 1 2018) In this way people are
more willing to be part in the program. This is e.g. possible to implement in the weekly coffee
shop. First there will be the program part such as singing and then the cake will be divided.
(Focus Group 1 2018)

Both problems, the lack of time and workers could be significantly improved if there would be
more planning in the organization. According to the participants it is possible to make time to
teach new skills such as peeling vegetables if you plan it into the work shop time beforehand
(Focus Group 1 2018). The workers need to be aware that a task will take more time, especially
if it is new to the service users. If the service users are given the possible to demonstrate that
they are able to learn they can show how good and capable they are (Focus Group 1 2018).

*"enemään suunnitella töitä niin ettei porkkanan kuoreminen kestä tuntia. […]
meidän täytyy suunnitella […] että meillä on aikaa ohjata ja antaa oppia
kyläläisille ketkä on hyviä ja käteviä […] jos annat mahdollisuuden niiden oppia"
(Focus Group 1, 2018)*

It is important for the workers to find out the strengths of the service users and support those.
For example, if somebody likes to do household chores which include a lot of walking such as
bringing the trash away or fetching vegetable from the garden, then they should be supported
in their interest and strengths (Focus Group 1, 2018). The workplace should be fitting to the
strengths and abilities of the service user (Focus Group 1 2018).

*"[…] heidän vahvuuksien kanssa. Työpaikkaan piti just liittyä niitä onnistumisia
[…] että tässä mä oon hyvä "* (Focus Group 1, 2018)

Another area of improvement which came up during the discussion several times, was
concerning the further development of the service user skills and the offer of hobbies which

should be expanded, so that they can do something more recreational in their free time (Focus Group 1 2018). There seems to be something missing. Some service users like to sing but the lesson is only once a week (Focus Group 1 2018). It was suggested to offer maybe karaoke. Other might like to read poems or listen to music more often (Focus Group 1 2018). There should be the possibility for the service users to follow their interests.

Summing up, it was mentioned that there should be better planning system, a data base created with the service user's skills, strengths and interests, a program which leads to more interaction with people from outside, more hobby groups created, time planned for developing the service users skills.

Unfortunately, there was not enough time to go through the topic card (Appendix 2). There was no time to bring up the topics even though I mentioned it in the introduction. The first question was enough to get the discussion going for one hour. The cards would have interrupted the whole discussion. Nevertheless, many topics were discussed despite not picking from the topic cards.

7.3   Results of the second focus group

Figure 3

For the second focus group the results were categorized according to the questions which were handed out in the beginning (Appendix 5). The figure gives some orientation on the structure. The results of the second focus group will start with an evaluation of the current situation, followed by an explanation of the village meeting. It is also mentioned that it is important to listen to the service users and consider their skills and abilities. The last section is about ideas how the services can be improved.

The first question was answered with an activity in the beginning. It started with a sheet of paper on which the participants should rate how well the service users are able to be part of decisions or are they doing things as told. The paper with the results can be found in appendix 4. It is visible the everybody made their point around the middle. Two points were with tendencies towards the left and other two points are closer to the right side, meaning that they think the service users can be part of the decision. One participant pointed out that the

question is hard to answer because it depends on the communication abilities of the service users (Focus Group 2). Those which are better capable of communicating can make more decisions. Some would be on this side and others on the other of the paper (Focus Group 2).

> *"osa kyläläistä… jos on helpompi kommunikoida… he saavat enemmän niin kuin päätöksiä läpi […] sen takia se on tosi vaikea vastata […] että osa laitetaan tänne ja osa tänne [näytä paperilla] […] se on sitten varmasti miks se on aika keskellä" (Focus Group 2, 2018)*

It was also mentioned that there is a difference depending in which situation the decisions need to be made. If the decision is for the work or if it is a decision concerning the service user's life. Especially during workshops, there are tasks that need to be done.

> *"Oman elämän päätös… se on vähän eri asia kun se työpäätös.", " […] paljon mitä on pakko tehdä" (Focus group 2, 2018)*

Sometimes decisions needs to be done in the favor of the wellbeing of the service users. Their wishes cannot be fulfilled if it would lead to trouble for somebody else. For example, the service user is asked to choose their workplace and answers that he/she wants to work with a certain person (Focus Group 2 2018). The other person would not like to be with him/her and work and it is visible that it would cause trouble have them share a work place. Then it needs to be decided for the well-being of both that they are kept apart (Focus Group 2 2018). On the other hand, it was mentioned that it can always be tried again if it works and they can be together (Focus Group 2 2018). It can also depend very much on the house itself, how much the service users are part of the decision making. First of all, because in each house there are service user with different skills and also the workers may have different working styles. "It is depending on each house what is happening there" (Focus group 2 2018)

This chapter is based question number 3 which aimed to find out ways in which the service user can be more involved. The village meeting was given as an example but it was asked how it can be further improved. The following will give an evaluation based on the participant 's answer to this issue. The village meeting which takes place once a week is a good possibility to speak about different topics. Everybody is invited, thus has the chance to talk to the whole village. The have the free space to talk about any issue they want to share with everyone.

> *"Kyläläisillä on oikeasti se vapaa tila, kun haluaa puhua, sitten voi", "kyläkokouksessa on minun mielestä hyvä, kun siellä on mahdollisuus kaikkille puhua". (Focus Group 2 2018)*

The meeting has changed over time, it used to be a more celebratory gathering according to a participant (Focus Group 2 2018). Nowadays it feels like nobody has something to say, there are not really topics to discuss (Focus Group 2 2018).

> "Silloin kun mää tulin the WLP organisationan, se oli hirveen juhlamainen kokous", " […] että arvostettiin enemmään", "Kun mää kävin viimeks kyläkokouksessa oli vähän niin kuin… ei ole asioita" (Focus Group 2 2018)

During the focus group (2 2018) it was then further discussed how the meeting could be improved. Many possibilities were share on how the meeting could gain its importance back. The first option was to prepare more in the houses beforehand. It could be discussed in the houses as well as in the workshops which topics are important for the whole village to know about (Focus Group 2 2018). In this way issues that only concern the house are not needed to mention in the village meeting, in the end it would be then more time to discuss the topics that affect everyone (Focus Group 2 2018). It was also said that one way would be to choose a topic for a certain amount of time to discuss about such as e.g. the new house which will be build. In this way it can be sure that all people involved understand the topic and its importance. Another way of making the meeting more interesting is to for example, show if somethings new was learned. One participant gave the example of on service user that visited a sign language course and in the next meeting showed a few signs that he/she learnt (Focus Group 2 2018). Another suggestion that was mentioned in the focus group (2 2018) was to make a seminar every second week instead of the meeting. The seminar topic could be chosen together. Of course, after the seminar would be still the chance to tell something important, if needed.

> "[…] että joka toinen viikko on semmoinen seminaari ja toinen viikko on tavallinen kokous. Päätetään joku aihe [ennen]." (Focus Group 2 2018)

It was pointed out that it is essential to talk about the village meeting afterwards in the houses as well (Focus Group 2 2018). Some service user may have not participated and don't know the topics that were discussed in the meeting. It is also a possibility to ensure that everybody understand what is going on in the village. So, reading for example the memo from the meeting together (Focus group 2018).

The next category was based on question no 2 and 4 (Appendix 5), meaning that workers listening what the service users have to say as well as considering their needs and abilities. The participants of the focus group (2 2018) said that it is important to listen to the service users. Therefore, it is necessary to understand how they communicate, some service users are more outspoken than others (Focus Group 2 2018). For example, on service user is deaf and others are not able to talk. They communicate in other ways such as using basic sign language or showing pictures. The workers need to get to know the service users and pay attention to their

preferences (Focus Group 2 2018). It is also important to know how the service user expresses when they don't like something (Focus Group 2 2018).

> *"[…] tutustumaan ihmisiin […] ottaa huomioon sen ihmisen mieltymys sille että tiedetään […] mikä on epämiellyttävää", (Focus Group 2 2018)*

One participant mentioned that she didn't know before that one of the service users has pictures to know what he/she means (Focus Group 2 2018). Sometimes the workers change and don't know the service user. Thus, the workers need to inform each other as well which is the best way to communicate with the service user if they are not familiar with them (Focus Group 2 2018). Otherwise it can cause stress for both, the service user and the worker. The new worker has to learn the way of communication, starting from zero (Focus Group 2 2018).

> *"ku vaik talois vaihtuu paljon ja talot vaihtaa muutenkin, työntekijät ja muut […] otat taas, niinku, alotat ihan nollasta ja sää opettelet sen kommunikoinnin […] mitä toi tarkoittaa[…] siinä on hirveä stressi hänelle ja itelle."*

The way the service user communicate is strongly connected with their abilities. Especially their ability to understand. It was said several times during the focus group (2 2018) that the workers need to make sure that the service users understand, in particular before the service user can make a decision (Focus Group 2 2018). They need to know the consequences and meaning behind that decision. It should be discussed thoroughly. It is the worker 's tasks to ensure that the service users have all the needed information in order to decide. The service user may need the time before making a decision (Focus Group 2 2018). It was also mentioned that it can be hard to make them go somewhere if they don't fully understand what it means, e.g. when going to the dentist (Focus Group 2 2018).

> *"Saada viesti perille", […] että keskustellaan enemmän niin kuin mitä se tarkoittaa ja mitä sitten tapahtuu ja kaikkea", "[...]enemmän aikaa tehdä se päätös, "People need time to think about decision." (Focus Group 2 2018)*

One participant also gave an example when a service user first said no after being ask if they want to go to a theatre play. After the worker explained the story and gave some more information the service user decided to go.

> *"Joskus oli uusi kyläläinen ja sitten kysyttiin: haluatko tulla mukaan näytelmään? No… ei… sitten mää kysyin, tiedätkö minkälainen näytelmä se on? … en tiedä… sitten kerrottiin tarina ja tarkoitus ja että sinne kuuluu laulu […] ihan konkreettisesti... ja sitten oli vaan: kyllä mää haluan." (Focus Group 2 2018)*

Another example was given in which the service user was told three hours beforehand that they are going to the train station later. The worker mentioned it several times during the morning in order to prepare the service user what is going to happen. So, when the time came, the service user "gets up with energy and says… we are going to the train station!" This shows how important the communication is and to take the time to explain.

One participant said that it feels like work (e.g. household chores) is more valued than the interaction with the service users. When workers are helping out in another house they are usually handed a list of tasks. This list often includes only chores such as cleaning the bathroom, not what the service users would like to do.

> *"I am only working sometimes in houses and when I arrive I get this lists of jobs what I should do… I should clean here… […] laundry […] but I never get a note about… this villager like to go for a walk"," Many times I get the feeling the works are more important […] when I am not doing the work […] they are afterwards saying I am lazy [...] When I for example just spent one hour on the sofa talking to the people, like giving attention ", "We are here for the villagers"(Focus Group 2 2018)*

There are many situations in which the workers need to pay attention to the service user's needs. For example, when in the work shop time it is visible during the morning that the service users are getting tired, one can ask if they want to make something less exhausting in the afternoon (Focus Group 2 2018). So, considering their need physical needs is important.

> *"Työpajassa… jos mää huomaan että alkaa väsymään mä kysyn […] iltapäivällä menäänkö metsään vai mennänkö tekemään jotain muuta?" (Focus Group 2 2018)*

Some improvement ideas that arose during the second focus group were already mentioned. In the following are more two more ideas which came up in the discussion.

One participant said that even though, there should be enough time to inform the service user and help them to understand the issues, it is not always possible to give the time because it would slow down some processes even more and then some decisions can never be made (Focus group 2 2018). So, the suggestion arose to always have one topic at a time which can be discussed (Focus Group 2 2018). In this way it is easier to focus on it and talk about it more detailed.It was also mentioned that it is not time to give the attention to the service user they need. One participant told that it can be enough to sit down with a service user for five minutes a day. This is also a way to get to know them better.

> *"[is] time the problem… I am not sure […] if you only take five minutes for somebody in your house to discuss and talk and listen. […] you only need a*

peaceful place. They start talking what they are wanting […] I know much more from my guys doing that." (Focus Group 2 2018)

It was suggested to create a group, maybe something like a well-being group which could be conducted once a week (Focus Group 2 2018). This group could for example focus on discussing more spiritual topics. In the WLP organization every morning a text from the soul calendar which is read and the bible is read every evening. The group could focus on the meaning behind theses texts. Furthermore, the group could be used to also talk about physical concerns such as sex or how to properly wash (Focus Group 2 2018). In general the well-being group should be seen as a place where people can feel safe, maybe once a week.

Concluding, it can be said that the second focus group was discussing most questions from the paper (appendix 5). Only two question were not answered. The discussion did not include the contact with people outside neither if the rules are too strict in the WLP organization (Appendix 5 Question 5,6).

Summing up, it was talked about how good the service users are involved at the moment. They are given possibilities to participate but on the other hand there is a difference between decisions in life or at the workplace. A good example when they are given the possibility to be part is the village meeting, which can be a little bit improved. The workers are listening to the villagers needs e.g. when they are tired and are aware of the importance of making sure the service user understand the decision they are making along with its consequences. The service user should have the time to fully understand. Some more ideas arose such as creating small groups to discuss different topics.

8   Discussion

The discussion part is connecting the results of the research with theory and the goals which were defined more in the beginning. This table will help to give an overview on the chapter. The structure of the discussion will follow the same pattern. First there will be an explanation of an issue which e.g. arose during the focus group. Then this issue will be reflected on using the fitting theory that was mentioned in this thesis before. In the end the possible solution or a way to improve will be described.
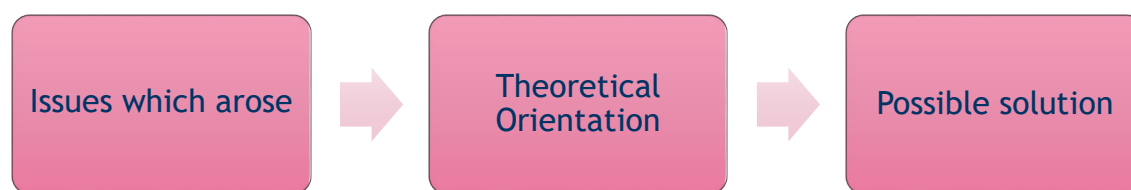
Issues which arose	Theoretical Orientation	Possible solution
Not knowing skills/abilities of service users	Empowerment	Improve Hilkka plan, better communication
Motivation of the service users	Causal Agency Theory	Raising awareness of the workers
More workers needed/ time management	Obstacles	Better planning
Decision-making possibilities	Decision-Making	Better planning, choice diversity model
Participation of the service users	Participation	Prepare meetings better, giving more time to understand
Support empowerment	Empowerment in organizations, critical practice	Forming a group using empowerment evaluation

Overall this research confirms the finding of other studies. People with intellectual disabilities are given more opportunities to act self-determined and make their own choices in community settings (Wehmeyer 2013). The workers when interviewed emphasized that the WLP organization is a good working place in which the workers pay attention to the service users. The service users are satisfied as well with the decision-making and participation in most areas of their lifes. Nevertheless, there are a few issues which was discussed about in the focus groups.

The first issue that will be discussed is the often missing knowledge about the service user's skills, interests and abilities. In both focus groups is was mentioned that it is important to take the service user's skills and abilities into account. In some situations, e.g. when helping in a different house, don't know a lot about the service users they are going to work with. Like mentioned in the theory part before, it is important to be aware of the service user's ability and competence in order to make meaningful choices. A structure within the organization should make it possible for the service user to have their voices heard. Therefore, the worker needs to find out how the service user is communicating and also consider their abilities and skills. During the first focus group, the Hilkka plan was mentioned but it seemed like some did not know much about it. The Hilkka plan was described in the beginning as a data base which is used by the WLP to gather information about the service users. It is not yet totally filled by every house. So, a possible way to improve would be to have information about each service

user in the Hilkka data base and make sure that everybody has access to it. Next to the plan it is of course necessary for the workers to get information of the service users by listening to the service users themselves. They know best what they like and dislike. Like mentioned in the second focus group it is essential to take time for the service users. Also, a better communication between the workers can help. For example, exchanging experiences and other knowledge about the service users.

One of the issues which arose during the focus group was the lack of motivation to come up with ideas for themselves. According to Reynolds (2002), a lack of interest on the service user 's side is the most perceived barrier for the implementation of creative leisure activities. Using the causal agency theory by Shogren et al (2015) there might not be enough socio-contextual support from the workers to empower the service user to be a causal agent. There might be already troubles in the action-control believes. Maybe the service user cannot connect themselves with a goal and don't believe in themselves and their strengths. This would mean that the workers need to take more initiative and give the service users more possibilities to make choices. When the decisions were successful and the service user starts understanding the correlation between their action and outcomes (opposite of learned helplessness) they might be more motivated to be part in decision-making. The aim is to create an atmosphere in which it is normal that the service users are part of the decision-making. It is important to raise awareness. It should be seen as normal for the service user to decide for themselves and not depend on other to tell them what to do. There is research which shows that if people with intellectual disabilities are given adequate training and possibilities in decision-making will promote self-determination (Wehmeyer 2013). Interventions can make big difference and research shows that even elderly people with intellectual disabilities can learn these skills. Therefore, the workers need to create an atmosphere in which it is normal to integrate them in decision-making. Only if they are used to it they can overcome learned helplessness. One example is the making and planning trips, half of the service user say that they are not the ones who are deciding where to go. So, half of the times it is the worker deciding. The service user need to learn to tell e.g. when they want to make a trip, often it is the worker deciding something and the service user just agree (focus group 1).

Another topic that was discussed in both focus group was the seemingly lack of enough workers which often results in a lack of time. The workers feel stressed and that they have too many responsibilities at once. The same problem was also discussed in the theory part. Brown et al (1993) say that tight schedules and having to follow certain aims (in this case e.g. house hold chores) the service users are given less opportunities to be part of the decision-making. The lack of time can often result in the "restriced menu" which was described by Hollomotz (2014). A way of improving this situation would be by planning better in advance. This was also the solutions discussed in the first focus group. For example, when the house decides to make a

trip together it could be planned in advance to ensure that there will be enough workers around.

This section will discuss the decision-making opportunities for service users in different areas. Even though the service users seem mainly satisfied with their choice-making, there was a discrepancy with the workers. For example, whilst the service users seem to be satisfied with the hobby offer, the workers mention that there are more offers needed. This difference in opinion might be cause because the service user are not aware of all possibilities they could have in their leisure. They are used to accept the available offer and not ask for more. So, learned passivity might be an impact to consider when comparing the results. It might be a good idea from the worker 's side to ask more often what the service users are interested in doing. Like pointed out in the obstacles part of this thesis, studies suggest that the decisions are often only implemented when it fits the organization's beliefs. Sometimes it is necessary to review the leisure decision and ask the service user if they want to change something. Like Hollomotz (2014) says it can be helpful to review the leisure offers every year. Also, the UN convention person with special needs should be able to participate in cultural offers. In the interview the clients said that they are all able to decide for themselves what to do in their leisure. Three mentioned they would like to become part of the swimming group, two wanted to start painting, one interviewee would like to go to the cinema and another participant wants to study something. The WLP is already offering creative leisure activities such as art therapy, eurhythmy and music lessons. According to Reynolds (2002) are important for the person 's self-esteem and self-awareness. It was mentioned that insufficient workers can be an obstacle for the offer of creative activities as well as a poor morale on the worker's side (Reynolds 2002). The workers recognized this problem during the first focus group and mentioned that there could be more recreational hobby groups in the WLP organization such as Karaoke, reading groups or drama. When it comes to financial issues all service user said that they are the ones deciding, some mentioned that they have a person who is helping with their financing. So, it is often a supported decision-making process, especially when it comes to bigger financial expenses. It is to rate positively that the service users are always part of the financial decisions. Almost everybody of the service user said that they are not able to decide in which house they are living. It is usually decided in a meeting, in which only the workers are present and the service user is then given the decision. In this process the service user could be more involved by e.g. participating in the meeting or being asked about their preferences. On the other hand, the decision about the living place is more complex and has many other factors to consider such as urgent moving when a renovation needs to take place. In this situation it might be hard to let the service user decide because of the limited space available. When it comes to decide where the service user goes to work, almost everyone who participated in the interview said that they are able to choose for themselves and that their wishes are respected. In the second focus group, it was mentioned that also during the workshops the service users are part of

deciding what tasks to do and that the worker consider their needs for e.g. rest by doing some easier work. Nevertheless, at times, it is hard to give enough possibilities for the service user to let them decide. Janssen (2005) conducted a research on the quality of live for people with disabilities. It focused on four dimensions: "(1) a judgment from different perspectives of the extent in which a person, given his intellectual capabilities, achieves (2) in certain domains of life (3) certain goals in life, that meet (4) certain basic norms in life and in care provision "(Janssen 2005, 58). As a result, the participants of the study were dissatisfied because of the lack of choices in areas of exercise activities, inviting people, going out, choosing furniture and other limits imposed on their personal life (Janssen 2005). So, it shows the difference, in the organization where the research was conducted, the service users seem a lot more satisfied in most areas. Overall, like mentioned in the second focus group, there should be more time for the service users to understand the decisions they are making and the consequences. This includes a better planning is part of the solution. It is important to note that the goal is autonomy and not total independence, some might not be able to articulate their needs and wants so it is the task of the worker to ensure that there are sufficient information available for the clients to improve their advocacy and listen to advise (Adams 2008). The introduction of the choice diversity model could help for those service users which are in need of more help. The workers could discuss how to handle the different situations during the day, so in the end everybody know how things are usually done. It is also important for the service user because they will get a routine and know what to expect.

When it comes to participation, the situation is good in that service users are given the possibility e.g. in the village meeting to make suggestions and tell what is on their heart. The service users themselves say that they feel like they are being listened to and have a person to contact in case of a problem. This are indicia for a good participation. The village meeting gives the service user the possibility to be part of medium-term decision making and exerting influence, like Brafield (2007) defined the third level of participation. The service user are given the chance to be an active part of the community (like Schwalb 2013 points out is important) but are not using the chance, according to the first focus group. The participants of the second focus group mentioned that the village meeting needs to be improved, the concept is good as such but at the moment is feels like there are no important things to discuss. The workers mention themselves that it would be a good idea to choose a topic for each meeting. Another way of improving the meeting would be to prepare more in the houses beforehand. Longer time ago there used to be a group in the WLP organization, which included service users. The purpose of the group was to discuss about the WLP organizations future. So, the participation level could be defined as three, maybe even four, meaning that the service users were able to exert influence, develop new policies and maybe even making decisions on how the service is run (Brafield 2007). Unfortunately, this group does not exist anymore due to lack of interest. Also, learned helplessness might be a factor. The service users are living in the

same organization for many years and are used to being told how things are going and what will happen. It might be confusing for them to be in a more deciding/suggesting position. The workers rated the participation possibility in the middle so admitting that there are still ways to include the service users even more and give more spaces for the service user to make decisions.

Within an organization it can be hard to find consensus when it comes to define empowerment, because it can mean different things (Adams, 2008). Using Adams (2008, 147) table of characteristics for empowering organizations, the WLP organization is quite empowering. It tries to satisfy the service user 's needs. The service user is seen as the most important person (focus group 2). The workers are critically reflecting their working style, like it was visible in both focus groups. They admit mistakes and have suggestion on how the service can be improved. This can be seen as critical practice, like it was mentioned in the theory part. The workers were open-minded in the focus groups and listened to each other's experiences, viewpoints and assumptions. This reflection can lead to change (Adams et al 2009). The feedback I got concerning my research showed interest and this can be seen as a sign that there is an attitude of responsiveness. There is only one area which needs to be improved and to be made more inclusive. The leading style and communication within the WLP organization is still from top to down and can be described often (not in all situations) as hierarchical. Communication from below needs to be supported in more decision-making processes. So, the power seems to be more apparent on the worker 's side. The concept of empowerment evaluation could be used to form again group in the WLP can formulate a mission, find relevant aspects, plans the future and develops new strategies (Theunissen 2013). It would also shift the power more to the service users side.

8.1   Achievement of personal learning goals

I think, I was able to achieve my main personal learning goal which was to get more insight. Through the research I was able to learn more about the work with people with special needs, how important it is to involve them in decision-making, motivate them to participate and also to give them sufficient information and time. I will definitely take all of these approaches with me in my later working life. Furthermore, I learnt to work in a reflective way. It is necessary from time to time to evaluate the way of working in order to provide the best service possible for the service users. It was the first time that I lead a focus group and I feel a little bit more confident in conducting discussions with colleagues. Later in work life, when I feel that the work approach needs to be changed it might be needed to involve other workers as well to bring some change. So, this is a first experience in doing so. I am aware of aspects that need some the next times but it is a good start in the right direction.

8.2   Co-operation with the working life partner

Overall, I would say that the WLP organization was very supportive in my research. I had a person I could talk to if I had any troubles or questions. We meet several times while I was conducting the research. I tried at what point I am at and what I am going to do next. Together with the person I had also longer conversation which gave me more insight in the organization and some more inspirations on things that can be mentioned. So, there was a constant exchange.

Many workers supported my research by giving me more input and ideas. In the very beginning they said that the topic is a good idea and that it is always important to talk about it. Overall, I would rate my relationship with the WLP organization as good. The results of my research were appreciated and they showed interest in implementing new approaches and improve the current ones.

The main problem I had during the research was finding participants for the focus group. Sometimes people would cancel because their plans have change, so it was necessary to find replacements. I had to be very flexible and always a plan B ready in case something does not work like planned. I was initially planning to conduct three focus groups but since all the postponing it was only time for making two. In the end, it turned out that two focus groups already provided enough material.

9   Conclusion

Coming back to the question from the very beginning. How well are the rights of people with special needs really taken into consideration in daily life. In case of the WLP organisation, I would say that there are definitely the organizational structures to support the decision making and being part of the community. The hierarchical system could be loosened and more possibilities for the service users to participate in complex decisions. This would also mean to spend more time to give information the service user so they are able to fully understand decisions and their consequences.

Another possible area for improvement is in the working style. Like one participant of the second focus groups mentions, it appears often to be more important to do chores than doing interactive things with the service user. The participant explains that he/she feels judged when sitting on the sofa and just talking. The service users could be considered the most important people in the organization and given adequate consideration.

The problems which were mentioned during the focus group and also interviews are not solely issues of the WLP organization the research was conducted in. Other places also have troubles with too little number of workers, tight schedules etc.

In general, the situation for people with special needs in Finland is, compared to other countries, very good. I hope that the politicians keep on emphasizing the rights and supporting people with special needs. They must not be excluded from society and given a chance to live like everybody else.

10 Proposal for further studies

This research was conducted in a limited time frame. The research took three month, so the proposal for further studying would be to have more time. In this way, the clients could be involved more by not just interviewing their viewpoints but teach and inform them more. They should know about their rights and how to make use of it.

This research has already a few similarities with action research in that it is contextual and small-scaled (Creswell, 2014). The aim of an action research is to bring alteration by reflecting and assessing pre-existing practice (Creswell, 2014). It is collaborative because the participation of others such as the colleagues is necessary to bring change and collect information. According to Cresswell an action research is conducted in a "four-stages cycle: planning, acting, observing, and reflecting." (Creswell, 2014,30) Therefore more time would be needed to plan, when conducting it, at least several months. One step further would be to turn the research into an emancipatory one. Barnes (1997) says that "these approaches [participatory and action] are concerned to allow previously excluded groups to be included in the research as it is whereas emancipatory strategies are concerned about both conceptualizing and creating a different game, where no one is excluded in the first place." (Barnes, 1997, 26) Action and participatory research is about improving the research method and not about challenging the existing ways of research (Barnes, 1997).

Another aspect that needs to be improved for further studies is the feedback system. It is a good way to ask the participant in person what they thought but maybe using a survey it could get more precise information about ways to improve and also to review if the participants e.g. learnt something new.

A interesting point of view would be to conduct a national or even international comparison. The researcher could use the same questions for the service users and conduct focus group with similar topic, so in the end the result would be comparable. For an international comparison it would be interesting to see how other countries that have also committed to the UN Convention for the right for people with disabilities, are implementing the principles.

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Focus Group 1 was conducted on the 9.08.2018 in Niinikoski. The participants were workers which are currently employed by the WLP organisation, a total of 6 plus moderator.
The topic was choice and self-determination of service users in the WLP organisation.

Focus Group 2 was conducted on the 24.08.2018 in Niinikoski. The participants were workers which are currently employed by the WLP organisation, a total of 6 plus moderator.
The topic was participation of service users in the WLP organisation.

Housemap is folder containing the latest information about the WLP organisation. Each house has one and also in the office is one example available.

Interviews with the service users were conducted in the period from 04.06.2018 until the 04-09-2018 and took place in Niinikoski. The total of interviewees was 10.

13   Figures

Figure 1 directly taken from Shogren, Karrie A., Michael L. Wehmeyer, Susan B. Palmer, Anjali J. Forber-Pratt, Todd J. Little, and Shane Lopez. 2015. "Causal Agency Theory: Reconceptualizing a Functional Model of Self-Determination." *Education and Training in Autism and Developmental Disabilities* Vol 50, no. 3.pp 251-63. http://www.jstor.org/stable/24827508.
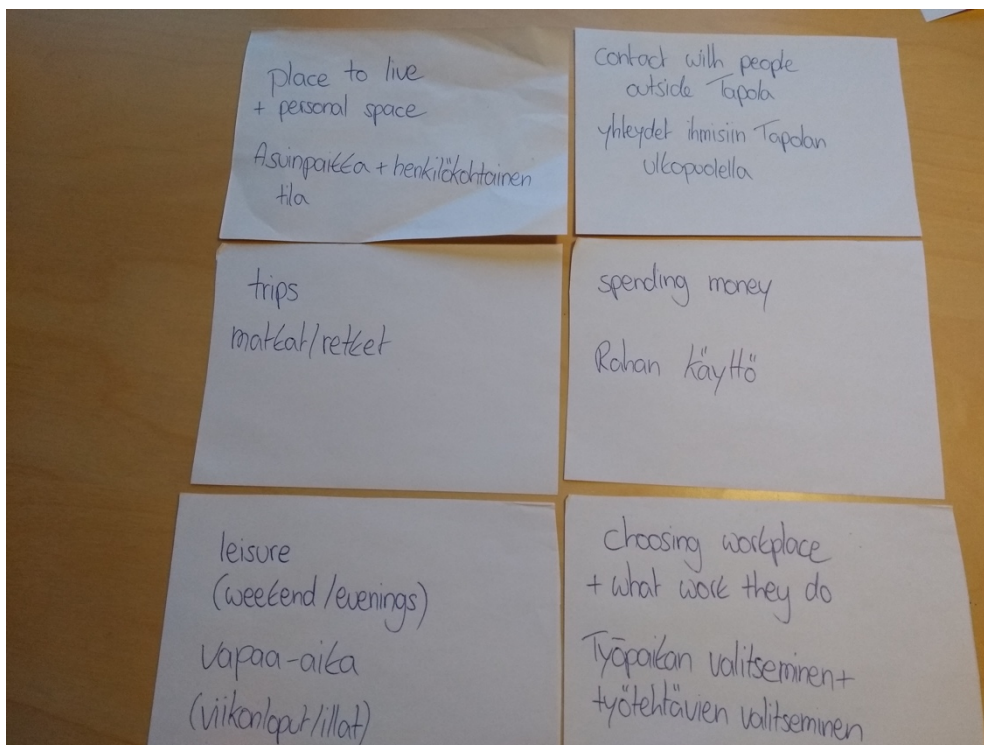
Figure 2/3
were created to give a visual overview of the results. The figures were made by the author on the 13.11.2018 using the bubbl.us webpage as a tool

14   Appendices

Appendix 1: Picture of the first focus group setting
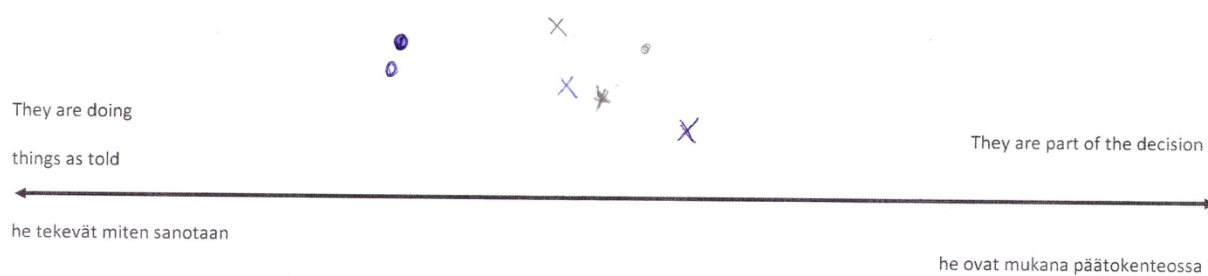
Appendix 2: Topics of discussion for the first focus group

Appendix 3: Picture of the second focus group setting

Appendix 4: Result of the first question of the second focus group

How would you rate the villagers possibility to be part of decisions?

They are doing

things as told

They are part of the decision

he tekevät miten sanotaan

he ovat mukana päätokenteossa

Appendix 5: Questions of the second focus group

1. Are the villagers part of bigger decisions? (Decisions that not only concern them)

2. Do the workers consider their opinions? Are they listening?

3. E.g. village meeting is a way of participating. How can the villagers be more involved?

4. Can the villagers articulate their needs?

5. Can the villagers be autonomous? Are there too strict rules?

6. How much contact do they have with people outside the WLP organisation?

Appendix 6: Question of the interview with the service users

11. What do you like to do in your leisure? Who decides what you can do in your free-time?
12. Can you decide how your personal space is decorated?
13. Who decides to which trips the house is going (Are you going on trips and can you decide where? Are your wishes heard?)
14. Who chooses the place where you live and are you happy with the decision?
15. Did you choose your job?
16. How often do you have contact with people outside the WLP organisation? Who?
    Can you take part in decisions concerning the house? Do you have the feeling that you are listened to?
17. What courses/activity would be interesting for you which are not currently offered in the WLP organisation?
18. Do you have a person to contact when you have a problem? Who? Do you tell when you have a problem?
19. Is there something you would like to improve?