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PROMOTING SELF-DETERMINATION OF ADULTS WITH INTELLECTUAL DISABILITIES

The right to self-determination in group homes

ABSTRACT

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Self-determination is an important part of everyone's life. To live an independent and fulfilling live one wants to make their own decisions, both big and small. But what if you have intellectual disabilities and are living in a group home? Even those with limited intellectual comprehension have the right to self-determination. Over the last decade the living situation of many adults with intellectual disabilities changed from institutional care to group homes. During the changes the group homes also changed, and self-determination moved more into the focus of the staff.

This thesis will look at the right to self-determination of adults with intellectual disabilities living in group homes in Finland. The staff members of group homes are responsible for the safety of the residents as well as the empowerment of independent living, and the right to self-determination. To research how the staff is promoting independent living and how self-determined the residents feel interviews were conducted within one group home. The residents were interviewed individually and the staff members in form of a group interview.

To analyze the results the two interviews were compared to show similarities and differences. Surprisingly the focus of the staff on self-determination was mostly orientated towards the eating habits of the residents. They are asking themselves whether they should support unhealthy eating habits or forbid them. They compared the changes in the residents and their self-determination to the times before the law changed. The residents on the other hand were quite content with their independence and self-determination, they understand that they cannot always decide everything, but enjoy deciding e.g., what to spend their money for.

The concluding main point of the research is that more time and communication is needed to fully empower the right to self-determination. The more time the staff spends with the residents, the more they communicate, and in return, the better they understand each other. Residents can talk about their wishes and the staff will understand how to make them reality – or how to explain that the implementation of the wish is not possible. Each resident is unique and needs unique communication, support, and rules.

Keywords: Self-determination, Intellectual Disabilities, Group home

CONTENTS

1 INTRODUCTION

Self-determination is an important part of each individual, and their identity, regardless of their age, gender, and intellectual capacity. Everybody wants to make small and big decisions themselves and live an independent life.

In my thesis I want to research the right to self-determination of adults with intellectual disabilities; specifically, those that are living in group homes, further referred to as residents. How does self-determination influence adults with intellectual disabilities and how can the social service professionals working with them promote it? In the group homes there are many decisions to be made by social service professionals, further referred to as staff. The staff makes decisions every day and there are many factors to consider, but how can these decisions empower the residents' right to self-determination?

Through my own experience of working in a group home I have encountered the struggle between, empowering the right to self-determination, and the responsibility to ensure the safety and health of the residents. The wishes of adults with intellectual disabilities are sometimes not the best decisions for their own health and safety. Therefore, I find it important to research the meaning of the right to self-determination, its understanding in practice, and how to enhance it.

Self-determination, in disability context, has been the subject of research and topic of theses before. For example, Senta Löffel's bachelor thesis "Decision-making, Participation, Self-Determination and Empowerment of People with Intellectual Disabilities in Community Care" (2018), Laura Löppönen's master thesis "The Paradox of assisted self-determination and Participation" (2021).

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2 KEY CONCEPTS AND CONTEXT

In this section adults with intellectual disabilities, group homes, the right to self-determination in context of intellectual disabilities, legislation concerning the right to self-determination, and previous literature will be introduced. The background information this section provides will help to understand the importance of self-determination of adults with intellectual disabilities in group homes.

2.1 Adults with intellectual Disability

According to the World Health Organization (WHO) intellectual disability describes the reduced ability to understand and learn new or complex information and skills. This can result into limited ability to act independently from childhood all the way into adulthood. In other sources intellectual disability is also described as being "characterized by deficits in cognitive and adaptive abilities", by Patel Patel, Greydanus, and Merrick in 2014. They further state that individuals with intellectual disability can be guided by providing medical care, early intervention, special education, and community-based support.

Intellectual disability affects the life in different ways and to various degrees. People with mild intellectual disabilities only need support in certain areas of their life and their independence is barely affected. Others, with more severe intellectual disabilities need continuous support throughout their lives. (Kehitysvammaliitto, 2016). The degree of the intellectual impairment can differ and can be divided into four categories: mild, moderate, severe, and profound. People with a mild impairment score between 50 and 69 on an IQ test, people with severe impairment score less than 50. (Bigby & Frawley, 2010)

Intellectual disability can have different kinds of causes and can occur at different ages. The cause can be genetic, related to substance abuse during pregnancy, lack of oxygen during birth, childhood illness, or injuries. Frequently, the cause remains undetermined. It is estimated that about 0,9% (50 000) of the Finnish population has some kind of intellectual disability. (Kehitysvammasliitto, 2016)

Based on the various degrees of intellectual disability, the different age groups, and the variation of support needed, it is necessary to closer specify the target group of the thesis. The focus will be on adults with intellectual disabilities needing continuous assistance and living in group homes.

2.2 Group homes for adults with intellectual disability

As of 2022 there are about 30 group homes in Helsinki. The city of Helsinki describes group homes functionality, where to find them and how to apply for one on their website. According to their explanation a group home for adults with intellectual disability means supported living with a social service professional available around the clock. The support offered depends on the needs of the residents and the resources of the group home. The services can be care of personal hygiene, guidance, meals, and support in daily activities. The goal is to support the residents to have a rich and independent everyday life, and to promote their right to self-determination. (City of Helsinki, 2022)

Every year a guidance plan is made for each resident. The plan is taking the wishes, health, and life circumstances of the resident into consideration. The employee creating the plan is also working in cooperation with the family, loved ones and work place of the resident. Residents often get one assigned employee, who is responsible for their finances. This employee is managing financial matters, bigger purchases, and is keeping record of expenses. The residents receive guidance and support also in social activities and the most suitable communication methods are used to do so. (City of Helsinki, 2022).

Not all Finnish cities give a detailed explanation of group homes, but the explanation provided by the city of Helsinki is also applicable for group homes in other parts of the country.

The group home subject to the research is located outside of Helsinki. Approximately 15 adults with intellectual disabilities live within the group home. Each has their own room in one of the three different houses. They work in workshops during the day and participate in hobby groups in the afternoon. For privacy reasons the name of the group home and the location will not be named.

2.3 Intellectual Disabilities and Self-Determination

As the word suggests self-determination is about determining about one’s own self. Self-determination concerns small and big decisions about oneself and one’s life. The term self-determination can be used for individuals as determination of one’s own fate and acting independently without restrictions and secondly for groups as independence of a commune. Self-determination is not physically measurable as it is a human construct. Self-determined behavior is shown through actions as “the primary causal agent in one’s life and to maintain or improve one’s quality of life” as Wehmeyer describes. (Wehmeyer, 2005)

In this thesis self-determination refers to “autonomy in regulating one’s behavior and making decisions that fulfil personal interest” (Shipton & Lashewicz, 2017, 946).

The term self-determination can lead to the presumption that it is something done alone and entirely independent, which would raise the question how people, that are dependent on others can act self-determent. People with intellectual disabilities can make many decisions for themselves and they can also be supported to be (more) self-determining. If a person with intellectual disability cannot make certain decisions independently, they should nevertheless be supported to act on their own will, others can make the decisions for them while taking into account the preferences, interests, values, skills, and abilities of the person. (Wehmeyer, 2005)

The Finnish National Supervisory Authority for Welfare and Health Valvira describes the patient’s right to self-determination as a guiding principle in social and health care. The patient must agree to any treatment and can therefore also refuse or cancel treatment. The patient’s own decisions must be respected, even if they can harm their own health and life. (Valvira, 2018)

The Right to Self-Determination is a basic right concerning everyone, including persons with intellectual disabilities, meaning the right to rule their own life and decide about their own affairs and matters. In any social services the wishes and interests of the client must be considered first. Connected to the right to self-determination is supported decision making. The person with intellectual disabilities should be encouraged to make their own decisions and receive support when doing so. (THL, 2022)

Creating an environment where persons with intellectual disabilities can communicate their wishes and determine about themselves is often a challenge. Bigby and Frawley state that to determine what a person with intellectual disabilities wants is not enough to simply ask. They might lack the knowledge, confidence, and communication skills to make and communicate an informed choice. Between 50% and 90% of persons with intellectual disabilities have difficulties communicating. While creating opportunities for persons with intellectual disabilities to communicate their wishes one must take their mode, strengths, and limitations of communication into consideration. The language skills are often over- or underestimated, and communication is too often relying on complex language which is difficult to comprehend. To support choices Bigby and Frawley further give several questions which should be explored with the person with intellectual disabilities: Are they aware of a decision or choice to be made? Are they aware of the potential options? Do they understand implications of each choice? Can they communicate choice? (Bigby & Frawley, 2010)

When restricting the right to self-determination it should always be examined whether there is a real need for restrictive measures. Restricting or limiting the right to self-determination without valid reasons can be considered a violation of human rights. The situation is, however, case dependent and should never lead to endangering the health and safety of the resident. (Kari et al., 2020)

2.4 Legislations and Conventions on the Right to Self-determination

The UN convention on the rights of persons with disabilities recognizes in the preamble section 14 “the importance for persons with disabilities of their individual autonomy and independence, including the freedom to make their own choices”. The convention also states in the next section (15) people with disabilities should be given the “opportunity to be actively involved in decision-making processes about policies and programs, including those directly concerning them” (United Nations, 2016).

In 1977, the Act on Intellectual Disabilities states that every person with an intellectual disability has the right to participate in society while their wishes, opinions, and needs must be taken into account and self-determination strengthened. The amendment of the act in 2006 reinforced the right to self-determination and independent coping. Restrictive measures can only be used to protect health and safety of persons when there is no less forceful solution (Ministry of Social Affairs and Health, 2021). Also, the Act on the Status and Rights of Social Welfare Clients, published in 2000 emphasizes the right to self-determination and participation in Chapter 2 section 8, and in section 9 the right to self-determination in special situations (finlex.fi, 2000).

2.5 Previous research and literature

As mentioned earlier, the topic of self-determination and intellectual disabilities has been subject to research and literature in the past. Matson's (2020) "Handbook of Intellectual Disabilities" talks about self-determination in the chapter "Philosophy of care" and "Problem Solving and Working Memory". Matson (2020) emphasizes that self-determination is teachable and care takers should create frequent opportunities to exercise self-determination.

In the book "Active support – Enabling and Empowering People with Intellectual Disabilities" the authors Mansell and Beadle-Brown (2012) explore the engagement in meaningful activity and relationships. They state:

> "Self-determination can only be achieved if people have options to choose from, the experience with which to make the choices and an accessible method of communication with which to make their choices known – central to doing this is access to and support in trying new things and finding ways to communicate choices" (Mansell & Beadle-Brown, 2012)

Research on how the right to self-determination is being implemented in practice using interviews with social service professionals in the field of intellectual disabilities or directly with adults with intellectual disabilities has been done in several places over the years. While bachelor and master theses of universities of applied sciences are not always academically reliable, they nevertheless show the importance and relevance of a topic.

In 2013 Diaconia University of applied sciences student Tiia Pesonen interviewed residents of a group home in Järvenpää to research how self-determination was seen for her bachelor thesis "Jokanen päättetaan itte omasta elämästä ja omista asioista", in English "Everyone makes their own decisions about their own life and affairs". According to the residents, they can decide about their own lives. Pesonen emphasizes the importance of planning in advance and that the right to self-determination often depends on the staff and their motivation.

In 2018 Laurea University of applied sciences student Senta Löffel published her bachelor thesis titled “Decision making, Participation, Self-determination and Empowerment of People with Intellectual Disabilities in Community Care”. The purpose of the thesis was to raise awareness and inform on the issues listed in the title using focus groups and interviews in an organization for people with intellectual disabilities. Löffel found that communication, planning and motivation could be improved, while the result also showed that the service users are overall satisfied.

In 2021 Laura Löppönen wrote her master thesis at Diaconia University of Applied Sciences with the title “The paradox of assisted self-determination and participation”, reviewing literature on professionals facilitating self-determination and participation of people with intellectual disabilities. She collected several factors to enable and create self-determination in her results. These factors where “the relationship between the staff and the people with intellectual disabilities”, “attributes related to the staff”, and “support from service providers and staff managers to the staff”. According to Löppönen a trusting listening relationship between staff and the residents enables and enhances their participation. The staff also hold great power over the quality of self-determination and participation. On the other hand, performance of the staff is influenced by the group home management, it is onto them to create a safe environment for the staff and the residents.

3 PURPOSE OF THE RESEARCH

The right to self-determination of adults with intellectual disabilities in group homes is concerning and influencing the everyday life of the residents, but also of the social service professionals. Therefore, the research questions of this thesis are also concerning both groups. Purpose of the questions and therefore this thesis is to emphasize the importance, prove the effect and empower the right to self-determination of adults with intellectual disabilities.

The first research question is looking at the effects of the right to self-determination, whether it is supported or denied.
How does self-determination affect adults with intellectual disabilities?
The second research question is looking for actions by social service professionals to promote and empower the self-determination of the residents.
How can social service professionals promote the self-determination of adults with intellectual disabilities?

4 DATA COLLECTION THROUGH INTERVIEWS

The following chapter will elaborate on the data collection through interviews. Important to consider therefore are consent, privacy, data storage, and the two target groups adults with intellectual disabilities and social service professionals. The data was collected through individual interviews and semi-structured focus group. Further, I will describe how I analyzed the collected data.

4.1 Consent, Privacy, and Data Storage

Informed consent to participate is important in research, as it is a central ethical principal in research with human participants (TENK, 2019). To ensure that all parties understand and give consent to be part of the research I handed out consent declaration forms after explaining the research. All participants were informed that they could withdraw their consent at any time, their data is going to be used solely for the research of this thesis, and that it will be destroyed once the thesis is published. The transcript as well as the written interviews do not contain the names of the participants, they are labeled with letters. After completing and publishing this thesis all material and data will be deleted, until then they are stored on my computer, to which no one besides me has access to.

4.2 Target groups

There are two target groups for this thesis. One is the residents of the group home and the other the social service professionals working in the same group home. I chose those two groups two get a perspective from two different sides. The right to self-determination is concerning the lives of the residents, and the social service professionals are expected to support and promote the right.

As all interviewees live or work within the same group home, the result will provide different viewpoints onto the same situation and makes comparing the answers easier. At the same time focusing on one group home limits the outcome. The answers give only an impression of a single environment and the situation at other group homes can be different.

I chose a group home for adults with intellectual disabilities in a Finnish city outside the capital area. Previously, I had worked in a similar group home in a more rural location, through this work I got familiar with said city group home and did a three-month internship. During the internship I got familiar with some of the residents and the general structures of the group home, which helped me choose the right days for the interviews and gave the residents a certain level of trust to talk to me and answer my questions.

4.2.1 Respect for vulnerable groups

Adults with intellectual disabilities are a vulnerable group as it cannot be assumed that they are always able to communicate their own interest. Usual procedures might have to be adapted to ensure the participants self-determination. Therefore, it is especially important to ensure that each resident is informed about the research and knows what she or he agrees to. Furthermore, it cannot be assumed that usual research methods are appropriate or can be used the same way as usual. (National Committee for research in Norway, 2006)

To adjust the interviews to the abilities and needs of the residents of the group home I choose a few, easy to understand questions (Appendix 1). I chose residents who are able to understand and answer the questions and can read and write. During my previous internship I got to know the different abilities of the residents, which helped choose potential candidates for the interviews. Enough time was reserved to explain my studies and my research to each resident in a way they could comprehend. I was careful to not create any pressure onto potential participants to participate. Everyone was informed that they do not have to answer any question they did not want to answer, and they can quit the interview at any time. I did not record their voices but wrote down their answers immediately to show them what exactly was written down about them. I ensured their privacy by letting them choose the interview location, they could choose between shared areas of the group home like the living room with others, alone in the common kitchen or in their private room. As we could close the doors of the kitchen, they did not need to invite me to their private room to answer the questions without others potentially listening. The three options made it possible for the residents to choose the environment they are most comfortable in. Furthermore, I explained how their privacy will be respected, and they will not be named in my research, neither would I tell the staff or other residents how each of them had answered the questions.

4.3 Qualitative Research and Semi-structured Interviews

As part of my qualitative research, I collected data by conducting semi structured individual and group interviews. Qualitative research is often used to explore, investigate, and learn to understand some dimension of social life. Qualitative research values people's subjective experience and the deep understanding even from smaller groups. (Leavy, 2017) As I wanted to collect people's subjective perception of self-determination qualitative research and semi-structured interviews provided the best method.

The semi-structured interview is one of the major forms of qualitative research. Typically, the researcher has a list of questions but is also flexible about when and how to ask the questions, and how the interviewees can respond. This allows more space for the interviewee to answer in their own pace. (Edwards & Holland, 2013). Semi-structed interviews were most fitting for my research as they allowed me to be prepared with questions while also having the freedom to collect more than just direct answers to my questions.

The interview questions (Appendix 1 & 2) were prepared beforehand and were formed through the research questions. To adjust to the conditions of the two target groups the interview questions were divided in two parts of five questions. The first set of questions were for the individual interviews with the residents of a group home, while the second set was for the group interview with the workers of the group home. Both sets of questions were similar but made fit for the target group.

4.3.1 Individual Interviews with the residents

The individual narrative interviews followed the idea of the interviewee telling their own narrative about self and identity (Edwards & Holland, 2013), or in this case perception of self-determination in their own life.

The questions prepared for the residents were meant to encourage them to think about their own life and the self-determination they have or do not have. While formulating the interview questions for the residents (Appendix1) I considered the possible variety in comprehension of the questions. The length of the interviews was intended to be quite short, estimated 10 to 20 minutes, taking into account eventual short attention spans and valuing the resident's free time. The interview questions for the residents are designed to answer the first research question (How does self-determination affect adults with intellectual disability?).

The first question focused on their basic understanding of self-determination, leading to the second question, in which it was asked for them to give an example of when they feel self-determined. As the term "self-determination" is not understood by everyone, I also asked easier questions. The last three questions were meant to encourage them to tell something about themselves. The examples could potentially give an insight on self-determination in their lives, even if they might not consider some situations or incidents as self-determination, they may in fact be. That includes feeling heard, having privacy, and something they are proud of. The answers are not necessarily connected to self-determination, but the questions are easy to understand and encourage the residents to tell me more about their life.

Because most interviewees do not speak English all interviews were conducted in Finnish language and later translated to English by me. Talking in their own language made the interviewees comfortable to answer questions and avoided misunderstandings. I did not share the same mother tongue as the residents, which also created a challenge for me and brought the risk of the residents maybe not understanding me. Thus, I found adults with intellectual disabilities to often have great patience with nonnative Finnish speakers. Also, at this time I was given much understanding and I am confident both parties of the interview understood each other.

I chose a Sunday afternoon to visit the group home and conduct the interviews. My intentions were to conduct my interviews on a weekend day to not interrupt any weekday activities or add stress to their day. I questioned two women and four men with different intellectual disabilities and different levels of understanding. Since there are more men than women living in the group home and not all women wanted to be interviewed it was not possible to have a more equal gender balance. I interviewed the 6 residents individually. There are about 15 residents living in the group home, I asked 10 of them if they want to be interviewed, four rejected. The four rejections had a positive effect for those participating to see that it is ok to say no and that they do not have to participate. Due to the time schedule of the group home, I was not able to ask the last five residents. 6 interviews are not a lot for one research, in this case the answers are similar and give a good enough perception on the topic. Individual answers cannot be seen as a generalization, nevertheless, each opinion and story are worth being heard and are valuable to this research.

I explained beforehand where and what I study, the topic of the thesis, and why I would like to interview them, then I asked them if they wanted to be interviewed and where they would prefer to be interviewed. Some chose to conduct the interview in the common living area, some preferred some privacy but were not comfortable to invite me into their own room; for these cases we conducted the interview in the kitchen. Others preferred more privacy and invited me to ask them my questions in their room. As mentioned earlier, I did not record the interview but wrote down the answers on my laptop. I found that way of collecting the interview data was easier to understand for the residents and I could show them what I wrote down after the interview. The answers were usually quite short, and all 6 interviews made 2 written pages in word using font Arial, size 12 and line spacing of 1,15. The table 1 below shows a list of the participants, to not reveal their identity letters are used instead of names, their gender, when the interview took place and how long the interview lasted in minutes.

Participant	Gender	Date	Length
A	Male	February 2022	15 min
B	Male	February 2022	10 min
C	Female	February 2022	15 min
D	Female	February 2022	25 min
E	Male	February 2022	5 min
F	Male	February 2022	10 min

Table 1. Individual Interviews with the residents of the group home

4.3.2 Focus Group Interview with the social service professionals

The day after the individual interviews I came back and took the opportunity of a staff meeting to ask 5 social service professionals my questions. This time in form of a focus group interview. A focus group interview includes a small group of six to ten participants, in which a topic previously chose by the researcher is discussed. The researcher moderates the discussion with a series of questions to guides its course. Focus group interviews give the opportunity to provide conditions in which the participants feel free to voice their opinions, agreements between the participants can lead to a more elaborated picture of their views, disagreements can lead to participants defending and explaining their views. (Edwards & Holland, 2013)

In this case the discussion was guided by the previously prepared questions (Appendix 2) and the small group consisted of three women and two men. They have different kind of professions (nurse, practical nurse, Bachelor of Social Services) and have been working in the group home for different amount of time (recently started up to a few years).

Before starting the interview, I explained my thesis, and asked for their consent to record the interview with the "Voice Memos" app on my phone, to which all agreed. The recording is 30 minutes long and after transcribing and translating it turned into 4,5 written pages in word using font Arial, size 12 and line spacing of 1,15. During the interview the participation was not equal between the interviewees, some were active and responded in great depth to each question, others were mostly listening and gave short answers. Nevertheless, the feedback of all participants was positive, and everyone said they profited from the discussion.

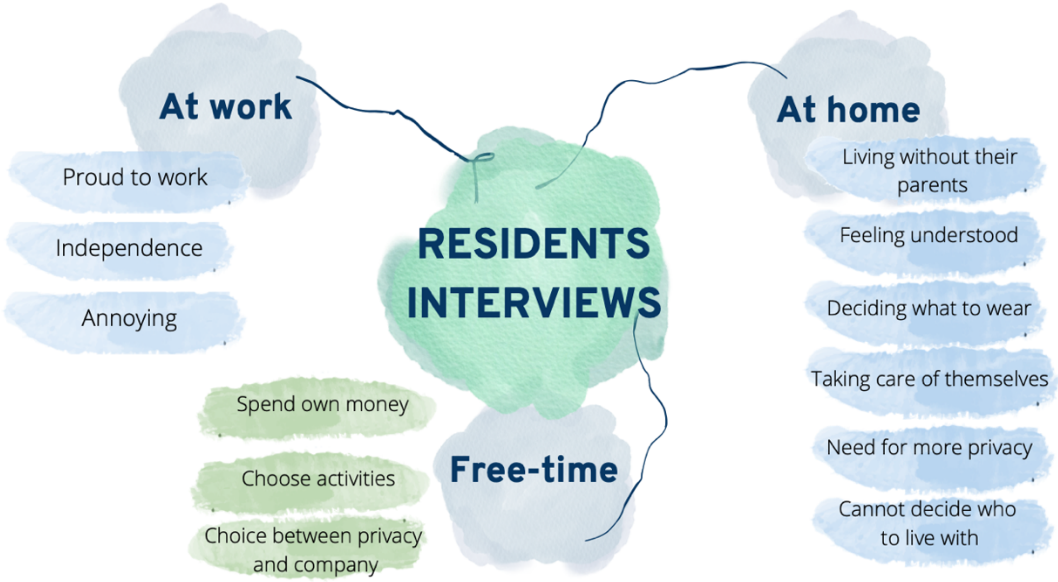
4.4 Content analysis

Analyzing qualitative data can be complicated and confusing. It often involves "taking all data in, digesting them, taking them apart, then putting it back together again" (Wellington & Szczerbinski, 2007). I used a content analysis to analyze the collected data guided by the steps for analyzing qualitative data provided by Wellington and Szczerbinski. According to the University of Helsinki content analysis is used to analyze concepts or themes from data to make inferences about the factors and actors around the data, requiring a close reading of a relatively small amount of text. (University of Helsinki, 2021)

The first step to analyzing the collected data was taking notes of the first impression directly after the interviews. This helped me to remember incidents and answers that I found especially interesting or of importance. Next step was the transcription and translation of the group interview, which also helped to remember important details, which I added to my notes. I listened and translated carefully to not change any details of what was said. To avoid mistakes, I divided the recording in three parts and re-listened to each part after transcribing it before moving onto the next.

Once all interview data and notes were collected in word documents, I organized and categorized the marked relevant parts by reoccurring themes, color coded into red for negative or critical comments and concerns, and green for positive like examples or empowerment of self-determination or independence.

To sort the newfound relevant parts and combine them with my previous notes I created themes, which I visualized in mind maps. Mind maps are often used in qualitative research to assist planning a research, collect qualitative data or to analyze data (Wheeldon & Ahlberg, 2019). First, I sketched the mind map on paper, then created a digital version on canva.com. In total I created three mind maps. The first (Graphic 1) for the interview with the residents, the second (Graphic 2) for the group interview with the staff and the third (Graphic 3) to combine and compare the first two. The themes for the individual interviews are “At home”, “At work”, and “Free time”. The graphic 1 below shows the first mind map.

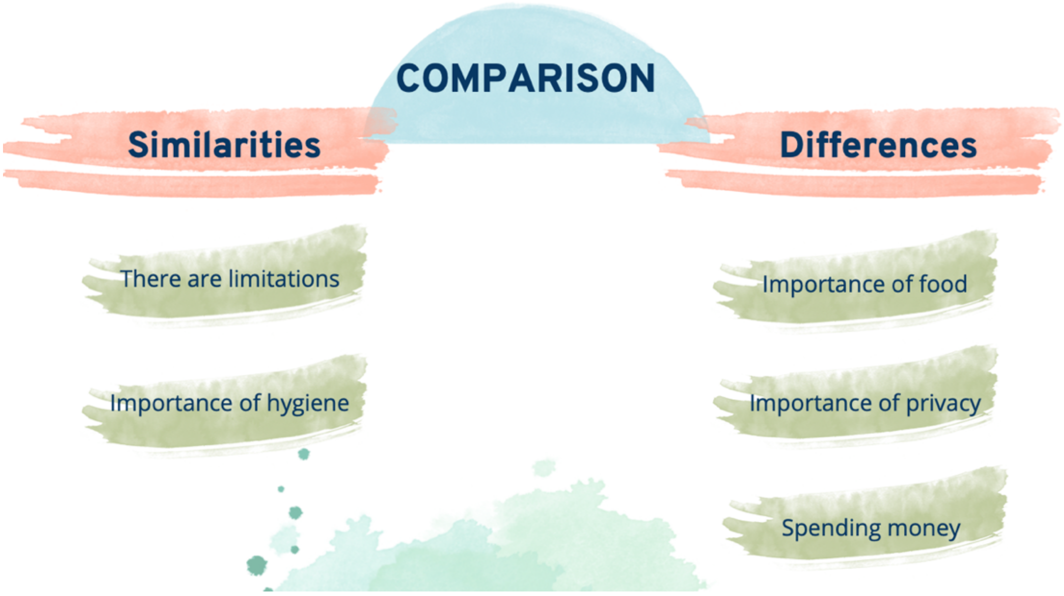


Graphic 1. Mind map Residents Interviews

The graphic 2 below shows the second mind map. The themes for the group interview are “Food and hygiene”, “Right and wrong”, “Changes before/now”, and “Communication”.

Graphic 2. Mind Map Group-Interview

The most challenging and interesting one was the last mind map, shown in the graphic 3 below, as it shows what the two groups share and where they differ. The themes for the comparison are “similarities” and “differences”. To combine the two interviews in the analysis I collected important topics both groups emphasized, and topics emphasized by one group, but not mentioned by the other.



Graphic 3. Mind map Comparison

Visualizing the content analysis in mind maps made it easier to extract relevant results and later draw following conclusions. The results of the content analysis and the mind maps are presented and explained in the next chapter.

5 RESULTS

In the following chapter I will present the results of my research. The chapter is divided in the results of the individual interviews, the group interview, and a short comparison of the two interviews.

5.1 Results of the individual interviews

The individual interviews showed that most residents were content with their independency and self-determination. From the interviews I was able to extract the most relevant keywords (in bold), which I am going to list here with further explanations:

Content with their life: 5 out the 6 told me they are happy with their life and the amount of decision they can freely decide each day.

Living in the group home without their parents: being able to decide what to wear, and to take care of themselves contributes a lot to the sense of independence and self-determination.

Their **workplace** contributes a lot to the overall feeling of being independent and having or doing something they can be proud of. 5 out of 6 mentioned that they are proud of their work, however, some also mentioned that having to get up in the morning to go to work is annoying.

Most residents (5 out of 6) knew about the right to **self-determination** and were able to give me a somewhat accurate description. They perceive the right to self-determination as the right to decide certain things in their life, more so in their free time. One stated that it is sometimes difficult to know when they should ask for permission first.

Spending their **own money** and deciding on what to spend it on, is one important part of their self-determination. They are aware that they only decide about smaller amounts and that other people (their parents/guardians) decide over greater sums.

Privacy, deciding when to spend time with others or being able to decide when to have some alone time contributes to the sense of independence and self-determination. Therefore, a lack of privacy is one main factor for most residents to not feel self-determined. One resident noted that she/he would like to choose who to live with and which of the staff comes to her home to help her. Overall, this participant was rather unhappy about her living situation, while she enjoys making smaller decisions in her live, she would also like to make those with a greater impact. She feels like nothing is "really great" and was also not able to tell me something she would be proud of.

5.2 Results of the group interview

The biggest focus while talking about self-determination was on what to forbid and what to allow. It was clear to forbid anything that could harm them or others. Less clearly, it seemed, were smaller decisions about everyday activities like food and hygiene. The example for the discussion was persons with intellectual disabilities who are obese or with limited communication abilities. Food and basic hygiene are something the staff feels responsible for, but also something the residents like to decide for themselves. Questions like how much to eat and how often to shower come up regularly according to the staff, and in their experience, common rules and open discussion helps best to find solutions and answers. When communication with the resident is limited, open discussion is more challenging, the question was "is it self-determination when all the person can say is Marabou and no?".

One staff member stated that self-determination is a very individualistic thing and must be seen differently for each resident, depending on their understanding and communication skills. The staff should not give their responsibility away too easily and allow everything just because it is the residents wish and call it self-determination.

The staff feels that they cannot expect the residents to obey rules they could not keep themselves, everyone likes to eat a little unhealthy every now and then, likes to stay up late, play video games or similar. But how to decide what is right and wrong is sometimes challenging according to the staff. Sometimes, input from outside helps to set rules. For example, when there are instructions from a doctor. Everyone has the right to self-determination, but it is not unlimited. Everyone must play by rules and respect others.

A comparison to how things were done before the law was changed came up. The old rules did not give them much self-determination but provided a sense of security for them. For example, the bedtime, how many glasses of milk were allowed with dinner, and many other little things. The staff pointed out that many of these old rules did not make much sense, but someone set them years ago and that was how it was done, and nobody questioned it. Many residents were used to having everything decided for them and when the law changed, they were rather overwhelmed with their new freedom and the choices they were expected to make. Especially so, in the older generation, that has spent many years in the group home and is used to the old rules. Being confronted with decisions they never had to make themselves before even scared some and created a sense of loneliness. Those residents need more guidance and support. The new law also challenged the staff to rethink every rule and to find ways to give the resident more self-determination. They found that the discussion within the team and with the residents was the best way to set new rules.

Communicating and explaining self-determination with the residents is important according to the staff. Some residents might think they can now decide everything and must learn what they can decide about and where rules and safety limit their self-determination. The starting point for self-determination is the wishes of the resident, but the staff must make sure the wishes are not coming from someone else, like their family or friends.

5.3 Comparison of individual and group interviews

While the staff often talked about conflicts with the residents, when having to restrict the right to self-determination, the residents seemed quite content with the amount of self-determination in their lives and accepted that they cannot always get what they want. Interesting was, that the most important aspects of self-determination, according to the residents, was not mentioned during the discussion with the staff like spending their own money and privacy. While the focus topics of the staff, regarding food and showers, was not mentioned by the residents. However, both groups recognized that self-determination is limited, and everyone must follow the set rules of the group home. Also, the importance of hygiene was mentioned by both groups; while the staff feels responsible to remind the residents to shower regularly, taking care of oneself is an important part of self-determination for the residents.

6 ETHICS AND RELIABILITY

This chapter will discuss and explain the impact and reliability of the thesis. The National Advisory Board on Social Welfare and Health Care Ethics (ETENE) highlights the importance of safeguarding the following: basic rights, human rights and right of choice. (ETENE, 2012). The research of this thesis is committed to adhere to ethical principles throughout all stages of the process. Research that includes persons, and especially persons with disabilities, carries a higher risk of ethical conflict, if whether intentionally or unintentionally offending participants. The research for this thesis followed the "ethical principles of research with human participants and ethical review in the human sciences in Finland" by the Finnish National Board on Research Integrity TENK guidelines (2019) and the guideline for research ethics in social service, law, and the humanities by the National Research Committee in Norway (2006).

The research of this thesis has been conducted responsibly, meaning, the requirements of the earlier mentioned guidelines are met, such as: consent of all participants, privacy protection, and omitting of plagiarism. The National Committees for Research Ethics in Norway explains plagiarism as duplicating or using ideas, work, quotations of others as one's own. Doing so is considered a breach in ethical standards and harms the credibility of the research. (The National Committees for Research Ethics in Norway, 2016)

Reliability of this research is influenced by the small quantity of participants. More interviews with more participants from several group homes would bring more clarity about the actual situation of adults with intellectual disability and their right to self-determination. The research provides an insight into the situation in group homes in Finland, but it cannot be generalized. The research was conducted and described transparently.

The researcher being familiar with their interviewees can often influence the reliability of the answers or can lead to presumptions. In the situation of this thesis the familiarity between me and the residents helped to have a certain level of trust, which is needed for honest and reliable answers. It was also important for me to see if they feel comfortable, which requires to know the person. On the other hand, the distance between the residents and me was big enough to not influence the reliability of the answers and therefore this thesis.

The language used during the interview (Finnish) differs from the language used in this thesis (English), therefore, there is a risk that some of the information got lost through the translation or the meaning of statements have been falsely translated or interpreted. My own mother tongue is neither of the used languages, however I am confident in all three. Therefore, I am confident that language has not influenced the reliability of this thesis.

7 CONCLUSION

The conclusion chapter is divided in four parts. Firstly, the first conclusions discuss what was standing out and which conclusion were drawn first. The second part is going back to the research question to discuss the answers the research has brought. Additionally, I will reflect on my own professional development and giver further recommendations.

7.1 First conclusions

The first conclusion drawn from the interviews was that what is important to the residents is not necessarily what the staff members see as important. Discussions and disagreements may occur about little things, but the overall feeling of independence is most important. For example, through the sole fact of living on their own within the group home and spending their own money. While every decision the resident can decide on their own empowers their self-determination, rules, a no, or other restrictions do not destroy self-determination. The staff members and research material emphasize that communication and discussing decisions and explaining consequences help to enforce the right to self-determination. Because every person with intellectual disability is unique in the abilities to communicate and understanding, the actual level of self-determination is dependent on the individual case. It is rarely possible to make ground rules for everyone. Discussing residents within the team of staff members is important for the staff to understand each individual resident in the best possible way and to provide the best support and understanding. The challenge here seems to be the limited time and the changes in the team. In a perfect environment each resident could have a choice which staff member comes to their home to support them, and each staff member would have enough time for each resident to listen to their worries and wishes.

The better the staff member knows the resident the better they can assess a situation and answer the question mentioned in chapter 3 made by Bigby and Frawley (Bigby & Frawley, 2010). The better the staff member knows the resident the better they understand the way the resident likes to communicate. Best possible communication avoids to over- or underestimate the resident's ability to understand the decision and its consequences. Knowing not only the resident but also their environment, friends and family makes it possible for the staff member to recognize whether wishes were potentially influenced or dictated by others. Which agrees with Löppönen (2021), that a trusting listening relationship between staff and the residents enables and enhances their self-determination, and Pesonen's (2013) conclusion that self-determination is depending on the staff.

7.2 Research outcome

To get back to and to answer my research questions I will repeat the questions and follow with my conclusion.

"How does self-determination affect adults with intellectual disabilities?"

Like Matson (2020) emphasized the importance of frequent opportunities for decision-making, the research leads to the conclusion that every decision made by the resident is contributing to their sense of independence. But, not only making little or big decisions on their own is an important part of self-determination for adults with intellectual disabilities, also, the fact of living on their own in the group home, without their parents, is perceived as self-determination. The residents enjoy embracing their independence through their work, own home, and spending their own money. Their participation within the group home community and work life contributes to the feeling of living a self-determined life. Overall, the residents are content with their self-determination, like in Löffel's and Pesonen's research.

When small everyday decisions or wishes are denied the mood for the moment is influenced but it seems to not damage to overall feeling of self-determination. When self-determination is denied, the residents often get in a bad mood, blame the staff or the person that told them "No", but also often accept that they cannot always decide everything. Denying self-determination does not only affect the residents but also the staff members, who usually get blamed. The staff seems to want to empower self-determination as much as possible.

"How can social service professionals promote self-determination of adults with intellectual disabilities?"

As mentioned before, every decision, or every option to make a decision counts. Social service professionals can promote the self-determination of adults with intellectual disabilities by creating and communicating these options, and by supporting them to try out new things. The last point is especially relevant for older residents, who have been living in group homes for many years and are still having to get used to living a self-determined life. This conclusion agrees with Mansell and Beadle-Brown (2012), mentioned in chapter 2.5, who emphasized the importance of options and accessible communication to support self-determination.

Social service professionals seem to find it difficult to draw the line between responsibility and self-determination of the resident. They often find themselves in between wanting to decide what is best for the resident's health and the wishes of the resident. One named example in the interview with the social service professionals was the consumption of unhealthy food. While everyone likes to consume sweet or other unhealthy food every now and then the excessive consumption can negatively affect one's health. Especially obese residents should avoid unnecessary calories. As circumstances like health and wishes would differ from individual to individual it is not possible to set simple rules for everyone. Therefore, the line is perceived more like a grey area in which the same decision can sometimes be made by the resident and sometimes not. While the safety and health of all residents must be guaranteed, the responsibility differs from case to case, as each individual resident can take on a different level of responsibility for themselves. The grey area is therefore room for communication, discussions, and assessment of the individual. Setting rules together can help them to understand while still allowing self-determination. For example, explaining the importance of their health, the influence of unhealthy food, setting a limit on unhealthy food together, and letting the resident decide what kind of unhealthy food they want to consume.

Like Löffel concluded in her thesis in 2018, communication is a relevant factor, which holds rooms for improvement. Accessible communication is the most important aspect when promoting and empowering self-determination. Explaining the circumstances, possibilities, options, and consequences in a way the resident will understand and comprehend will empower the resident to make their own decision. In situations the resident cannot decide for themselves communication is even more so important, so the resident understands the reasons. As mentioned earlier, the better the staff knows the residents the better communication can be, and the better self-determination can be promoted.

7.3 Professional development

Throughout the thesis process I developed a better understanding of research methods, gained experience in conducting interviews, and academical writing. Further, I was motivated to conduct the best possible qualitative research to develop my understanding of self-determination of adults with intellectual disabilities.

Combining academical literature with my own research from the working life, finding differences and similarities has been a great learning opportunity and helped me develop my professional skills for my career in social services and eventual further studies.

Academical sources, the interviews and the analysis gave me a better understanding of the right to self-determination, from the resident's point of view and from the staff's point of view. The research helped me to further develop my empathy for both groups.

The support and empowerment of persons with intellectual disabilities will be a personal topic for research and advocacy also in the future. Since the focus of this thesis lays on the situation in Finland, it aroused the interest on the situation in other European countries and especially developing countries.

7.4 Further recommendations

Even though most residents seem to be content with their lives within the group home, and the staff is supportive, there are a few recommendations to empower their self-determination further. The recommendations are for group homes in Finland and for decision makers in higher position, who make funding decisions.

First recommendation is to embrace the communication with the residents and between the staff members. Communication should be made as easy and accessible as possible. For example, by using the communication method chosen by the resident, and connecting to the second recommendation, more time for the individual. The staff should be given enough time, especially when they first start working in the group home, to get to know each resident. They should be able to get to know their personality, wishes, ways of communication etc. This recommendation is not only directed at the staff but also at those in higher positions who decide over funding, and those who plan the work shifts.

This thesis will be made available to the staff members of the group home to expand their understanding of self-determination and to hopefully keep them motivated to empower self-determination of adults with intellectual disabilities.

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APPENDIX 1. INTERVIEW 1 QUESTIONS

Interview questions for the resident of the group home for adults with intellectual disabilities

In English
What does self-determination mean to you? What do you think it does not mean?
In which parts of your life do you feel especially self-determent?
Do you feel understood when talking about your opinions and wishes?
Do you have enough privacy?
What is something you did that you are proud of?

In Finnish
Mitä itsemäärääminen tarkoittaa sinun mielestäsi? Ja mitä se ei tarkoitta?
Missä osissa elämääsi tunnet erityisen itsevarmuutta?
Tunnetko olevasi ymmärretty, kun puhut mielipiteistäsi ja toiveistasi?
Onko sinulla tarpeeksi yksityisyyttä?
Mistä olet ylpeä?

APPENDIX 2. INTERVIEW 2 QUESTIONS

Interview questions for the social service professionals of the group home for adults with intellectual disabilities.

In English
What does self-determination mean to you? What do you think it does not mean?
What do you think is the most important aspect of self-determination?
What do you consider easy or difficult about embracing self-determination?
In your own experience, how does self-determination affect adults with intellectual disabilities? When supported/granted and when denied.
How do you think social service professionals can promote and support self-determination?

In Finnish
Mitä itsemääräämisoikeus merkitsee sinulle? Mitä se ei mielestäsi tarkoita?
Mikä on mielestäsi itsemääräämisoikeuden tärkein osa?
Mikä on mielestäsi helppoa tai vaikeaa itsemääräämisoikeuden tukemisessa?
Miten itsemääräämisoikeus vaikuttaa oman kokemuksesi mukaan kehitysvammaisiin aikuisiin? Kun tuetaan/myönnetään ja kun kielletään.
Miten sosiaalialan ammattilaiset voivat mielestäsi edistää ja tukea itsemääräämisoikeutta?