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Thesis, 2021

THE PARADOX OF ASSISTED SELF-DETERMINATION AND PARTICIPATION

**A literature review on professionals facilitating the
self-determination and participation of people with intellectual
disabilities in group homes**

ABSTRACT

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The Paradox of Assisted Self-determination and Participation – A literature review on professionals facilitating the self-determination and participation of people with intellectual disabilities in group homes

66 Pages. Two appendices.

September 2021

Diaconia University of Applied Sciences

Master of Social Services

Community Development and Conflict Resolution

The 19th article of the United Nations Convention on the Rights of Persons with Disabilities of 2008 obligates the ratifying states to realise the right of persons with disabilities to live in communities rather than in institutions. Based on this article, in 2012 the Finnish government ruled the decision in principle mandating that after 2020 no person with disabilities in Finland would live institutionally but in smaller scale group homes. The transition from bigger institutions into smaller group homes provides a more intimate and natural living environment and thus more opportunities for self-determination and participation for their residents.

Assisted self-determination and participation pose a paradox. This paradox is part of the ordinary life for many people with intellectual disabilities (PWID). The aim of this thesis is to explore through narrative literature review which factors promote and which hinder the self-determination and participation of PWID in their group homes and immediate surroundings. The literature review consists of ten articles published between 2015 and 2021 that were analysed through thematic analysis method.

The two research questions set in this thesis are: Which factors enable and create space for self-determination and participation for people with intellectual disabilities in their everyday lives in their group homes and immediate surroundings? Which factors negatively affect and hinder this self-determination and participation? Through the analysis three themes were derived to answer the first research question of enabling factors: Relationship between the staff and the PWID, Attributes related to the staff, and Support from service providers and staff managers to the staff. To the second research question set of hindering factors four themes were derived: Attributes related to the staff, Attributes related to the people with intellectual disabilities, Physical and organisational restrictions, and the Lack of resources.

In the chapter “Results” these findings are presented, furthermore in the chapter “Conclusions” discussing how based on the research of this thesis, the professionals working in the group homes of PWID can most effectively and committedly work towards the actualisation of self-determination and participation of PWID.

Keywords: Intellectual disability, Self-determination, Participation, Group home

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1 INTRODUCTION

Self-determination and participation are undeniably essential to the human nature. These concepts in their core carry the denotation of independent and self-imposed action. Thus, a paradox arises when a person needs outside assistance to exercise their self-determination and participation.

This thesis studies the concepts of self-determination and participation among the PWID. Its focus group are people with such severe intellectual disabilities that they need constant assistance in their daily lives thus are living in group homes. The thesis focuses on the literature review through which the themes of both supporting and obstructing factors of self-determination and participation of the PWID in group homes are derived and presented to the reader.

There are an estimated 50,000 people with developmental disability, 55,000 people with autism and 6,000 to 7,000 people with cerebral palsy in Finland. People who have cerebral palsy do not necessarily have intellectual disability; this thesis includes those who do. These three groups together form a group of people with intellectual disabilities (PWID) that is discussed in this thesis. Besides these three, several other forms of disabilities belong in the group of intellectual disability, too. (Autismiliitto n.d.; CP-liitto n.d.; Kehitysvammaliitto n.d.)

According to the United Nations' Convention on the Rights of Persons with Disabilities of 2008 a "full inclusion and participation in the community" must be enabled for people with disabilities. This in the article is elaborated to include e.g., "personal assistance necessary to support living and inclusion in the community" (Convention on the Rights of Persons with Disabilities, 2008, 19. article.) Based on this article, and on its Finnish equivalent, the 19th article of Finnish Agreement on the Rights of People with Disabilities, the Finnish government decided in 2010 on reducing the institutional care of people with disabilities, and in 2012 the government ruled the decision in principle that after 2020 no person with disabilities in Finland would live institutionally but in smaller scale group homes (L 27/2016.) During the last decade this shift from institutional living into living in group homes within regular

communities and neighbourhoods has been put into effect both internationally, based on the United Nations' article mentioned above, as well as domestically even though in Finland the goal was not yet perfectly reached by the end of 2020. However, as of 2021, most of the PWID that need residential care now do live in group homes. (Kehitysvammaisten Palvelusäätiö 2015, 3; Super – Hoitoalan Ammattilaisten Verkkolehti 3.12.2020; THL 2020.)

Before, the staff working with PWID in mentioned institutionalised care were focused on providing care and protecting the PWID from any harm that society might bring to them. This recent shift into group home settings with self-determination and participation encouraging environment aspect thus is a shift towards the new mindset of the staff working with the PWID (Overmars-Marx, Thomése & Meininger 2017, 1).

2 IMPORTANCE FOR WORKING LIFE

A master's thesis conducted in the university of applied sciences is required to benefit the working life and is in most cases executed with a working life partner. This thesis process was moulded by the sudden new reality that our world quite drastically was drawn into in the beginning of 2020, the pandemic of Covid-19. Negotiations with three different non-governmental organisations working with people with disabilities the author of this thesis originally was interested in working with all fell through futile. The methodology of the thesis was then changed into literature review. The aim to benefit the working life stayed the same.

For around the last five to ten years in Finland there has been year by year intensifying public discussion of the living conditions of people with disabilities in their group homes. Finnish Autism and Asperger Union states that the negative feedback from family members of the PWID has visibly increased over the last years, the core of the critique being the lack of professionalism of people working in the group homes. In the public discussion it appears that the transition into the self-determination and participation facilitating group homes of the PWID is facing challenges. (Yle 2019a). (Tehy lehti 2019; Yle 2018; Yle 2019b; Yle 2021.)

This thesis aims to reach people working in the group homes of the PWID, or those in other ways involved and advocating for the PWID. It aims to help the professionals to excel in their work through equipping them with the findings of ways of self-determination and participation of PWID actualising or being hindered in group homes to find out the factors that can also be applied in the Finnish group homes of PWID to strengthen their self-determination and participation.

It is estimated that social and healthcare sectors in Finland will need 30,000 more healthcare workers by the year of 2030. As one part of the solution for this it has been presented that more work force must be brought into the country from abroad. Besides the national workers, this thesis can be serving those non-Finnish-speaking professionals already working, as well as in the future coming to work, in this field in Finland. (Yle 2019c; Yle 2019d; Yle 2021c.)

3 THEORETICAL CONCEPTS

In this chapter the central theoretical concepts of this thesis are presented and defined. These theoretical concepts are self-determination and participation, disability (in this thesis more precisely intellectual disability and from within the broader concept of intellectual disability developmental disability, autism, and cerebral palsy) and group home

3.1 Self-determination and participation

In 2001 The World Health Organization (WHO) published the classification system of International Classification of Functioning, Disability and Health (ICF). It analyses both factors related to a person's functional ability as well as the outside factors, the impact of one's surroundings. According to this classification, a person's ability to perform consists of three different areas. These are a person's body, its structure and physiological operation; meaningful actions on personal level and participating on communal level; and a person's immediate surroundings – society, culture, technology and living environment – that affect on one's independent surviving or need for help. (Malm et al. 2012, 10-11.)

There are many ways to define self-determination and participation in different contexts. Participation is a central aspect of human functioning and it is highly researched among the subjects within intellectual disability field. Still, no commonly accepted definition of participation that guides research and practice exists in the field (Dean, Fisher, Shogren & Wehmeyer, 2016, 427.) Finnish organisation 'Tukiliitto' working with people with developmental disabilities determines participation to compose of three elements: autonomy, democracy and communality (Tukiliitto n.d.) In psychology, self-determination is defined as an important concept in each person's ability to make choices and it plays an important role in psychological health and well-being. Self-determination in essence allows people to feel having control over their decisions and lives. It also impacts a person's motivation as they feel what they do will influence the outcome. (Klein 2019.)

In this thesis the core of self-determination compresses into four short questions that all also reflect into each other: “what do I want to do, when do I want to do it, where do I want to do it, with whom do I want to do it”. Self-determination in this thesis is defined as to autonomously regulating one’s own behaviour and making decisions which fulfil one’s personal interests (Shipton & Lashewicz, 2017, 946). This combined with the need for outside assistance to facilitate it naturally makes the process of self-determination not very straightforward and the pursued autonomous regulation and fulfilling one’s personal interests sometimes autonomous in physical aspect only, other times in mental aspect only. Sometimes that action may not be total self-determination in either way but the best compromise possible between giving as little assistance towards the self-determination and as much freedom towards it as possible considering all that plays towards its actualisation in the lives of PWID in group homes. Vaucher, Cudré-Mauroux & Piérart (2020, 112) state that existing studies find a range of factors, e.g., personal characteristics and environmental variables, shaping self-determination among the PWID.

Kåhlin, Kjellberg & Hagberg (2015, 341 – 342) define participation as doing and as feeling giving as precondition for participation the PWID resident related factors, social environmental factors, physical environmental factors, and organisational and policy factors. These four factors in group homes should be to their highest capability moulded into serving the work towards the self-determination and participation in the resident’s life. It is highly important to note that the participation of the PWID may often look different compared to others, given their restrictions, e.g., physical restrictions. Thus, it is crucial to see participation not only as doing but equally importantly as feeling, too. This is how participation in this thesis is defined as – being both doing and feeling. Besides doing things with others, participation often in the lives of the PWID actualises as being in someone else’s doing, being in the space when others are doing the doing thus establishing a feeling of participation.

To participate is not simply to be somewhere together with others doing something but personally to want and choose to be there – to exercise one’s self-determination. Self-determination and participation are inseparably knit together. Svanelöv (2020, 1422, 1433) defines this as a “meaningful involvement in activities and decision-making processes, being able to express one’s voice, and the right to contest when participatory rights are denied”. This combination – self-determination and participation – often in

group homes of the PWID proves a tricky task to smoothly combine. PWID in group homes are by law entitled to self-determination and participation yet they also simultaneously need and are entitled to strong professional care in their daily lives (Convention on the Rights of Persons with Disabilities, 2008, 19. article; L 27/2016).

Their self-determination and participation then paradoxically are dependent on others – in this thesis, the professionals working with them – participation of the PWID largely depending on other people's capacity and willingness to facilitate their interactions. It is important to pay attention that this self-determination and participation in fact is properly and professionally facilitated, as it is central in constituting to quality group home care, as identified by the PWID themselves (Shipton & Lashewicz, 2017, 950). (Kåhlin et al. 2015, 341, 344; Kåhlin, Kjellberg & Hagberg 2016, 131; Talman, Stier, Wilder, & Gustafsson 2021, 98, 99.)

3.2 Disability

Throughout the world history, in every nation and every era, there have been people living with disabilities. 'Disability' is a word used to cover a wide variety of different kinds of scenarios where some specific quality of human function (e.g., sight, hearing, mental understanding, or body part) is either completely missing or is decreased in its function. In Finland people with disabilities during the last century were generally called by names describing their specific disability, such as 'deaf-mute' or 'crippled' – the use of the word 'disabled' (in Finnish, 'vammainen') is rather recent. In this thesis the concept of 'people with intellectual disabilities' is used, the concept more commonly used in English speaking world than merely '(intellectually) disabled'. It also is the concept the author of this thesis prefers and professionally perceives as more proper and applicable. No person in nature is merely 'disabled'. Person may have a disability or many disabilities, yet there are so many other – and more important – factors that determine them and make them who they are. Estimated 10% of the people in the world have some sort of disability. (Kivirauma 2015, 6; Malm, Matero, Repo & Talvela. 2012, 9.)

It is important to note that disability is not same thing as disease. As well as inborn, disability may also be the result of a disease or an accident. Disability may be physical or intellectual. This thesis concentrates on the latter, people with intellectual

disabilities (PWID). Concurrently, intellectual disability can also be called developmental disability. In this thesis the term of intellectual disability is being used. It is important in the society to constantly pay close attention when building up concrete surroundings, on how those with physical disabilities, can best be included in different communities by enabling them to be able to independently move around in their daily lives. It is important to continue developing equipment, public policies and public environments that help these individuals towards the life of increasing independency and inclusion.

However, the focus of this thesis is on the people with intellectual disabilities and how their independency and inclusion – through true self-determination and participation – into their immediate living surroundings and community can be supported. In this thesis the actualisation of self-determination and participation of the PWID is researched in the context of the group homes – their homes – and their immediate surroundings. (Malm et al. 2019, 9; Teittinen 2006, 8.)

3.3 The spectrum of intellectual disabilities

World Health Organization (World Health Organization. Regional Office for Europe n.d.) defines intellectual disability as “a significantly reduced ability to understand new or complex information and to learn and apply new skills (impaired intelligence)”. This impaired intelligence begins before adulthood, has lasting effect on development and causes reduced ability to cope independently. Besides child’s health conditions or impairments, the disability heavily depends on the environmental factors either supporting or not supporting the child’s full participation and inclusion in their society. Intellectual disabilities in their severity vary anywhere between very mild to very severe, nevertheless in some way effecting the person’s capacity to understand, learn and take care of themselves.

Intellectual disability may sometimes also be referred to as ‘mental disability’. However, the term is not to be mixed with mental illnesses or disorders. Person with intellectual disability in some weight lacks the cognitive ability to have or understand certain thoughts. Mental illness or disorder – e.g., depression, anxiety, or schizophrenia – in nature does not directly impact cognitive abilities though it naturally impacts a person’s mood, perceptions and thought processes and in so doing is able to

have massive impact in their function. Mental illnesses and disorders however are that – illnesses and disorders – thus are possible to be cured of or they can go into remission. Intellectual disabilities on persons are not possible to cure. People with intellectual disabilities – e.g., autism, learning disability, Fetal alcohol syndrome (FAS), Williams Syndrome or Down Syndrome – can and should however be cared for with quality care, and with the disability that indelibly is part of them be helped to achieve their individual fullest potential in life. The 24th article of the Finnish Convention on the Rights of Persons with Disabilities (L 27/2016) ensures the sufficient care to persons with disabilities for development in their personality, talents, and creativity to reach their fullest potential. In the article the same enabling possibility through sufficient care to reach their highest individual potential is also ensured to them in their mental and physical abilities. (Metteri, Valokivi & Ylinen 2014, 142 – 143.)

This thesis will not present every different group inside the gathering category of intellectual disabilities but presents three of them whose self-determination and participation the studies reviewed in this thesis explore: developmental disability, autism, and cerebral palsy.

3.3.1 Developmental disability

In this chapter for the reason of clarity the concept developmental disability (“kehitysvammaisuus”) is used, though it would be grammatically correct to also call this group “people with intellectual disabilities”. However, in this thesis the concept of intellectual disability includes three kinds of intellectual disabilities: developmental disability, autism, and cerebral palsy. These forms of intellectual disability are presented in the ten studies that this thesis analyses.

Developmental disability is one form of the overarching category of intellectual disability. Down Syndrome is one example of this kind of developmental disability. According to the Finnish legislation, a person with a developmental disability is defined to be a person whose development or psychological action is prevented or disturbed by disease, defect, or disability that they are either inborn with or have developed during the age years of child development, and who through no other existing legislation cannot obtain the services they need (L 519/1977.) In practice, this

definition gathers in every major impediment during the development of person. In Finland, the IQ (intelligence quotient) of under 70 and visible difficulties in social interaction in life of a person under the age of 18 form the criteria for the definition of intellectual disability. Developmental disability appears in a person before the age of 18. (Malm et al. 2012, 165; Seppälä 2017, 38 – 39.)

Developmental disability affects a person's ability to understand and to comprehend. Learning new things and conceptual thinking is challenging to a person with developmental disability, though as with any other person, the upbringing, individual experiences in life and living environment all influence the development of a person with developmental ability from child to adult. As any other person, a person with developmental disability also has their own personality, strengths, weaknesses, and talents which to develop. The effect of developmental disability in individual's life varies a lot as the disability may be mild, severe or anything in between. Person with severe developmental disability needs constant care provided by others. (Kehitysvammaliitto n.d.; Malm et al. 2012, 165; Seppälä 2017, 40.)

Developmental disability can be caused by many reasons. It can be caused by genes, problems during pregnancy or due to consumption of alcohol by the expectant mother. Developmental disability may be caused if the child severely lacks oxygen during the birth or due accident or disease in the childhood. Around 50% of the causes are prenatal, 12% perinatal (meaning, causes are linked either to birth or lesions appearing during the time span of one month after the birth) and 8% are postnatal. In around 30% of the cases the cause of developmental disability remains unclear. In the cases of more severe form of developmental disability it is more likely that the cause of disability will be found out about than in the cases of more mild developmental disability. In Finland an estimated 50,000 persons have developmental disability. Only part of them have been medically diagnosed with developmental disability. Also, only part of them uses the services or receives benefits granted due to developmental disability. (Kehitysvammaliitto n.d.; Malm et al. 2012, 167.)

3.3.2 Autism

The word "autism" derives from the Greek word "autos", "self", describing the retreating of a person with autism into themselves and the exceptionalism in the way

they communicate with others. Autism is a neurobiological developmental disorder in the brain, affecting the ability of interaction and communication of a person with autism with other people – an estimated half of all people with autism never learn to talk – as well as how they experience and perceive the surrounding world. Many that do learn to speak have problems in speaking clearly and thus may struggle to become understood. This can lead into misunderstandings, then causing the person with autism anxiousness and behaviour disorders. In childhood people with autism are less interested in their peers – the severer the autism the less interest there is – and when reaching adulthood, it is challenging for them to create and keep friendships. It is estimated that worldwide around 1 to 1.2% of the population has autism, which in Finnish scale means around 55,000 people with autism in our society. Around 75% of them are male. Autism varies from very mild to very severe: this is commonly referred to as Autism spectrum. This means that persons with autism either do not need at all or need care of different volume – some little support while others constant care. People with autism often have sensitiveness with regulating different senses e.g., oversensitivities relating to touch, light, sound, taste, and smell. People with autism tend to observe details well, concentrate well in matters that personally interest them and have a strong sense of justice. (Autismiliitto n.d.; Malm et al. 2012, 219 – 220.)

Often people with autism pose visible symptoms when under three years old, challenges in social interaction, in verbal or non-verbal communication, they keep repeating the same behaviour, and strongly react when their senses get overstimulated. It is also possible to be diagnosed autistic in the adulthood especially if the symptoms are on the lighter spectrum of the scale. (Autismiliitto n.d.; Malm et al. 2012, 219.)

3.3.3 Cerebral Palsy

Cerebral palsy, as well as developmental disability and autism, externalises in spectrum from very mild to very severe. In Finland there are an estimated 100-120 children born with cerebral palsy each year making the total number of people with cerebral palsy around 6,000 to 7,000. Cerebral palsy is caused by damage in the parts of brain that regulate movement, balance, and position. Its severeness depends on the scale, location, and time of when the damage happened. The damage can happen during fetus state, during birth, or latest during the early childhood and is permanent though the symptoms can be alleviated through rehabilitation. Cerebral palsy is more

common among male than female. Most people with cerebral palsy also have other conditions. (Cerebral Palsy Guidance n.d.; CP-liitto n.d.)

Cerebral palsy is a group of neurological disorders and disabilities, not only one condition. Cerebral palsy causes different degrees of motoric disturbance to person's balance, posture, and movements. It can also affect the movement of muscles needed in producing the speech making verbal communication stiff and inaccurate. Oversensitivity towards different senses often goes along with cerebral palsy, as well as many other add-on symptoms such as challenges in memory, challenges with intestine and bladder, challenges of eating and nutrition and emotional and behavioural challenges. Some people with cerebral palsy also have developmental disability but cerebral palsy does not automatically equal developmental disability. Those with cerebral palsy in the studies reviewed in the analysis of this thesis also had developmental disability according to the focus group of this thesis, the PWID. While there is no cure to cerebral palsy, treatments and therapies often significantly help a person with cerebral palsy to maintain or to increase their physical abilities. (Cerebral Palsy Guidance n.d.; CP-liitto n.d.)

3.4 Group home

The focus group of this thesis are people with such severe intellectual disabilities that they need constant assistance in their daily lives thus are living in group homes. An academic Merriam-Webster dictionary simply defines group home as "a residence for persons requiring care or supervision" (Merriam-Webster n.d.) The word 'home' in the term immediately implies to the reader that it is a smaller scale place compared to an institution. A group home is a substitute home, usually located in a residential neighbourhood, providing foster care for people with disabilities, or other groups of people such as children in foster care, or elderly people. It is a dwelling place that is licenced to operate, and funded by the government, or a non-governmental organisation. The make-up and staffing of group home varies according to the needs of the group home's residents. In group home residents share common areas and live either in their own rooms, or own apartments, that are attached to the group home. (USLegal n.d.)

4 BRIEF HISTORY OF THE SELF-DETERMINATION AND PARTICIPATION OF PEOPLE WITH INTELLECTUAL DISABILITIES IN FINLAND

From the 17th century until the year 1916 in the area of nowadays Finland there existed a system ('ruotuhoito') in which poor people with disabilities were through auctions placed into the care of households which received money from church to support them. They were placed under the control and will of others and denied the basic rights, such as to move to another place by their own will, or to marry. In the 1930s societal conversation turned its focus and interest from merely taking care of social problems into precautionary and society supporting actions. It was noted how great number of people with disabilities were placed in 'ruotuhoito' and whereas before taking care of the people with disabilities was merely seen as a financial burden to the society, the focus now turned into considering actions that could be supporting the working ability of these people thus making it more likeable that they in fact could benefit the society through their work. Obviously, those with disabilities perceived as being with intellectual capacity enough, were the only ones from whom this could be expected from (Kivirauma 2015, 23 – 24, 26 – 27; Seppälä 2017, 23.)

Finnish movement for the people with disabilities can be seen in force to become to life in the 1970s when the movement, 'New Disability Movement' ('Uusi Vammaisliike'), advocating for the people with disabilities was born. The central ideas and values to it were that also the people with disabilities should be able to decide on their own life, to live like any other individual in the Finnish society. In 1988 the right to personal assistant(s) for those people with disabilities that were proven needing the service was documented in the law of the disability service ('vammaispalvelulaki'). It was first established in 1987, partly replacing the former law of the invalid service ('invalidihuoltolaki') of 1946. The change in the way of thinking can be seen when reflecting these two sets of regulations. While the invalid service law four decades earlier perceived people with disability objects of actions, the law of the 1987 aims to enable those with disabilities to have entrance into the whole scale of what the society offers to all its members and to be able to truly lead their own lives. (Laitinen & Saraste 2014, 6 – 7, 13 – 14, 30 – 31, 34; Vilmi & Jokinen-Virta 2000, 7, 9.)

As discussed in the Introduction, today, to carry out the PWID's full inclusion and participation in community as required by the Agreement on the Rights of People with Disabilities (L 27/2016), the shift over the last decade of the PWID moving from larger institutions into smaller group homes within regular Finnish communities and neighbourhoods has taken place. To enhance the self-determination and participation of the PWID in this law are also documented e.g., the right for liberty (14th article) and movement (18th article), freedom of expression and opinion (21st article) and the PWID's right for education (24th article) and work (article 27th) of their choice. However, as discussed in the chapter "Importance for working life", these do not always actualise in the lives of the PWID.

5 RESEARCH METHODOLOGY AND PROCESS DESCRIPTION

5.1 Research questions

This study aims to answer the following research questions:

Which factors enable and create space for self-determination and participation for people with intellectual disabilities in their everyday lives in their group homes and immediate surroundings? Which factors negatively affect and hinder this self-determination and participation?

These are the two questions that the academic thematic analysis of selected literature will find answers for, presented in the chapter “Results”. Based on these results the reader is then able to form insight in how the professionals can effectively support and committedly work toward the actualisation of self-determination and participation of the PWID in their group homes and in their everyday life environments. Correlatively, the reader will be able to observe what kind of factors to avoid.

5.2 Literature review and narrative literature review

There are many different forms of literature review usable in various kinds of research forms. Common to them all is that they all follow the recognised stages of the research process. For this thesis the method of narrative literature review was selected and used. A literature review first sets a clearly defined research question or questions. It then comprehensively appraises, evaluates, and summarises the literature that is available on the topic into essential – the core – and aims to show how it fits in the larger picture presented in the review. It seeks to give its reader compound and comprehensive information on the chosen topic. The methodology of literature review surveys resources of scholarly articles and other relevant publications. Literature review provides an overview of the sources used in the critical analysis of the investigated subject. (Aveyard 2019; Dawidowicz 2010; Fink 2014; Stolt, Axelin & Suhonen 2016.)

Narrative literature review provides an overview to the subject researched without strict and specific rules and with no methodological rules guiding the choosing of the material. Research questions can be set to be broader compared to many other forms of literature review. Narrative literature review can provide broader picture on the subject researched, and it aims to compress and to combine previous research executed on the subject researched and to carve out convergent or differing results amongst them. In narrative literature review it is possible to use combined review material representing different methodologies. (Salminen 2011, 6 – 7; Stolt et al. 2016.)

5.3 Search strategy

To extract the literature for my literature review I executed searches in four databases: Ebsco Academic Search Premier, ProQuest, CINAHL (Cumulative Index to Nursing and Allied Health Literature), and Medic. Ebsco ASP contains indexed and abstracted journals wide both in variety as well as in quantity. Thus, this database with its multidisciplinary content could well provide for the needs of this thesis. ProQuest is another vast multidisciplinary source of academic literature providing indexes and full texts. CINAHL being the world's most comprehensive database for full-text nursing and allied health journals was an obvious choice of source for the literature research. Lastly, Medic was also chosen to be searched. This Finnish database is rather small compared to the international databases and contains literature of health science. (Bettany-Saltikov, 2012; Stolt et al. 2016.)

5.3.1 Search words

To help form the search words PICO -tool was selected. The acronym PICO also carries another meaning when all its letters are capitalised, but the PICO-tool used in this thesis – only the first three letters being capitalised – carries the meaning of 'Population, Interest and Context', which is suit for the qualitative methodology (Butler 2016, 2.) Search words of 'intellectual disability' and its synonyms, 'participation' and its synonyms, and 'residential unit' and its synonyms were selected. Preliminary searches in selected databases were executed with fewer search words and new synonymous words found in the titles of search results were then added to the final lists of search words to widen the final search sentences to their fullest potential. See in the following page the table of the search words selected according to the PICO -identification tool.

P = Population	I = Interest	Co = Context
mentally disabled OR mental disabilit* OR intellectually disabled OR intellectual disabilit* OR developmentally disabled OR developmental disabilit* OR mentally handicapped OR mental retardation OR physical retardation	participation OR engagement OR involvement OR self-determination OR inclusion OR self-advocacy OR independenc*	residential unit* OR residential care OR residential living OR group home* OR assisted living OR living facilit* OR compound OR group living OR supported living OR nursing home* OR community living OR community group home OR co-residential care

TABLE 1. PICo -identification tool.

5.3.2 Search sentences

MESH -term search sentences for Ebsco ASP and CINAHL were: (mentally disabled OR mental disabilit* OR intellectually disabled OR intellectual disabilit* OR developmentally disabled OR developmental disabilit* OR psychically disabled OR psychological disabilit* OR mentally handicapped OR mental retardation OR psychological retardation) AND (participation OR engagement OR involvement OR self-determination OR inclusion OR self-advocacy OR independen*) AND (residential unit* OR residential care OR residential living OR group home* OR assisted living OR living facilit* OR compound OR group living OR supported living OR nursing home* OR community living OR community group home OR co-residential care). Search mode of Boolean/Phrase was selected as well scholarly (peer reviewed) journals included in the search in the Ebsco ASP. In CINAHL it was manually checked that the sources were peer-reviewed. Time span of published date was in the searches of all four databases set from January 2015 until December 2021.

When searching ProQuest, Ebook Central was ruled out of the search, and peer-reviewed sources included in the search only. Following search sentences were used in ProQuest:

noft(mentally disabled OR mental disability* OR intellectually disabled OR intellectual disabilit* OR developmentally disabled OR developmental disabilit* OR psychically disabled OR psychological disabilit* mentally handicapped OR mental retardation OR psychological retardation) AND noft(participation OR engagement OR

involvement OR self-determination OR inclusion OR self-advocacy OR independenc*) AND noft(residential unit* OR residential care OR residential living OR group home* OR assisted living OR living facilit* OR compound OR group living OR supported living OR nursing home* OR community living OR community group home OR co-residential care).

In Medic database following search word lists were used:

mentally disabled mental disability intellectually disabled intellectual disability developmentally disabled developmental disability mentally handicapped mental retardation physical retardation

participation engagement involvement self-determination inclusion self-advocacy independency independent

residential unit" "residential care" "residential living" "group home" "assisted living" "living facility" compound "group living" "supported living" "nursing home" "community living" "community group home" "co-residential care"

See below the table of the search sentences used.

MESH -term search sentences for Ebsco ASP and CINAHL

(mentally disabled OR mental disabilit* OR intellectually disabled OR intellectual disabilit* OR developmentally disabled OR developmental disabilit* OR psychically disabled OR psychical disabilit* OR mentally handicapped OR mental retardation OR psychical retardation) AND (participation OR engagement OR involvement OR self-determination OR inclusion OR self-advocacy OR independen*) AND (residential unit* OR residential care OR residential living OR group home* OR assisted living OR living facilit* OR compound OR group living OR supported living OR nursing home* OR community living OR community group home OR co-residential care)

Search sentences for ProQuest

noft(mentally disabled OR mental disability* OR intellectually disabled OR intellectual disabilit* OR developmentally disabled OR developmental disabilit* OR psychically disabled OR psychical disabilit* mentally handicapped OR mental retardation OR psychical retardation) AND noft(participation OR engagement OR involvement OR self-determination OR inclusion OR self-advocacy OR independenc*) AND noft(residential unit* OR residential care OR residential living OR group home* OR assisted living OR living facilit* OR compound OR group living OR supported living OR nursing home* OR community living OR community group home OR co-residential care)

Search sentences for Medic

mentally disabled mental disability intellectually disabled intellectual disability developmentally disabled developmental disability mentally handicapped mental retardation physical retardation

participation engagement involvement self-determination inclusion self-advocacy independency independent

residential unit" "residential care" "residential living" "group home" "assisted living" "living facility" compound "group living" "supported living" "nursing home" "community living" "community group home" "co-residential care"

TABLE 2. Search sentences.

Medic is much narrower database than the three others. After the initial search in Medic did not result in usable articles, or ‘hits’, a broader search was executed. First search contained all three sentences and the second search first two sentences presented above. Even with the custom broader search executed, Medic ended up being the only database out of all the four used that did not provide usable articles for this literature review.

5.3.3 Inclusion and exclusion criteria

Included in the search were peer-reviewed full text articles written either in English or in Finnish that were published between the years of 2015 and 2021. As in more details is presented in the chapter “Introduction”, the disband of the institutionalised living arrangement of the PWID is a rather young concept both in Finland, as well as internationally. Therefore, based on this deinstitutionalisation process being very young, and still in process, the time span of the searched articles was seen best to be

limited within five years. This was decided on to limit off studies executed within institutional settings, to be able to find already tried and noted to be working practices of self-determination and participation within the group home settings.

Search words were to focus on people with intellectual abilities. Disabilities of other nature were ruled out from this study. The age group of the focus group was adults and older people with intellectual disabilities. Children and youth were not part of the focus group. All study designs except literature reviews were considered in the search process if they provided answers to the research questions set. Inclusion and exclusion criteria are also presented in the table below.

Included	Excluded
<ul style="list-style-type: none"> - Written in English or Finnish - Published 2015 - 2021 - Full text articles - Peer-reviewed - Intellectual disabilities - Adults to older people - Answers to the research questions set - All study designs except literature reviews 	<ul style="list-style-type: none"> - Non-English or non-Finnish language articles - Published before 2015 - Non full text articles - Not peer-reviewed - Disabilities of other nature than intellectual - Children to youth - Does not answer to the research questions set - Literature reviews

TABLE 3. Inclusion and exclusion criteria.

5.4 Search outcomes and selecting the articles

All together the searches of the four databases resulted 1,527 hits. In this gathering number the results of the second, broader search in Medic, is used. Ebsco ASP yielded 405 hits, ProQuest 832, CINAHL 220 and Medic (the broader search) 70 hits. Out of the total of 1,527 hits ten articles were written in language other than English or Finnish and based on this ruled out. Out of the 1,517 remaining articles then in their separate databases every title and abstract were read and based on that 60 articles selected. At this point the duplicates – 26 of them were found – were eliminated from the process resulting in 34 remaining articles. Full texts of the remaining articles were then read through, and those articles that did not provide answers to the research questions, eliminated. Such reason could be e.g., that the study statistically measured

very specific results of a certain time span in a certain group home, strictly focusing on that context only.

Finally, ten articles were found fit to provide answers to the research questions set. Out of the ten articles five were Swedish, two Dutch, and from Switzerland, Canada, and United States one article from each. While regrettably no Finnish article for this study was found, it was perceived positive that nearly half of the articles used in this study came from the neighbouring country of Sweden. All the articles of the study come from the Western countries yet still the closest cultural comparison society to be found for Finnish society undeniably is one of the other Nordic countries. Thus, hopes were high for good quality analysis findings – applicable for the use of the Finnish group homes of the PWID, too – to be found. See figure of the search process below.

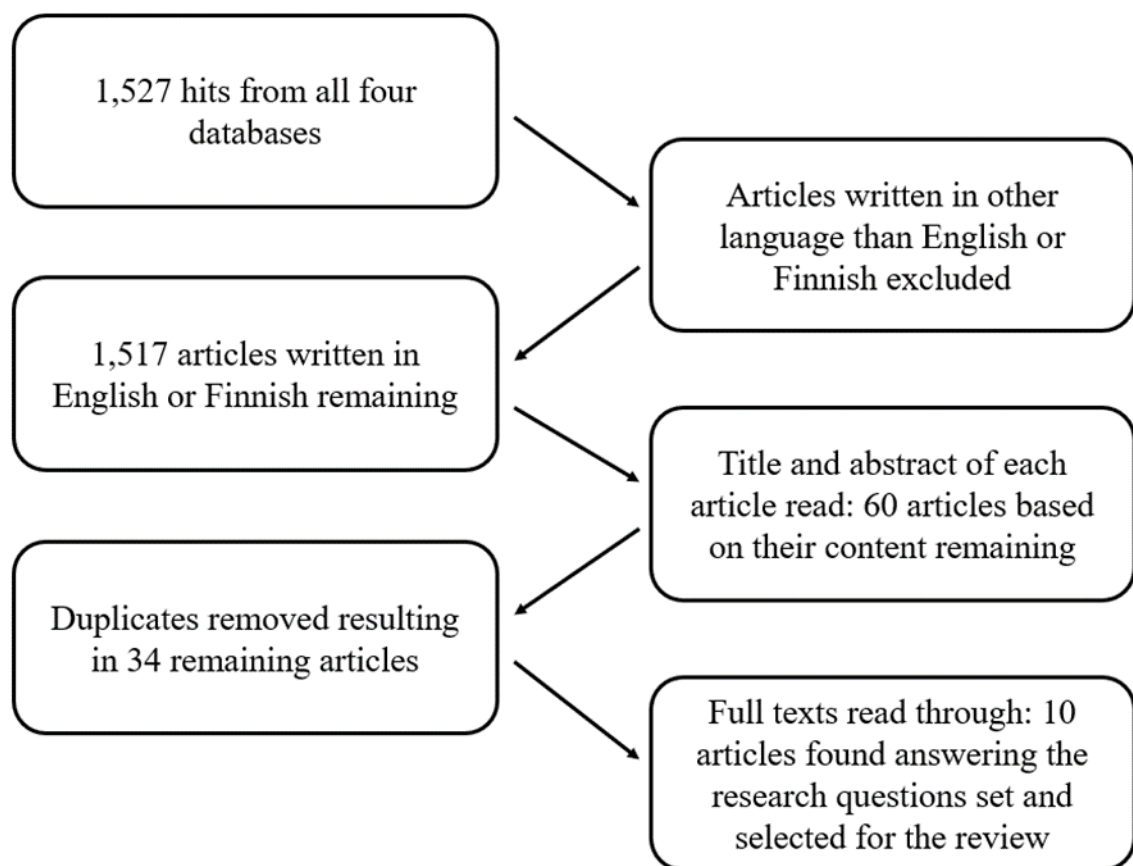


FIGURE 1. Search process.

5.5 The literature selected

Three of the selected studies used observation as their method. One (Svanelöv 2020) executed its research through disciplinary power as the theoretical perspective, one (Kåhlin et al. 2016) combined observations with the interviews of residents and staff and analysed the findings using the computer software package MAXQDA. One (Talman et al. 2021) used the model of Shier's ladder of participation to analyse the data. Two studies were executed using the qualitative interviews of staff as their way of approach. One of them (Berlin Hallrup, Kumlien & Carlson 2019) analysed their content with thematic content analysis whereas the other (Kåhlin et al. 2015) used descriptive phenomenological method for theirs.

Three studies included focus group interviews. One (Overmars-Marx et. al. 2017) executed semi-structured focus group interviews with the staff. The interviews of all nine group homes were audiotaped and transcribed verbatim after which they were content analysed through ATLAS.ti software. The last of the studies using focus group interviews (Vaucher et al. 2020) executed these both among the self-advocates as well as the professionals working with them. The results were then analysed in three parallel phases: a longitudinal analysis, a cross-sectional comparative analysis and lastly a practical analysis. While the research of Sandjojo, Aglaia, Gebhardt, Hoekman, Dusseldorp, den Haan & Evers of 2018 also included the focus group interviews of the staff, the focus of the study was the questionnaires of the PWID. A mixture of statistical and qualitative analysis was used to analyse the results of this research.

The study of Shipton & Lashewicz of 2017 executed a secondary analysis of the data gathered from nine focus group discussions with the PWID, their families and their caregivers. The study of Spassiani, Meisner, Abou Chacra, Heller & Hammel of 2019 utilized interviews and photovoice of self-advocates and their direct support caregivers. The data collected was then analysed through content analysis and the triangulation of data. Detailed chart of the ten articles included can be found in the Appendix 1.

The age focus group of the thesis are adults and ageing people. Two of the articles concentrate especially on people ageing with intellectual disabilities in group homes. While much of the same principles of self-determination and participation naturally

can be implemented into supportive professional work towards both the groups of younger and older adults, it is noteworthy to understand the specific challenges the people ageing with intellectual disabilities (PAWID) are facing. On top of the challenges to participate caused by intellectual disabilities, now with the age-related (growing number of) physical health challenges, such as hindrances in mobility, tiredness, risk of falling and inattentiveness, participation becomes even harder. With PAWID one huge challenge in the way of participation that the staff in group homes needs to carefully address, is also the fact that the PAWID have lived most of their lives in institutions without many opportunities of self-determination or participation. On another note, there are indications that PWID have a faster biological aging process than others. Thus, the findings from the studies concerning primarily the PAWID are beneficial for to understand both PAWID as well as younger in numeric age adult people with intellectual disabilities. (Kåhlin et al. 2015, 336; Kåhlin et al. 2016, 128 – 129.)

Nine out of the ten studies used the term ‘group home’. One (Vaucher et al. 2020) used the term ‘residential facility’, even though the authors appeared to be talking about a similar place as the others who were using the term ‘group home’. The obviously mostly used term ‘group home’ was then selected to be used in this thesis.

5.6 Data-analysis

Thematic analysis was selected as the method of the data-analysis. It can be described as a translator in between different research methods to communicate with each other (Nowell, Norris, White & Moules 2017, 2.) With this method the first step is to identify themes which the selected articles provide. The themes are generated from the main findings or results of each article. The themes are then defined and named; the themes selected are supposed to directly reflect and address the research questions set. When all themes are, concerning all results and discussion of the reviewed articles, extracted, and allocated from the articles, the next step is to merge them. When all the information is being put together and the entirety is visible to the researcher it is time to revisit each theme considering if the theme is fittingly named or after evaluating from smaller components more fitting overarching name to the theme can be found. Also, careful reconsideration needs to be given to whether all the individual themes still fit under the bigger theme or if some of them need to be moved into the box of another theme.

(Aveyard 2019, 141 – 144; Efrat Efron & Ravid 2019, 90 – 92; Nowell et al. 2017, 10; Stolt et al. 2016, 86.)

At this point the similarities and differences in the review findings begin to emerge. There may either be a consensus found in all the studies or conflicting results. Linkages between different themes begin to take shape. In the case of the themes derived not supporting each other it is the responsibility of the researcher to consider the context of each article from where the theme rises, with both the strengths, as well as the limitations of the research approaches taken. Through critical appraisal the articles should be considered. Were there, and which, factors and differences resulting in different results in different studies? Larger sample size indicates it probably being more reliable compared to smaller sampling. Study executed on the same issue but one in a big city and one in a small town could explain differing result. Sometimes no obvious reason can be found in which case the situation needs to be openly addressed in the review. (Aveyard 2019, 144 – 146; Stolt et al. 2016.)

For the analysis the ten articles were carefully read through and any self-determination and participation factor found underlined with green colour. Any hindering factor found correlatively was underlined with red colour. The articles were then reread, and the condensed meaning of every underlined sentence considered. Accordingly, the quote (underlined sentence) was then placed under some preliminary theme group – the preliminary themes began to form and widen as more sentences were added into the developing table. After every quote was added to the preliminary table, they then were moved in between the different boxes of different themes to form more coherent thematic groups. There were some quotes that did not correspond with other quotes and some that did not carry enough weight of information in them. Thus, they did not develop any theme and were removed from the table. An example of the analysis process in Table 4 can be found in the following pages.

Main category	Subcategory	Condensed meaning of quotes	Quotes
RELATIONSHIP BETWEEN THE STAFF AND THE PEOPLE WITH INTELLECTUAL DISABILITIES (1, 2, 5, 10)	Professional yet humane, "normal", relationship (1, 2, 5, 10)	<p>Intentional relationship building crucial</p> <p>Intentional relationship building</p> <p>Staff participating in the doing of PWID</p> <p>Creating respectful relationship</p> <p>PWID hope for real relationship with staff that they spend their days with</p> <p>Professional, yet humane relationship</p> <p>Professional, yet equal, relationship</p>	<p>"First, staff must create a relationship built on trust with the service users. It is important. If they have no relationship with the individual, nothing will work." (1 p. 430)</p> <p>"Another strategy stated by the informants was to establish a trusting relationship between staff and service users. The informants assumed that a trusting relationship was necessary to develop at an early stage in order to establish sustainable opportunities for participation." (1, p.432)</p> <p>"Communication and interaction were also mentioned as important for the experience of a feeling of participation. Several informants mentioned the importance of properly sitting down and watching TV together, playing a game or singing a song. Actually having coffee with the residents, as opposed to just serving them coffee, was considered important." (2, p. 342)</p> <p>"Attention is also paid to the importance of fostering self-worth and building an equal, trusting and respectful relationship with clients." (5, p. 842-843)</p> <p>"Participants saw the social care relationship as a key context for promoting self-determination among people with intellectual disabilities. Indeed, residents considered the presence, support, and encouragement of social care professionals to be key resources. For instance, staff might encourage residents to be more assertive and develop their decision-making abilities, or support them in the achievement of a goal once they had made a choice." (10, p. 110)</p> <p>"Based on our data, professionals can also facilitate self-determination among people with intellectual disabilities by listening to them, trusting them, valuing their actions and decisions, and refraining from expressing judgments or attempting to influence choices." (10, p. 110)</p> <p>"Staff described being able to co-construct relationships based on partnership when they abandoned their need for control, when they reassessed existing approaches, when they revealed themselves, and when they shared their own life experiences with residents. These co-constructed relationships were considered crucial to promoting self-determination among people with intellectual disabilities: 'When all is said and done, we're in a relationship. And in a relationship, you need to do your part. Because I trust him, I can also contribute. I think this is an essential part of building partnership. Without it, we'll never really have</p>

		<p>Listening relationship</p> <p>Relationship crucial to participation and self-determination of PWID</p>	<p>a real partnership. We won't be able to talk about self-determination because that can only be achieved when you can reveal yourself and you can count on the other person's respect'." (10, p.110)</p> <p>"Meanwhile, residents emphasized the importance of communication for promoting self-determination. Thus, people with intellectual disabilities need to be able to express themselves and their desires through words or actions, to discuss their goals and how to achieve them, and to have someone who will listen attentively." (10, p.110)</p> <p>"Our study confirms the results of others (McConkey&Collins 2010; Wehmeyer 1996) that highlight the crucial role played by the interpersonal relationship between residents and professionals in promoting, supporting, and maintaining self-determination among people with intellectual disabilities." (10, p. 113)</p>
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TABLE 4. Analysis example.

Above the reader can see an example of a derived subtheme. Relationship between the staff and the PWID was discussed in many of the articles. Two subcategories were derived under the main theme of "relationship between the staff and the people with intellectual disabilities", out of which "professional, yet humane, "normal", relationship" was one. In this subcategory concepts such as "intentional relationship building", "creating respectful relationship" and "professional, yet equal relationship" were found in the texts. Within this subtheme the ideas of a warm, intimate and acceptive relationship between the staff and the PWID are found to be self-determination and participation enhancing factors. This is recognised by the PWID themselves, as well, as one of the quotes under this subtheme presents:

"Participants saw the social care relationship as a key context for promoting self-determination among people with intellectual disabilities. Indeed, residents considered the presence, support, and encouragement of social care professionals to be key resources. For instance, staff might encourage residents to be more assertive and develop their decision-making abilities, or support them in the achievement of a goal once they had made a choice." (Vaucher et al. 2020, 110)

5.7 Evaluating the quality of the literature selected and the analysis process

To ensure the quality of the literature selected and the process of analysing it academic protocol was strictly followed. Searches for literature were made only in academic databases. Articles selected were all peer-reviewed. The process of literature search is explained in this thesis and can be repeated by the reader if they so wish to do. As described by Nowell et al. (2017, 3) to achieve dependability, one conducting the research should ensure that the research process is logical, traceable, and clearly documented.

Thematic analysis, like any other form has its advantages and disadvantages. It excels in examining perspectives of different methods of research, translating in between them, easily highlighting similarities and differences, and generating unanticipated insights. Thematic analysis excels in summarising key features of a large data set but while it is flexible, this flexibility may lead to inconsistency and a lack of coherence as it develops themes derived from the research data – something that the executor of this thematic analysis constantly kept in mind to ensure the quality of the analysis. (Nowell et al. 2017, 2.)

6 ETHICAL AND AUTHENTICITY ISSUES

The selected methodology of this thesis tends to pose slightly lighter chance with potential ethical and authenticity issues, given that it itself is executed right, than when executing the research through many other methods of research. It gathers the information it processes from different researchers making it statistically more improbable that all the research combined selected through academically executed search would pose serious ethical and authenticity issues, compared to one single research itself (Stolt et al., 2016.) By using methods that include involving actual living people in the process carry higher risk for direct ethical conflict, if unintentionally, or in worst case, even intentionally offending the participants in the process or violating their rights (Bell, 2006.)

While using literature review as the method I perceive the risk for ethical offending smaller than with many other methods I certainly do not see it non-existent. Words carry weight, spoken and written ones. Published thesis will be available for anyone to access online. To ensure its quality, it is important that the thesis is built on strong academic foundation and on the values of honesty and respect. The thesis must be able to portrait an ethical picture of the group of people it focuses on and to talk about them in a respectful way. Literature review is to be objective. It is noteworthy to point out the importance of separating the own views and thoughts of the author of the thesis from of those of the articles reviewed. (Dawidowicz, 2010.)

The data was collected and analysed through academic protocols. The process in details is explained in this thesis giving the reader the possibility to repeat the search if they so will, and to easily find the articles selected for the review should they be interested in reading one or more of them themselves in depth. Every article providing answers to the research questions was included in the review and the results of this thesis are solely based on the collected data.

7 RESULTS

In this chapter I explain the findings of my research of which factors enable and create space for the self-determination and participation of the PWID in their group homes and surroundings, and which hinder and negatively affect it. As this thesis concentrates on how the professionals working in the grassroots level can most effectively and committedly work toward the actualisation of self-determination and participation of the PWID (versus e.g., a research on how to work towards this goal on a higher service provider/state level) it was a positive finding that so many of the answers found and thus themes derived from the articles through the literature review in fact did focus on the attributes of the staff itself.

7.1 Factors enabling and creating self-determination and participation

There were three themes that derived through thematic analysis to identify factors enabling and creating self-determination and participation. These were “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”. Thus, the themes derived through this study were very people centred. Table of the mentioned themes can be seen in the next page.

Main category	Subcategory
Relationship between the staff and the people with intellectual disabilities	Professional, yet humane, "normal", relationship
	Staff producing participation as a feeling to PWID in relation to them
Attributes related to the staff	Staff longevity
	Staff's education
	Staff's (personal) attitudes towards the work
	Staff strongly helping the PWID to do and take responsibility of tasks by themselves
Support from service providers and staff managers to the staff	Staff's focus on person/individual centred approach
	Strong, readily available, daily leadership of staff managers
	Training for the staff
	Facilitating peer mentoring

TABLE 5. Factors enabling and creating PWID's self-determination and participation.

7.1.1 Relationship between the staff and the people with intellectual disabilities

The theme regarding the relationship between the staff and the people with intellectual disabilities was presented in four of the studies out of all ten of them (Berlin Hallrup et al. 2019; Kåhlin et al. 2015; Sandjojo et al. 2018; Vaucher et al. 2020). It is a crucial factor in the process of participation and self-determination of PWID. As Berlin Hallrup et al. (2019, 430) find in their study,

“First, staff must create a relationship built on trust with the service users. It is important. If they have no relationship with the individual, nothing will work.”

While the relationship in nature is professional, it simultaneously should also be a humane one, trusting relationship between the staff and the PWID – a relationship that, as Sandjojo et al. (2018, 842 – 843) describe, is an equal, trusting, and respectful relationship. Kåhlin et al. (2015, 342) and Vaucher et al. (2020, 110) both highlight the importance of a listening relationship – taking time to just be with the PWID, giving them time to express what is on their heart and to be content in trusting that they will be heard. That way, by the staff abandoning their need for control, the PWID will have a real chance of self-determination when the staff is simply listening,

trusting, and valuing them and their actions and decisions. Kâhlin et al. (2015, 341 – 342) note that besides action, participation is feeling. Thus, by having a trusting listening relationship with the PWID the staff not only enables the PWID’s participative action but through simply being there – having a discussion or not – is in fact enhancing their participation.

The study of Vaucher et al. (2020, 113) sums up the importance of relationship between the staff and the PWID when it

“...highlight[s] the crucial role played by the interpersonal relationship between residents and professionals in promoting, supporting, and maintaining self-determination among people with intellectual disabilities.”

7.1.2 Attributes related to the staff

The theme of “Attributes related to the staff” was the most visible within the section of factors enabling and creating self-determination and participation. It in many of its subcategory themes nods towards the first theme discussed above. What qualities does a member of the staff need to be capable of producing and committing for the relationship to be the kind of as described in previous subchapter? Only one study (Spassiani et al. 2019) did not contribute into this theme. This points out how extremely crucial the role of the staff is in enhancing the self-determination and participation.

The subcategories under this theme were staff longevity, staff’s (personal) attitudes towards the work, staff’s education, staff’s willingness to strongly help the PWID to do and take responsibility of tasks by themselves and staff’s focus on person/individual centred approach.

Considering the importance of the first theme discussed it is no wonder that the staff longevity is an important factor toward the participation. When there is staff turnover, creating relationship needs to start all over. Vaucher et al. (2020, 110) find out that staff who remain in a place long term can better promote the PWID’s self-

determination through the formed relationship. Staff longevity also has potential to help shape the culture of a group home (Berlin Hallrup et al. 2019, 433).

As work in group homes of PWID is very much done through one's personality, the staff's personal attitudes towards the work play a big role. The staff pose a huge power in the quality (or vice versa, the lack of it) of enabling and mediating self-determination and participation of the PWID, e.g., staff's willingness to possibly step outside their comfort zones to support and guide the PWID with social inclusion in their neighbourhood, if relations with their neighbourhood is what they themselves wish for, as Overmars-Marx et al. (2017, 2, 6) describe. In work in group homes persistence is often needed to understand residents who could have trouble in communication (Talman et al. 2021, 103).

This brings us to the subcategory of the staff's focus on person/individual centred approach discussed in five of the studies (Kåhlin et al. 2015; Kåhlin et al. 2016; Shipton & Lashewicz 2017; Talman et al. 2021; Vaucher et al. 2020).

“Skills present in residents have proved to be real levers for support for self-determination; some professionals have indeed mentioned the importance of being aware of this and of relying on these existing resources in their support practices. So that these resources can be fully expressed, it is however a question of allowing the accompanied persons to mobilize them in autonomous learnings which make sense for them.”
(Vaucher et al. 2020, 107.)

Both by encouraging, and by creating room for them to helping the PWID to find their inner gifts (Vaucher et al. 2020) as well as closely listening to the needs and wishes of the PWID at given moment are ways of enhancing their self-determination (Talman et al. 2021, 106).

While the personality of the staff and their focus on the individual centred approach, as well as them staying long in a workplace are important, two of the studies also point out the importance of the staff's education. To successfully facilitate the PWID's self-determination and participation, it is important that the staff is knowledgeable in e.g., disabilities and pedagogical approaches and in managing diverse needs and intricacies

in the residents' behaviours (Berlin Hallrup et al. 2019, 431; Shipton & Lashewicz, 2017, 955).

This perspective of education can also be very helpful when it comes to the last subcategory of this theme, the staff strongly helping the PWID in doing and taking responsibility of tasks by themselves, when the staff through education comes to understand its importance. When the staff do encourage the PWID to think and handle things themselves, to perform tasks within their zone of proximal development, the staff facilitates the PWID's learning process. Thus, the PWID's general problem-solving skills enhance through the staff's encouragement to the PWID to try and find solution by themselves. This therefore can help the PWID to become more self-determinant. The staff should be committed to less automatic thinking and listening to the PWID more, letting go of control, letting them take more charge themselves. (Sandjojo et al. 2018, 841 – 842, 846.)

Vaucher et al. (2020, 111) compress the subject in their study stating that

“...staff reported being better able to support self-determination among people with intellectual disabilities when residents felt responsible for their own choices and actions, and when they were given an opportunity to influence decisions made at their residential institution.”

This seems an obvious element to self-determination, but, as will be discussed in the next section of the negatively affecting factors and hindrances, it does not always actualise well.

7.1.3 Support from the service providers and the staff managers to the staff

The last derived theme in this section was “Support from the service providers and the staff managers to the staff”. Like the two previous themes, this one also discusses the theme in a people centred way, instead of physical attributes of the service provider's provision towards the group home. While the first theme focused on the relationship between the staff and the PWID, the last theme of this section discusses the relations between the staff and those leading them.

The service providers and the staff managers could support the staff in their work toward the self-determination and participation of the PWID firstly through strong, readily available daily leadership (four studies discuss this: Berlin Hallrup et al. 2019; Overmars-Marx et al. 2017; Sandjojo et al. 2018; Spassiani et al. 2019), and through providing training for the staff as well as facilitating peer mentoring between them.

Spassiani et al. (2019, 1473) find that peer mentoring can be a key facilitator in sustaining participation initiatives, since direct support staff play a vital role in its actualisation, and staff turnover rates within group homes may be high. Spassiani et al. suggest that peer mentoring thus should be given more weight. Overmars-Marx et al. (2017, 8) explain how peer to peer mentoring is a helpful way of sharing good practices, discussing barriers the staff experience, and discussing and suggesting possible ways of encouraging social inclusion. Overmars-Marx et al. (2017, 1, 8) also discuss the importance of staff management directly providing the training to staff, specific training, and counselling to advancing the participation of the PWID.

Most prominent subcategory, discussed by all four studies, under this theme was the daily direct support the management offers their staff. Team cohesion must be facilitated by the management as it greatly influences the staff's performance (Overmars-Marx et al. 2017, 8.) It is important that the leader develops and maintains strong relation within their team working in a group home, creates safe environment for open discussion and is present in group home supporting and giving instant feedback and can be role models in the ways of working to the staff – this is important for enabling conditions for participation. In the study of Spassiani et al. (2019, 1470) good communication between management and staff is noted not only sustaining participation initiatives but also improving them (Berlin Hallrup et al. 2019, 432; Overmars-Marx et al. 2017, 8.).

7.2 Negatively affecting and hindering factors

When measured by simple glance, this section in content analysis sheet ended up being the longer one – roughly 10 pages compared to the 6 pages of enabling and creating factors. Of this second research question also one more theme than of the first one was derived. The themes around negatively towards the self-determination and participation affecting and hindering factors were “Attributes related to the staff”,

“Attributes related to the people with intellectual disabilities”, “Physical and organisational restrictions” and the “Lack of resources”. Compared to the three people-centred themes derived from the first research question, out of the four derived from the second question set two themes include also physical factors instead of merely people-centred ones. Also, noteworthy is that while there was a clear theme of “Attributes related to the people with intellectual disabilities” found in the themes for the second question, it was very much missing when it comes to the first question set. This implies that the strengths and personal gifts of the PWID are not that much considered when it comes to their self-determination and participation, as are their weaknesses. See below the table of the themes derived.

Main category	Subcategory
Attributes related to the staff	Staff turnover
	Staff longevity
	Staff’s lack of abilities and/or knowledge
	Staff’s negative attitude/lack of interest
	Staff perform activities instead of involving PWID
	Staff choose activities instead of letting PWID to choose
	Staff’s insensitivity and power exert
	Staff’s conflicting roles: care vs. inclusion
Attributes related to the people with intellectual disabilities	Physical condition
	Psychological or cognitive condition
Physical and organisational restrictions	Lack of common space in group home
	Group home’s layout
	Power exerts through physical environment
	Day structure: (pre)set routines
Lack of resources	Staff’s lack of time in their work
	Lack of training and support from the management to the staff
	Lack of funding

TABLE 6. Factors negatively affecting and hindering self-determination and participation.

7.2.1 Attributes related to the staff

Out of all seven themes, the theme “Attributes related to the staff” was the one yielding most content. Every one of the ten studies contributed to this theme, focus lens being on the second research question of the self-determination and participation negatively affecting and hindering factors.

Interestingly, both staff turnover (by four studies: Berlin Hallrup et al. 2019; Spassiani et al. 2019; Talman et al. 2021; Vaucher et al. 2020) as well as staff longevity (by three studies: Berlin Hallrup et al. 2019; Kåhlin et al. 2015; Talman et al. 2021) derived to this theme. Based on what was covered in 6.3, the negative effect of staff turnover is easier to understand. As covered in 6.3.1, the relationship between the staff and the PWID in group homes is the basis on which the self-determination and even more so, participation, build on. With high staff turnover the PWID need to constantly be creating new relationships with new staff, starting all over again each time. 6.3.2 discusses the importance of individual approach, meaning here that the new staff needs to get to learn the PWID with their personalities and personal preferences, which takes time. (Berlin Hallrup et al. 2019, 433; Vaucher et al. 2020, 104.)

Staff turnover could also be a positive factor since Berlin Hallrup et al. (2019, 431, 433), Kåhlin et al. (2015, 345) and Talman et al. (2021, 108 – 109) state the staff longevity too often causes non-PWID-engaging culture withing group homes where things have been done the same way year after year without really questioning why and the staff members believe that they already know the PWID’s preferences thus limiting their ability of inviting the PWID into decision-making processes, self-determination, and active participation. However, Talman et al. (2021, 108) find that

“...when transitions occur, staff often blindly adopt their colleagues’ approaches to working with particular residents, rather than reassessing individual needs and specific circumstances.”

Subcategorised under this theme were both staff lacking abilities and/or knowledge (six studies: Kåhlin et al. 2015; Overmars-Marx et al. 2017; Shipton & Lashewicz 2017; Svanelöv 2020; Talman et al. 2021; Vaucher et al. 2020), as well as staff’s negative attitude or lack of interest (four studies: Overmars-Marx et al. 2017; Shipton

& Lashewicz 2017; Talman et al. 2021; Vaucher et al. 2020). Staff's lack of education and/or lack of self-confidence did show in the first one.

“Most informants said they were aware that participation was a cornerstone of disability policy, and that they worried when they as individuals, failed to put it into practice in their daily work with the residents. Some of them related this concern to their own abilities, knowledge and interests.” (Kåhlin et al. 2015, 344.)

The lack of knowledge or abilities could mean that the staff did not understand what participation in essence is and how it was to be achieved (Shipton & Lashewicz, 2017, 948; Vaucher et al. 2020, 109), did not master the right way of working without unintentionally practising power exert (Svanelöv 2020, 1419 – 1421) or had wrong assumptions of the abilities of the PWID. In the latter case, the staff did not work towards the PWID's participation because the staff perceived it unreachable for them (Talman et al. 2021, 105). These factors are easier to work on through education and management support when the staff is unknowledgeable, but harder to work on if the staff, instead of lacking knowledge or ability, lacks interest and shows downright negative attitude.

Under the subcategory of the staff's negative attitude and/or lack of interest were derived e.g., passive 'wait-and-see-attitude' instead of them actively promoting the PWID's participation (Overmars_Marx et al. 2017, 5; Shipton & Lashewicz 2017, 948, 955), disrespectful treatment (Shipton & Lashewicz 2017, 948) and blatantly turning down resident's invitation to come play with his toys perceived by the staff to be childish and boring (Talman et al. 2021, 104) as well as instead of promoting the PWID's participation the staff's tendency to gather to spend time together just by themselves (Talman et al. 2021, 109).

Related, three studies discussed staff insensitivity and power exert (Svanelöv 2020; Talman et al. 2021; Vaucher et al. 2020). Examples of this range from resident having to apply moisturise to his skin even though he did not need it (Svanelöv 2020, 1428) and another resident denied of having food in her apartment due to an institutional decision (Svanelöv 2020, 1430) to resident denied coffee during lunch but allowed it after lunch imposing that the staff knows the correct way and time of drinking that

coffee and overall what is good for the resident (Svanelöv 2020, 1431) to doors being used as tools of power practice when a door to a resident's apartment was opened or closed not according to their own will but sanctioned through institutional agendas (Svanelöv 2020, 1434.)

“The institutional structure of group homes creates a sovereign and disciplinary power that seeks to shape ideal behaviour;” (Svanelöv 2020, 1429.)

Power exert in group homes very much plays with the ideas of others better knowing how participation is to be constituted as well with institutional ideas of a ‘good resident’ (Svanelöv 2020, 1431, 1434.)

Power exert could also be unknowingly executed when staff tried to balance the conflicting roles of care versus participation. As Overmars-Marx et. al. (2017, 2) state

“To enhance social inclusion, a shift from “caring for” to “supporting” people with intellectual disabilities is necessary.”

Staff may hinder the PWID's participation if they are giving more weight on perceived possible risks (outside the group home such as neighbour encounters, or even inside) than they put weight on the actualisation of participation (Kåhlin et al. 2015, 7). Vaucher et al. (2020, 108) state that professionals need to learn to hold back, let go of their own fears and the need to overprotect the person to enhance the self-determination and participation. Svanelöv (2020, 1421) words it well when he says

“The group home is a context where staff often struggle to balance control, autonomy and guidance, while residents struggle with individuality, identity and intrusions into their private lives.”

Facilitating social inclusion may be a challenging task as the staff may want to protect their residents outside the group homes from what they perceive possible risks in the expense of social inclusion (Overmars-Marx et al. 2017, 7). Even within the group home settings the staff – as well as the relatives of the PWID – may build barriers to

the PWID's self-determination while overprotecting them trying to balance control, autonomy, and guidance (Svanelöv 2020, 1421; Vaucher et al. 2020, 108).

Above discussed protective nature of the staff may be one reason why the staff, instead of encouraging the PWID to choose the activities and be active actors in activities, perform the activities themselves. More often in the studies it appears though that the staff simply find it easier and faster to do tasks by themselves and fail to participate the PWID even if there was time for that activity such as cleaning (Kåhlin et al. 2015, 344 – 345; Sandjojo et al. 2018, 846). Staff members thought they knew the residents well and could therefore decide on their behalf (Talman et al. 2021, 107), simply did not discuss the activities with the PWID (Kåhlin et al. 2016, 131) and often drew on their own preferences when making decisions for the residents (Talman et al. 2021, 109).

“In particular, some people with intellectual disabilities are accustomed to having a passive attitude, to being docile, and having others take responsibility for their decisions and actions. Staff associated these behaviours with a lack of self-confidence, which can trigger withdrawal in residents when their ideas are not accepted.” (Vaucher et al. 2020, 107.)

This is seen in staff performing activities which they perceive easier and faster to do by themselves, such as cleaning the PWID's apartment, even though there would be enough time to involve the resident themselves (Kåhlin et al. 2015, 344-345, Sandjojo et al. 2018, 846). Staff also often choose activities they prefer instead of letting the PWID choose, thus hindering their self-determination. The staff in one of the group homes perceived themselves knowing the PWID well and knowing what they wanted thus the activities were seldom discussed. (Kåhlin et al. 2015, 131; Talman et al. 2021, 107, 109.)

7.2.2 Attributes related to the people with intellectual disabilities

As previously mentioned, while the theme of “Attributes related to the people with intellectual disabilities” did not derive out of the first research question, it did of the second. One study mentioned physical condition as the PWID's self-determination and

participation negatively affecting factor, study concerning the PAWID (Kåhlin et al. 2015). Four discussed psychological or cognitive conditions which were plenty to be found (Kåhlin et al. 2015; Overmars-Marx et al. 2017; Shipton & Lashewicz 2017; Vaucher et al. 2020). Sometimes they were real barriers, other times mistaken by the staff to be hindrances.

Social inclusion was difficult for the PWID for they might not understand their neighbours' behaviour as well as the neighbours did not understand theirs e.g., the PWID's claiming behaviour or them stopping by every day (Overmars-Marx et al. 2016, 4, 5) – on the other hand the PWID might also themselves be conscious of their own 'limitations' thus preventing them from pursuing social inclusion opportunities (Shipton & Lashewicz, 2017, 948; Vaucher et al. 2020, 105 – 106). The self-determination of the PWID was influenced by personal characteristics such as IQ score, further influencing social integration (Shipton & Lashewicz, 2017, 948).

7.2.3 Physical and organisational restrictions

Under this theme – discussed in six studies (Berlin Hallrup et al. 2019; Kåhlin et al. 2015; Kåhlin et al. 2016; Overmars-Marx et al. 2017; Svanelöv 2020; Vaucher et al. 2020) – were through thematic analysis placed two kinds of structures – physical and organisational. Both in the beginning human made – building planned and constructed by people, day and week structure of group home planned by and set in motion by people – but which unlike the previous themes discussed are not inherently people-centred.

Biggest physical restriction was the lack of common space in group homes. This disabled social interaction between residents, staff, and visitors (Berlin Hallrup et al. 2019, 431; Vaucher et al. 2020, 104). Common areas also, if existing, were described small and narrow, not well facilitating for the use they were meant for (Kåhlin et al. 2016, 345). Moreover, group homes were described inaccessible and not particularly inviting to neighbours, thus diminishing the social neighbourhood inclusion (Overmars-Marx et al. 2017, 7). Related to the theme of power exert of staff, the physical environments of group homes were particularly mentioned being tools for power exert e.g., residents needing 'permission' to entry the common areas as well as doors to them kept close (Svanelöv 2020, 1429, 1432).

Organisational restrictions to self-determination of the PWID were posed through strict (pre)set routines and schedules. Residents could not decide on the times of their basic actions such as showering or eating when hungry – institutional clock set times for these ‘support services’ that these normal to every human actions thus became (Svanelöv 2020, 1426 – 1427, 1428). In one group home residents only went out when the staff had scheduled time to support them and could not even do simple doing as to draw outside the scheduled time (Svanelöv 2020, 1427, 1431). While in some group homes daily schedule seemed to be power exert willingly performed by the staff, in others the staff found themselves torn between the desire to encourage self-determination and participation among the PWID while they were obliged to follow institutional procedures and daily routines set for their group home (Vaucher et al. 2020, 113).

7.2.4 Lack of resources

Last of the themes – “Lack of resources” – like the previous one is also not completely people-centred. While naturally the decisions on the things discussed within the theme of theme are man-made, too, in the daily lives of the group homes this is perceived more abstract thing, yet drastically affecting staff’s ability to perform well (or fail) in their work. Lack of funding is seen e.g., in staff cuts. This theme also gathers lack of support to the staff from the management, as it is a highly important factor that the staff themselves are supported with enough mental resources in their effort in supporting and facilitating the participation and self-determination of the PWID.

The subcategories under this theme tangle into each other closely. Five studies (Berlin Hallrup et al. 2019; Kåhlin et al. 2015; Overmars-Marx et al. 2017; Shipton & Lashewicz 2017; Vaucher et al. 2020) mentioned staff’s lack of time for not performing in their work as well as possible, which often is a direct result of the lack of funding. Other times the reason behind can also be the lack of employees available to hire. Staff’s lack of time directly correlates to the PWID’s self-determination and participation. With less staff they cannot do spontaneous things with the PWID. The staff will not be able to answer to the act of self-determination of the PWID, e.g., spontaneously leaving for picnic (Kåhlin et al. 2015, 346). The PWID themselves reflected the importance of the staff facilitation and identified the lack of one-on-one time with staff as a barrier of social inclusion (Shipton & Lashewicz 2017, 948).

Lack of time also takes away from really developing a relationship between the staff and the PWID (Vaucher et al. 2020, 108). Lack of funding may prevent and even cancel already in affect programs aiming to better the participation – such was the case in one group home where the person specifically hired to work as an inclusion ambassador was let go because of the lack of funding (Overmars-Marx et al. 2017, 6). Funding cuts often mean reduce of staff which directly means lack of time for the remaining staff in facilitating the PWID’s self-determination and participation, ability to take them on spontaneous trips, in worst cases even getting to go outside to fresh air (Shipton & Lashewicz 2017, 952, 954; Spassiani et al. 2019, 1471).

Besides the lack of funding the lack of training and support from the management to the staff was by two studies perceived as hindrance to PWID’s participation (Overmars-Marx et al. 2017; Talman et al. 2021). There was no support available or at least it was not willingly promoted to the staff, not encouraging the staff that would need support themselves supporting the self-determination and participation of the PWID (Overmars-Marx et al. 2017, 7).

8 CONCLUSIONS

“Everybody needs some kind of closeness, and I think that is what they get here, either from each other or from us [the staff]” (Kåhlin et al. 2015, 341 – 342.)

Vaucher et al. (2020, 99) point the reader to the fact that practices for the promotion of self-determination usually take place within the interactions between the PWID and the professionals of the group homes thus this relationship is something that needs to be given a strong emphasis. As we see in the results in chapter seven, the themes indeed revolve a lot around the staff, discussing many aspects of them and the – in best case – self-determination and participation strongly and effectively facilitated by them. Whereas “Attributes of the staff” derived as a theme in the enabling factors section of the analysis no proper theme of the PWID’s contributing attributes towards themselves was found. Their skills were occasionally very shortly mentioned, touched on, yet not really specified what the skills particularly were (e.g., Vaucher et al. 2020, 107).

Since the skills of the PWID were not discussed it may imply that they rarely, or only in small quantities, show in many group homes. Thus, it is crucial to focus on how the professionals – to whom so many positive factors were attached to in the studies – working in group homes can most effectively work towards the goal of the PWID’s self-determination and participation. Through the literature analysis the key finding is that the staff – in good and in bad – is the most central part in facilitating this. When they excel in their work is when the PWID are most able to experience self-determination and participation, that they should, and by law also are entitled to (Convention on the Rights of Persons with Disabilities, 2008, 19. article; L 27/2016.)

In the conclusion section of their study Vaucher et al. (2020, 115) state their research suggesting the potential for self-determination of the PWID being defined by the constant interplay between the PWID and their environment – meaning e.g., society, their care facility, education, family, friends, and partner. Thus, it is crucial for the PWID to develop trusting relationships with individuals that can provide them support, advice, and active listening in their decision-making processes. Through the thematic

analysis of the ten articles of this study in the context of group home similar result of the importance of the staff's committed and humane work attitude was derived.

Both enabling and hindering factors derived the theme of the staff in detailed attributes. Besides the above discussed strong relationship with the PWID the most significant qualities – the one most significant in day-to-day work – were staff's positive attitude towards the residents and their work, as well as strongly practicing individual centred approach with willingness to carefully listen to and yield decision making processes to the PWID. The importance of the theme was observed e.g., in the high number of quotes in these subcategories, which derived from the majority of the studies analysed. This was the most central of the findings for how the staff most effectively could support and work towards the PWID's self-determination and participation.

Presented above is one side to the staff of group homes. The other side, as presented in the results of chapter six, is: staff not perceived to be capable or skilful in their work due various reasons such as lack of knowledge or ability, sometimes real lack of interest in the work they do or bad attitude (Kåhlin et al. 2016, 344; Shipton & Lashewicz 2017, 948; Svanelöv 2020, 1419 – 1421.) The results of the analysis highlight the role of management of the group home playing a huge role even before the staff has become staff – interviewing, finding, and hiring the people suitable to work in the field. Once the member of staff – the most central factor to self-determination and participation of the PWID, as the analysis finds – has signed their contract and started the work it is crucial that the management excels in their role of being tangibly present and available for the support of the staff (Berlin Hallrup et al. 2019, 432):

“Creating a safe environment is an important condition for discussing these topics and it is therefore important that service providers invest in developing and maintaining strong relations within the teams working in a group home. Team cohesion is a strong determiner for staff members' motivation and greatly influences how staff members perform.” (Overmars-Marx et al. 2017, 8.)

Significant factor contributing to the sufficiency of the number of staff is funding. Staff's lack of time directly correlates to the PWID's self-determination and

participation. The PWID themselves acknowledge the importance of the staff facilitating their self-determination and participation (Shipton & Lashewicz 2017, 948). Cuts in funding often lead into reduction of staff which then directly leads into lack of time for the remaining staff in facilitating the PWID's self-determination and participation (Shipton & Lashewicz 2017, 952, 954; Spassiani et al. 2019, 1471).

9 DISCUSSION AND FURTHER RESEARCH

Prior to this thesis I have conducted a Bachelor's thesis with a partner. Besides Master's thesis in its nature being more demanding from Bachelor's thesis, also the fact that I did conduct this thesis by myself, has helped me to grow professionally. Conducting this thesis alone has challenged me but created a trust, that I am professionally capable to execute a project this scale – to consider what needs to be done, to plan, and to commit to the work. The subject of the thesis is selected according to my personal professional interests, as I consider the upcoming working life with a Master's degree. Executing this thesis has given me an opportunity to study the nature of the intellectual disability in more depth, its Finnish context, and the concepts of self-determination and participation, concentrating on their enabling and hindering factors in the context of group homes of the people with intellectual disabilities. This also was my first time executing an academic literature review. Now knowing how to execute one will be a valuable skill in the coming working life. I perceive this thesis process strongly enhancing my professional development.

The purpose of this thesis was to research the factors contributing to and hindering the PWID's self-determination and participation in the context of group home. One of the studies, Talman et al. (2021, 100), lists according to the model of Shier's ladder the five levels of participation, first being the very basis and starting point, last one equating full participation. Shier's ladder of 2021 is a newer recreation of the original Arnstein ladder of 1969. This original model presents eight levels of participation (Arnstein 1969). Here I use the term the PWID as the group of experiencing the participation while adjusting it into Shier's ladder: The PWID are listened to. The PWID are supported in expressing their views. The PWID's views are considered. The PWID are involved in decision-making process. The PWID share power and responsibility for decision-making. Reading through the selected articles of my thesis I personally find this model describing the different stages, the possibilities, of participation rather well. It is my hope that the reader after reading this thesis will be able to reflect the findings of the analysis and the heart of the Shier's model and to feel equipped to support the PWID in step by step climbing this ladder higher up.

Domestically, the field of disability work in Finland has been suffering a lack of suitable and knowledgeable workforce for years (Yle 2020). Finland has for years been a known and honoured actor in the international circles through education and community development projects furthering the rights and quality of life of the PWID around the world. Finland had a central role in humanitarian summit in Istanbul in 2016 when declaration was given on central humanitarian organisation of United Nations enhancing and increasing their work with people with disabilities. Finland is also an active actor on rights of people with disabilities in the European Union and has been funding several UN- as well as non-governmental organisation run projects. Considering all this, I was a little surprised when not a single Finnish study that could have qualified in the literature of this thesis was through the search found. No study answering the set research questions executed within the Finnish context was found in the databases used. However, it is possible that with different search criteria such articles could have been found. (Ulkomministeriö 2018.)

Finland may be a strong actor in the field of disability work abroad, globally – how is it then that we can bring back more of it into our own Northern country, too? A Finnish professional working as a project manager with project aiming to bring new workforce into the field, speaks out her observation of how many people working in the field initially actually have ended up there by chance or by accident – then realising, while already in there, how interesting working with people with disabilities can be (Yle 2020). I also personally know many such professionals.

This thesis focused on deriving themes of tangible ways of self-determination and participation actualising or not actualising in group homes, so that out of the information best ways for hands-on-staff to facilitate self-determination and participation can be observed from. Through the analysis of this thesis it was found out that the lack of staff – sometimes caused by the lack of funding and other times for other reasons in the studies this thesis discussed – is as rampant and the pace of overturn as fast as it is in Finland, too. Thus, I would suggest further research on this. I perceive it would be a great research topic to further study the factors behind people ending working in the field, and from there derive into how more of suitable work force could be reached through more goal-directed way of approach than simply ‘by chance or accident’ ending up there. The PWID’s right to participation, imposed by law (Convention on the Rights of Persons with Disabilities, 2008, 19. article; L

27/2016), is under threat in the case of if not enough staff is to be found. As this thesis has in its findings presented, though in international context, staff is both the most important factor as well as very complex and sometimes possibly also most hindering factor (when unfit for the work or when the staff turnover is high) to the self-determination and participation of the PWID. Same is not academically proven, at least not through this thesis, domestically, but can be perceived from the public discussion (Yle 2018; Yle 2019a). For these reasons I see value on executing a study on how to find, reach out to and engage suitable long-term staff. (Yle 2020.)

Another interesting possible topic of research in the near future I perceive as interesting and important, is the in the beginning of this thesis briefly mentioned possible social- and healthcare reformation, if it indeed in the coming years actualises (THL 2021). Will the massive change in how services for people with disabilities previously have been put in order bring with it enhanced policies and ways of improving the self-determination and participation of the PWID? Will it manage to enhance the quality of life of the PWID – or will it diminish it?

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APPENDIX 1. Description of included articles.

Authors	Year	Title	Country	Purpose/ Aims	Method	Results/Main findings
Berlin Hallrup, L. et al. <i>Journal of Applied Research in Intellectual Disabilities</i> , 2019, 32(2), 427–434.	2019	Service managers' experiences of how the participation of people with intellectual disabilities can be promoted in Swedish group homes.	Sweden	To explore how service managers through supporting staff promote participation in Swedish group homes for adults with intellectual disabilities.	A qualitative research design, individual interviews with 14 service managers.	How to create preconditions for participation/what are barriers for participation. Importance of everyday promoted participation.
Kåhlin, I. et al. <i>Scandinavian Journal of Disability Research</i> , 2015, 17(4), 335–352.	2015	Staff experiences of participation in everyday life of older people with intellectual disability who live in group homes.	Sweden	To explore in which ways staff in group homes experiences participation, and what participation means for PWID.	Qualitative interviews with 15 members of staff.	Carefully planned strategies needed to ensure participation of PAWID with both intellectual and age-related factors challenging it.
Kåhlin, I. et al. <i>Scandinavian Journal of Occupational Therapy</i> , 2016, 23(2), 127–137.	2016	Choice and control for people ageing with intellectual disability in group homes.	Sweden	To understand how choice and control in PAWID's everyday life is expressed and performed in the group home's semi-private spaces.	Participant observations and interviews with residents and staff in four group homes.	PAWID are vulnerable in maintaining choice and control which supposedly is due many of them living the majority of their lives in institutions.
Overmars-Marx, T. et al. <i>Society, Health & Vulnerability</i> , 2017, 8(1), 1395676.	2017	Social inclusion in the neighbourhood and the professional role identity of group home staff	The Netherlands	To investigate how the staff perceive their professional role in promoting	Semi-structured group interviews with staff from nine group homes.	Very few of the staff actively promoted neighbourhood social inclusion. Staff focused on care tasks and wished to receive

		members: Views and experiences of staff regarding neighbourhood. social inclusion of people with intellectual disabilities.		neighbourhood social inclusion for PWID.		experienced support from service providers on the matter of social inclusion.
Sandjojo, J. et al. <i>Journal of Applied Research in Intellectual Disabilities</i> : JARID, 2018, 31(5), 840-850.	2018	Training staff to promote self-management in people with intellectual disabilities.	The Netherlands	To gain insight on the effectiveness of a staff training of promoting self-management in PWID.	26 PWID filled questionnaires assessing the effectiveness of training. Trained staff's focus group.	Intensive training brought results of significant increase in independence and self-reliance of PWID. Trained staff reported limited new information gained but had changes in their attitude and working method.
Shipton & Lashewicz <i>Journal of Applied Research in Intellectual Disabilities</i> , 2017, 30(5), 946–957.	2017	Quality Group Home Care for Adults with Developmental Disabilities and/or Mental Health Disorders: Yearning for Understanding, Security and Freedom.	Canada	To uncover and understand factors affecting the quality of care of PWID and/or mental health disorders.	Secondary analysis of data gathered from nine focus group discussions with PWID, their family and caregivers.	Social inclusion and self-determination facilitated by staff contribute to residents being understood and experiencing security and freedom.
Spassiani, N.A. et al. <i>Journal of Applied Research in Intellectual Disabilities</i> , 2019, 32(6), 1465–1477.	2019	What is and isn't working: Factors involved in sustaining community-based health and participation initiatives for people ageing with intellectual and developmental disabilities.	United States of America	To explore supports and barriers to sustaining community-based health and participation initiatives (CBHPI).	Interviews and photovoice with 35 PAWID and 35 management support agency staff. Content analysis and triangulation of data.	CBHPI as a method was valued yet due to limited resources and lack of training difficult to sustain.
Svelöv <i>Disability & Society</i> , 2020,	2020	An observation study of power	Sweden	To identify how participation	50 hours of observation in two group homes	Institutional structures construct practices of

35(9), 1419–1440.		practices and participation in group homes for people with intellectual disability.		constitutes and is constituted by practices of power in group homes of PWID, to identify practices of power.		power, residents in subordinate power position, staff struggle in balancing control, autonomy and guidance.
Talman L. et al. <i>Journal of Intellectual Disabilities</i> , 2021, 25(1), 98–113.	2021	Participation in daily life for adults with profound intellectual (and multiple) disabilities: How high do they climb on Shier's ladder of participation?	Sweden	By using concrete tool, model of Shier's ladder, to observe and describe participation in daily life for PWID.	A qualitative deductive observation study approach, model of Shier's ladder. 60 hours of observation.	On the five-level ladder PWID mostly stayed rather low, only one only once reaching the fourth level. Staff needs to share their power with PWID.
Vaucher, C. et al. <i>Scandinavian Journal of Disability Research</i> , 2020, 22(1), 97–117.	2020	Environmental, Personal, and Relational Barriers and Facilitators to Self-Determination among Adults with Intellectual Disabilities.	Switzerland	To examine barriers and facilitators to self-determination among PWID living in facilities.	13 focus group discussions, in total 10 PWID and 10 social care professionals participating.	Among PWID potential for self-determination is defined by continual interplay between the individuals and their environment.

APPENDIX 2. Content analysis sheet.

Which factors **enable** and **create space** for **self-determination** and **participation** for people with intellectual disabilities in their everyday lives in their **care homes** and **immediate surroundings**? Which factors **negatively affect** and **hinder** this self-determination and participation?

Main category	Subcategory	Condensed meaning unit	Quote derived from
ENABLE AND CREATE SPACE FOR PARTICIPATION AND SELF-DETERMINATION			
RELATIONSHIP BETWEEN THE STAFF AND THE PEOPLE WITH INTELLECTUAL DISABILITIES (1, 2, 5, 10)	Professional yet humane, “normal”, relationship (1, 2, 5, 10)	1 Intentional relationship building crucial 2 Staff participating in the doing of the PWID 5 Creating respectful relationship 10 PWID hope for real relationship with staff that they spend their days with 10 Professional, yet humane relationship 10 Professional, yet equal, relationship 10 Listening relationship 10 Relationship crucial to participation and self-determination of the PWID	1, p. 430, 432 2, p. 342 5, p. 842-843 10, p. 110 10, p. 110 10, p.110 10, p.110 10, p. 113
	Staff producing participation as a feeling to PWID in relation to them (2, 10)	2 Crucial part of producing participation but a true feeling of it 2 Intentionally working in a way the PWID can feel participation 10 Boasting the PWID’s feelings related to the theme of participation to support it	2, p. 341-342 2, p. 342 10, p. 107
ATTRIBUTES RELATED TO THE STAFF (1, 2, 3, 4, 5, 6, 9, 10)	Staff longevity (1, 10)	1, 10 Staff staying for long may pose positive effect 10 Long-term staff able to facilitate the PWID’s self-determination	1, p. 433 10, p. 110
	Staff’s education (1, 6)	1 Intentional continuous education of the staff	1, p. 431

		6 True professionalism needed in the staff	6, p. 955
	Staff's (personal) attitudes towards the work (4, 9)	4 Staff pose a huge power in the quality of participation of the PWID 4 Staff's attitude directly correlates to the participation of the PWID 4 Inbuild willingness to work towards the good, and true actualisation of participation of the PWID 9 Pursuit to meet and understand the PWID	4, p. 2 4, p. 2 4, p. 6 9, p. 103
	Staff strongly helping the PWID to do and take responsibility of tasks by themselves (5, 6, 10)	5 Clear vision to strongly engage the PWID in action in order to reach goal of participation and self-determination 5 Role of mentor to encourage the PWID to do by themselves instead of staff doing for them 5 Staff needs to realise the importance of strongly involving the PWID 5 Careful listening, supporting the PWID's own vision of doing 5 Careful consideration of the PWID's needs, involving them 6 Involving the PWID in planning of their own doing 10 PWID executing individual choices enhancing the self-determination	5, p. 841-842 5, p. 842 5, p. 843 5, p. 846 5, p. 84 6, p. 948 10, p. 111
	Staff's focus on person/individual centred approach (2, 3, 6, 9, 10)	2, 3 Individualised encounters 6 Perceiving and supporting the individual needs of the PWID and group homes 9 Answering to the PWID's needs of a moment 10 Perceiving and using the individual skills of the PWID in enhancing their participation 10 Individual encounters enhancing the self-determination of the PWID	2, p. 343-344 3, p. 133 6, p. 949 9, p. 106 10, p. 107 10, p. 110
SUPPORT FROM THE SERVICE PROVIDERS AND THE STAFF MANAGERS TO THE STAFF	Strong, readily available, daily leadership of the staff managers (1, 4, 5, 7)	1 Present leadership, supporting the staff in daily work toward the PWID's participation	1, p. 432 4, p. 8

		<p>4 Staff's direct correlation in actualisation or non-actualisation of the participation of the PWID</p> <p>6 Staff not understanding what creates participation</p> <p>8 Lack of knowledge of proper way of working</p> <p>9 Untrue and dismissive assumptions of the abilities of the PWID</p> <p>10 Absurd ideas keeping the staff from working toward the PWID's participation</p>	<p>6, p. 948</p> <p>8, p. 1419-1421</p> <p>9, p. 105</p> <p>10, p. 109</p>
	Staff's negative attitude/lack of interest (4, 6, 9, 10)	<p>4 Lack of interest to actively perform</p> <p>6 Disrespectful treatment</p> <p>6 Staff's provocative behaviour</p> <p>6 Unwillingness to promote participation</p> <p>9 Staff did not promote participation they personally found boring/unattractive</p> <p>9 Staff used time that could have been spent toward participation for their own unwinding</p> <p>10 Staff reluctant to professionally improve</p>	<p>4, p. 5</p> <p>6, p. 948</p> <p>6, p. 948</p> <p>6, p. 955</p> <p>9, p. 104</p> <p>9, p. 109</p> <p>10, p. 108</p>
	Staff perform activities instead of involving PWID (2, 5)	<p>2 Staff find it easier to do tasks themselves instead of participating the PWID</p> <p>5 Taking things over from the PWID</p>	<p>2, p.344-345</p> <p>5, p. 846</p>
	Staff choose activities instead of letting PWID to choose (3, 9)	<p>3 Staff chose activities</p> <p>9 Keeping the PWID from choosing the activities</p> <p>9 PWID not in charge of their own activities</p> <p>9 Staff's preferences of activities over the PWIDS' preferences</p>	<p>3, p. 131</p> <p>9, p. 107</p> <p>9, p. 100-101</p> <p>9, p. 109</p>
	Staff's insensitivity and power exert (3, 8, 9, 10)	<p>3 PWID's right for privacy broken</p> <p>8 Certain doings imposed on the PWID</p> <p>8 PWID's compliance put over their self-determination</p> <p>8 Staff imposed rules on the PWID over their will</p> <p>8 PWID's own will denied</p>	<p>3, p. 132</p> <p>8, p. 1428</p> <p>8, p. 1429</p> <p>8, p. 1430</p> <p>8, p. 1431</p>

		<p>8 PWID's compliance over self-determination</p> <p>8 PWID's compliance over participation</p> <p>8 Staff rules created participation</p> <p>8 Physical realms of group home used for power exert</p> <p>9 Staff practicing power exert over PWID when choosing their preferred activities over PWID's</p> <p>9 PWID rarely involved in decision making processes</p> <p>10 Asymmetric relationship between staff and the PWID posing hindrance to participation</p> <p>10 Staff misusing their power toward the PWID</p>	<p>8, p. 1431</p> <p>8, p. 1433</p> <p>8, p. 1434</p> <p>8, p. 1434</p> <p>9, p. 100-101</p> <p>9, p. 106</p> <p>10, p. 104</p> <p>10, p.108</p>
	Staff's 'conflicting' roles: care vs. inclusion (4, 8, 10)	<p>4 Need for "from caring" to "supporting"</p> <p>4 Weighing protection from possible risks more important than participation</p> <p>8 The complex combination of simultaneous care and participation challenging for staff to execute</p> <p>10 The complex combination of simultaneous care and participation challenging for staff to execute</p>	<p>4, p. 2</p> <p>4, p. 7</p> <p>8, p. 1421</p> <p>10, p. 108</p>
ATTRIBUTES RELATED TO THE PEOPLE WITH INTELLECTUAL DISABILITIES (2, 4, 6, 10)	Physical condition (2)	2 Physical restrictions toward participation	2, p. 342
	Psychological or cognitive condition (2, 4, 6, 10)	<p>2 PWID's inattention to hindrance participation</p> <p>4 Residents' mental state may make it challenging for social participation with their surroundings</p> <p>4 Staff perceive residents' intellectual disabilities as hindrance from social participation</p> <p>6 PWID find their mental state hindrance for participation</p>	<p>2, p. 342</p> <p>4, p. 4</p> <p>4, p. 5</p> <p>6, p. 94</p> <p>6, p. 948</p>

		<p>6 PWID's IQ, thus ability to process things, negatively affects participation</p> <p>10 PWID have fears related to their mental performance which then cause hindrance to the actualisation of their self-determination and participation</p> <p>10 PWID accustomed to having a passive attitude, which triggers lack of self-confidence which negatively affects the self-determination</p>	<p>10, p. 105-106</p> <p>10, p. 107</p>
<p>PHYSICAL AND ORGANISATIONAL RESTRICTIONS (1, 2, 3, 4, 8, 10)</p>	<p>Lack of common space in group home (1, 2, 10)</p>	<p>1 No proper space allowing participative interaction</p> <p>2 No proper common areas enabling and enhancing participation</p> <p>10 Lack of space available for interaction between staff and PWID</p>	<p>1, p. 431</p> <p>2, p. 345</p> <p>10, p. 104</p>
	<p>Group home's layout (4)</p>	<p>4 Group home's layout as a hindrance for neighbourhood participation</p>	<p>4, p. 7</p>
	<p>Power exerts through physical environment (8)</p>	<p>8 Denying residents' entrance into certain common areas</p> <p>8 Need of permission to use common areas, not in free use</p>	<p>8, p. 1429</p> <p>8, p. 1432</p>
	<p>Day structure: (pre)set routines (3, 8, 10)</p>	<p>3 Set meal times dominating the day schedule</p> <p>8 No possibility for adapted self-determined day schedules</p> <p>8 Even most simple doings tied into schedule, not to be performed freely</p> <p>8 No freedom to decide on when to do basic things, such as shower</p> <p>8 Schedule determines when residents can start their day</p> <p>8 Possibility to go out only on scheduled time</p> <p>10 PWID cannot build their own natural day schedule</p> <p>10 Staff conflicted on both keeping the set schedule and simultaneously encouraging self-determination</p>	<p>3, p. 131</p> <p>8, p. 1426-1427</p> <p>8, p. 1427</p> <p>8, p. 1428</p> <p>8, p. 1430</p> <p>8, p. 1431</p> <p>10, p. 104</p> <p>10, p. 113</p>
<p>LACK OF RESOURCES (1, 2, 4, 6, 7, 9, 10)</p>	<p>Staff's lack of time in their work (1, 2, 4, 6, 10)</p>	<p>1 Lack of time affecting the quality of work</p> <p>2 Reduction in funding, leading to less staff, leading to worsening of</p>	<p>1, p. 432</p> <p>2, p. 346</p>

		<p>the PWID's opportunity for self-determination and participation</p> <p>4 Lack if time worsens and ability to gather for participation diminishes through staff cut outs</p> <p>6 Not enough one-on-one time between the staff and the PWID which would enhance social inclusion</p> <p>10 Lack of time for the PWID and staff to really meet each other</p> <p>10 Staff's lack of time to form proper relationship with the PWID needed for real participation</p>	<p>4, p. 6</p> <p>6, p. 948</p> <p>10, p. 104</p> <p>10, p. 108</p>
	Lack of training and support from the management to the staff (4, 9)	<p>4 Accessibility to training needed lacking or not properly promoted to staff by management</p> <p>4 Lack of support to staff by management</p> <p>9 Management failing to produce support for staff to support participation</p>	<p>4, p. 7</p> <p>4, p. 7</p> <p>9, p. 101</p>
	Lack of funding (2, 4, 6, 7)	<p>2 Reduction in funding means staff cuts which means they have less time to facilitate the PWID's self-determination and (spontaneous) participation</p> <p>4 Lack of funding cutting off personnel specifically working for the PWID's enhanced participation</p> <p>6 Funding cut directly means the PWID's worsened chance of going to visit outside the group home</p> <p>6 Too few staff employed for financial reason hinders the PWID's possibility of social participation</p> <p>7 Budget cuts affect everything in group home, especially staffing levels</p> <p>7 Not enough personnel hired to facilitate the PWID's participation</p>	<p>2, p. 346</p> <p>4, p. 6</p> <p>6, p. 952</p> <p>6, p. 954</p> <p>7, p. 1469</p> <p>7, p. 1471</p>

1) Berlin Hallrup et al., 2019, 2) Kåhlin et al., 2015, 3) Kåhlin et al., 2016, 4) Overmars-Marx et al., 2017, 5) Sandjojo et al., 2018, 6) Shipton & Lashewicz 2017, 7) Spassiani et al., 2019, 8) Svanelöv 2020, 9) Talman et al., 2021, 10) Vaucher et al., 2020